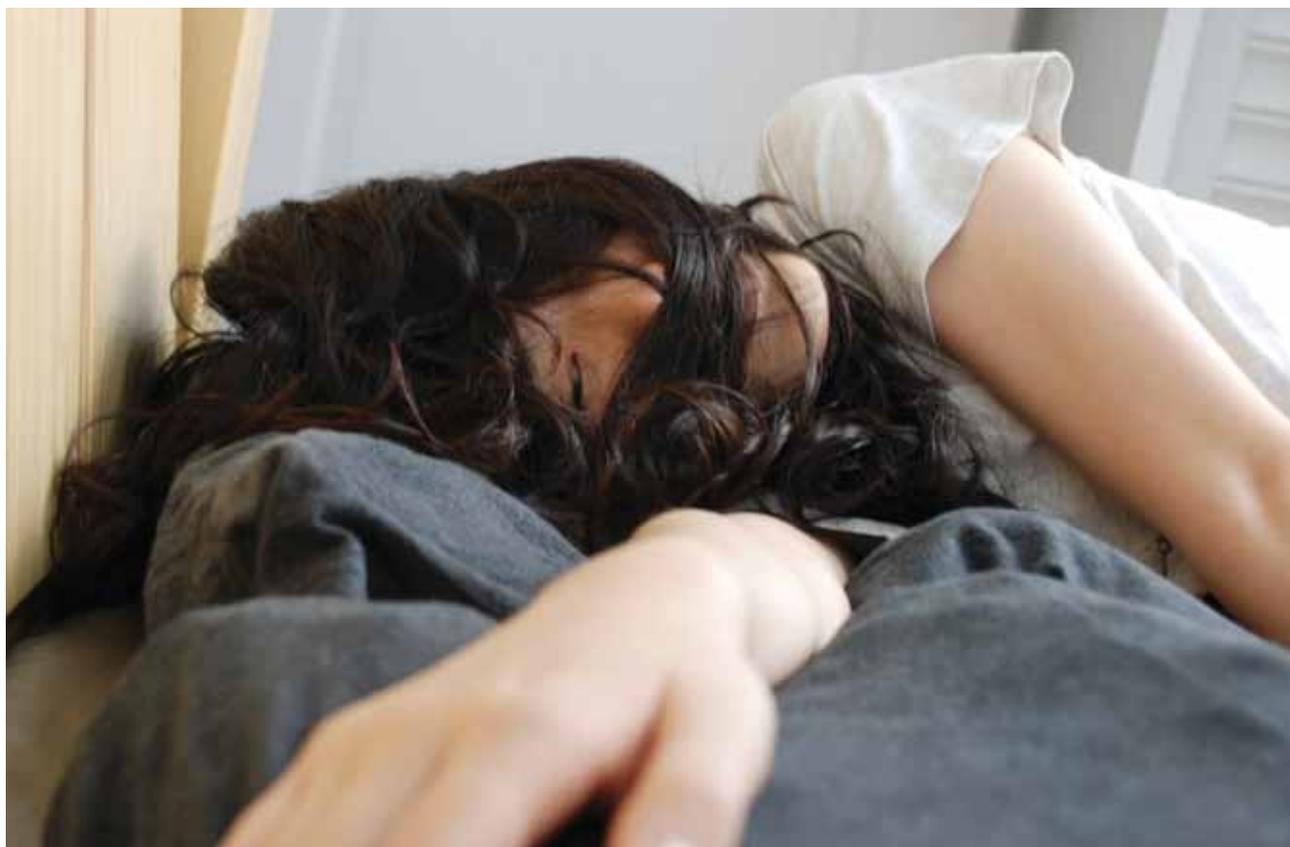




# "My life stopped..."

Voices from Action for M.E.'s 2014 survey



*Severe M.E. Time to Deliver* report by Dr Andrew Pates

14 November 2014

# Introduction

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

For those most severely affected by M.E. – around a quarter of all patients – the impact is devastating. People with severe M.E. 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.

Symptoms of M.E. include post-exertional malaise (a period of intense exhaustion that lasts for more than 24 hours following exertion), chronic pain, sleep disturbance, cognitive problems and 'flu-like symptoms such as headache, sore throat, painful lymph nodes, dizziness and nausea.

Action for M.E. is a charity for people affected by M.E., led by people affected by M.E. Our mission is empowering people with M.E. 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.

## How this report was prepared

This report focuses on the experiences of 298 people identifying themselves as severely affected (out of 2,081 total respondents with M.E.) who took part in Action for M.E.'s 2014 health, welfare, employment and education survey.

Along with statistics from our initial *M.E. Time to Deliver* report ([www.actionforme.org.uk/timetodeliver](http://www.actionforme.org.uk/timetodeliver)), substantial qualitative analysis has been solely undertaken by Dr Andrew Pates. We are profoundly grateful to Dr Pates for the considerable time, energy and expertise he has shared with us.

"Responses to seven open-ended questions from the survey have been analysed separately, and combined into a data-book organised by question," explains Dr Pates. "The main themes identified in this data-book have then been collated into a lengthy report combining data from across the different questions, of which this is a summary document."

"The data are qualitative data, expressing how the respondents experience their lives with severe M.E. As such they provide a graphic account of this debilitating condition, and reflect the situations repeatedly experienced by respondents. The quotations I have included are indicative of dominant experiences, unless otherwise indicated.

"Given the power of the responses, the data have been reported as much as possible in the language of the respondents. My only interpretation has been to group them into categories, each with a selection of typical responses.

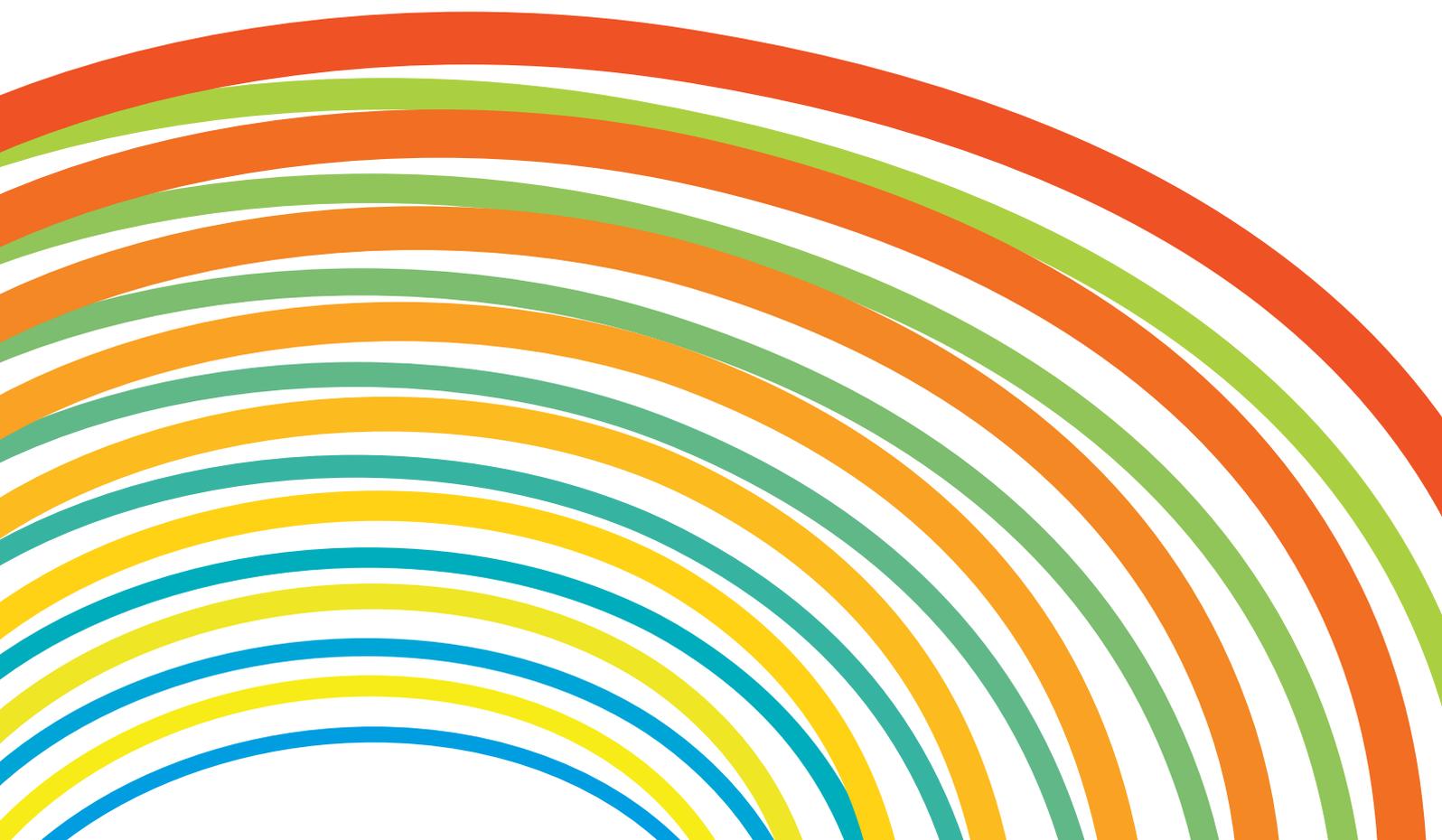
"The data analysed are extensive and, given the nature of the open-ended questions in the survey, responses do overlap and range beyond the immediate subject matter."

# Contents

“The experience of being afflicted with severe M.E. impels one to start with people’s accounts of their lives in the stark terms in which they report them,” says Dr Pates. “There is considerable overlap in the data reported here for each theme: this is a reflection not just of the open-ended nature of the questions but of the degree to which M.E. affects the whole of people’s lives.

“Indeed, the enormity of the experience of severe M.E. could be the connecting theme for this report. Unfortunately it is mirrored by a second and complementary theme: the degree to which other people in the lives of those most severely affected – including family members, friends, healthcare professionals and worryingly often employers and welfare benefit staff – do not identify M.E. in this way, if they genuinely recognise it at all.”

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# The impact of severe M.E.

The words “My life stopped” and similar phraseology indicating an end to life, an almost virtual death, summarises in essence the impact of severe M.E. This was expressed in a number of ways.

“I don’t have a life.”

“I struggled on without diagnosis for eight years. Retired aged 30. My life ‘stopped’ at age 36 years, and has been reduced to merely surviving symptoms on an hourly, sometime minute by minute basis.”

“Life, in a normal sense, stopped 26 years ago.”

“Symptoms have totally limited my ability to live, mostly just exist.”

Note that this life-changing experience was a long-term effect, not something which might be treated and cured as with other medical conditions: very, very few mentioned remissions or substantial improvements.

Action for M.E.’s survey<sup>1</sup> found that 77% of respondents with severe M.E. had experienced symptoms for five years or more, and 65% for 10 years or more.

This condition of life ceasing was also expressed in terms of the loss of different activities important to the respondent’s life: many of the respondents reported previously often very active lives.

“Used to exercise three times a week, work full time, do short courses, go to bars to socialise, dance, walk, go to vintage markets, backpack travel in interesting places meeting interesting people, volunteer at Crisis Christmas shelter... All gone. Been a wheelchair user for five years now, and housebound longer than that (within two years of diagnosis). Too weak to do anything much. Have learnt to live within my energy envelope.”

Of those survey respondents with severe M.E.:

- 96% said they had stopped or reduced household tasks
- 95% had stopped or reduced social contact
- 74% require full or part-time care
- 70% were no longer able to leave their home independently

Such active lives could quickly change to a state where those severely affected by M.E. had to abandon these activities (discussed further on p 9) and were reduced to a state of often total immobility.



“My life stopped suddenly and catastrophically in 1999. It was as if the old me had died, never to return.”



"As my condition gradually worsened I repeatedly had to cut back on all my activities until I became housebound/bedbound for over a year – I'm still mostly housebound."

"I am totally incapacitated 24/7 with exhaustion."

"I am 100% bedbound and have not left the house in three years."

"Always in bed with pain in back, spine and shoulders. Gross fatigue, can't walk."

The condition of severe M.E. means that the main concern of those affected is frequently just surviving day-to-day, in a state of near total debility.

"Everything given up except eating, drinking and showering once a week."

"I am fully bed bound and catheterised with a feeding tube. I cannot leave the house in any circumstance other than in an ambulance to A&E, but only in life threatening circumstances."

"Unable to Hoover or dust house without help from 83 year old mother or my daughter."

"Most days only able to wash, dress and have main meals (microwave ready meals)."

"I have spent over 19 years ill in bed, only getting up to attend to the basic functions of living such as washing, eating, very light housework."

In the worst cases, this can be akin to solitary confinement.

"Lie in silence, in solitary confinement, can't talk, write/read a little, often eye mask, fed, electric bed, bedpan, bed baths, no stimulation, can't listen at all."

"I was 34 when I was struck down by viral pneumonia sudden onset and didn't recover, became M.E. fairly rapidly (huge muscle pain weakness etc). My life stopped at that point. Ever since it's been coping with illness".

Slow or delayed diagnoses has often added to the stresses of severe M.E.

"Ill since young child but attributed to other illness or overanxious mother."

In some cases, the onset of M.E. was apparently triggered (or perhaps masked) by other conditions.

"Had mild/moderate for 14 years then became more and more severe after poor dental treatment/antibiotics."

Some respondents noted the need for flexibility in others since M.E. is not always consistent.

"As M.E. is unpredictable, so the decisions and plans from day to day have to be flexible. This is not always accepted."

**"Totally bedbound. Unable to tolerate light or sound."**



**"Unable to prepare and cook a main meal."**



**"I was totally paralysed for two years, unable to lift, sit or stand for a further five years, need constant help."**

**Action for M.E. asks:** "How might targeted support and care be provided to those facing the complex challenges of the most severe form of M.E.?"

# The social, financial and emotional cost of severe M.E.

Since those most severely affected by M.E. may be completely reliant on others for care and support, social care issues become significant.

**“Completely changed my life for the worse. Very restricted life requiring carers for regular care and main meal preparation.”**

Action for M.E.'s survey<sup>1</sup> found that 60% of people with severe M.E. 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., or if additional conditions were taken into account).

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

This care is often provided by family members: parents or parent, partners, occasionally siblings, sometimes children.

**“My mother is my official appointee – I am reliant upon having someone with me at all times – in my room most of the time.”**

**“I am mainly housebound and not well enough to work. I live with my parents who do the cooking and most of the housework.”**

**“I have been housebound for the past five years, losing my job as a lecturer. My wife is my carer and I rely upon her to provide me with everything.”**

**“Feel cut off from the world depend greatly on my husband and two children. Very low never seem to see any hope to get better.”**

Research<sup>2</sup> by Carers UK has found that 70% of carers are more than £10,000 worse as a result of caring, while 30% had seen a drop of £20,000 a year in their household income.

But other family members may have their own health problems, especially when the carer is a parent, frequently an ageing parent, leading to doubly critical care situations.

**“Ill from Jan 1980. Had to apply for early retirement in 1995. Mum looked after me until she got Alzheimer's in 2004. Now on my own.”**



**“Haven't worked since 1986, had three long periods of live-in care, currently have carers come in for two or three short visits a day.”**



**“My husband takes care of me, I am mostly bedridden, get out perhaps once a month, frequently less. My husband does everything for me, I eat my meals in bed.”**

Additionally, family members are not always available.

“Single parent, no support from family or friends, basically left to rot.”

“My husband and children help me whenever they can, but a lot of the time I have to manage myself.”

Many respondents continue to live in their existing homes though a significant number have had to move back in with their parents. For others, accessing suitable accommodation may be a critical factor in providing a more supportive environment.

“Ideally need to move to more suitable accommodation eg. centrally heated bungalow. But so far attempts to do this have resulted in relapse – catch 22.”

When people are so debilitated, mobility is a major issue. Many respondents cannot leave their homes without support.

“I do not go out to places I do not know anymore. I do not go anywhere without support.”

“Can only go out using mobility scooter or powered wheelchair.”

Going out was not only determined by mobility issues but also on account of the effect of going out.

“I am restricted to the house, going outside (unless 80°F+ with no wind) causes infections within a couple of hours.”

Mobility in order to access support services were also issues.

“Having hospital car to take me to appointments, and wish had M.E. clinic in county.”

“Transport available with a bed in for travelling to appointments.

“Possibly transport by ambulance.”

“Transportation to and from – unable to use buses alone – use walking aids due to reduced mobility.”



“My whole life has stopped because the fatigue and brain fog stopped me from working. I made the decision to stop driving in 1995 due to weakness in arms and legs, also lack of concentration. I stopped taking my children bowling, to football matches and horse riding. They lost me as they knew me when they were 11, 10 and eight.”

## Isolation and loss

Losing a life involves not just being rendered inactive and the loss of previous activity. It also involves a severe emotional impact.

"M.E. won't kill me but it had a bloody good try at killing my spirit, my confidence, my life."

"I feel like a burden to society and my mother. I struggle to feel relevant."

It frequently leads to isolation, a commonly reported experience.

"Feelings of being isolated and having no-one to turn to."

"My severe M.E. has affected every aspect of my life, and left me socially isolated."

"Constant viruses and infections. Pressure on family/my children. Lost friendships due to non sociability. Feel worthless."

"Live on my own but have now lost all contact with former friends and family and too damn tired to care."

## Family and friends

As noted above, family are the most frequent carers and some of the implications of parents as carers have been touched upon. However, severe M.E. affects family relationships in different ways.

"My family have never been supportive and don't help. My mum was my rock and carer and she died last year, my dad has got more supportive over the years but rest of family alienate me. Don't have many friends who understand, just one or two, except M.E. friends."

The role reversal implicit in an ageing parent having to suddenly care for an adult child adds to the stress and creates a growing long term care issue.

"Two elderly parents now caring for their child. Concerns of what happens when they pass away. Friends frustrated as they can't help and painful for them to see me as a shadow of my previous self."

"I can no longer help mum and dad who are in their 70s around the house or with shopping – I am dependant on them. Cannot go out with them places, I am mostly housebound – one walk (short) is all I can do."

While many partners were referred to as solid source of support, it was clearly a strain for many relationships.

"My husband is most affected but has enormous patience and is my main carer. Without him I couldn't exist. Family members have a mild tolerance."

"My wonderful husband carries all the responsibility of running the home etc but is himself receiving counselling and is currently suffering from depression and anxiety."



"I was bed-ridden for 12 years from the age of 30. No-one seems to comprehend the isolation and sense of loss of so much."



"For a number of years my daughter from the age of nine was 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 among my extended family."

Siblings were referred to as sources of support but also frequently referred to as unsympathetic (or worse), often showing total incomprehension about M.E.

“My parents who I live with and look after have accepted and give me support but my brother doesn’t believe it which is hard.”

People with severe M.E. also have dependents of their own.

“I lost my job six months after getting M.E. I had two children aged nine and 11 and wasn’t able to do school runs and take them out.”

It is not just immediate family that are affected: severe M.E. has an impact on the whole fabric of wider family life.

“This will be our first Christmas that we’re not all together. Massive impact on all those close to me. We used to spend every Sunday together but I can only manage a couple of people extra at a time if they are quiet. I don’t see my nephews as often as I would like.”

Difficult to maintain contact with family and friends, many lost. No social life, great strain on marriage.”

On the whole, friends tend to disappear.

“I am reliant on other people to help with daily activities and to take me out of the house. I had to stop work and my hobbies. After a few years most of my friends disappeared.”

## Employment and education

Apart from the impact on daily life and family as discussed, those most severely affected by M.E. typically experience major disruption in their education and/or employment. This manifests itself in a number of ways which, however we tease out, are interrelated.

Action for M.E.’s survey<sup>1</sup> showed that 93% of those most severely affected by M.E. were not undertaking any kind of paid work, volunteering, training or education.

For younger people severely affected by M.E., education was very much a concern.

“Had BSc chemistry and started PhD when lost balance, suffered pain etc. so had to return home to be cared for by parents 10 years ago.”

Some were still able to attend education on a part-time basis and/or with help and support.

“I have in the past with help from support workers. Tried conventional higher education and part-time distance-learning but had to give up university and cut hours on the distance learning due to relapses. Cut very small amount of voluntary work due to relapse.”



“Severely reduced circle of friends. Main friend took on role of carer, at great cost to her family. Nearly all remaining friends have no true idea of M.E.”



“I had to leave university in 1997 due to severe M.E. Never been well enough since to return to university or work. M.E. has affected all areas of my life.”

The importance of work in the lives of respondents was repeatedly stressed.

“I loved life and work (head of special needs department in large secondary school) at 110mph. Now I never leave the 30mph zone.”

But some people with severe M.E. never been able to work.

“I have never had a job or been able to drive as I was 14 when I became ill. I also had to drop out of school immediately, without any qualifications.”

Research<sup>3</sup> 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.

Many have had to cut short active and much-loved careers.

“I had to make the heart-breaking decision to leave a wonderful career in 2011. My husband is my full-time carer.”

“I have had to give up a well-paid job, I was a pharmacy technician but because I couldn't work I couldn't carry on with continuing my development. I lost my technician status. My husband lost his job due to the care he had to give me, I have two new grandchildren and cannot spend much time with them or have them to stay over.”

“Diagnosed 1999, working full-time as a teacher prior to this. Took three years to get back to part-time, worked until 2008 with a dedicated support worker and adjustments at work. Had operation in 2008, massive relapse, now ill-health and housebound/bedbound.”

“I was granted ill health retirement in 2010. After getting M.E. in 2009 I tried with help from the NHS M.E./CFS clinic to return part-time but severely worsened and was unable to return to work.”

“I have gone from a fit, healthy and active 37 year old with a job that I loved and a toddler I adored and done everything with, to being bed bound/housebound most days and completely reliant on my mum and husband should I wish to leave the house as I have to use a wheelchair. I'm about to lose my job. My daughter, who will be three in April, can't ever remember her mummy being well. I require a great deal of help and support around the house and to help me care for my daughter. My journey so far with M.E. has been soul destroying/heartbreaking/devastating. I'd give anything to have my life back.”



“Due to fatigue, pain and weakness, I have lost three jobs and the ability to go out on my own. I've gone from being a police officer and nurse to being totally unable to perform normal tasks.”



**Action for M.E. asks:** “How can appropriate information about self-management and self-care be shared with those who have the most severe form of M.E. and their carers?”

# Healthcare for people with M.E.

The experience of those most severely affected by M.E. with the healthcare system is mixed. Some provide reports of superlative service, identifying high performing medical personnel by name (some being mentioned several times).

**"Very good, he's a star."**

**"Very good. Seems to have good understanding of how debilitating M.E. is."**

**"My GP is very supportive but can only offer medication, pacing/ lifestyle management and a listening ear."**

**"Very good, I chose her because I liked her warm gentle approach."**

Others were frustrated by the lack of knowledge of M.E. on the part of their medical practitioners.

**"There is very little on offer and no real understanding of this illness, so when you do see someone they don't know how to help."**

Action for M.E.'s survey<sup>1</sup> asked people with severe M.E. 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.

This lack of knowledge extended to scepticism about the condition itself.

**"Doctors being sceptical about M.E./CFS."**

They sometimes felt that they had to educate GPs about the condition.

**"GP is very willing to listen and try anything new I provide research about."**

Action for M.E.'s survey found that only 9% of people with severe M.E. 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.

Research<sup>4</sup> 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., before and after diagnosis.



**"I have a good GP of over 20 years, he is understanding but admits he doesn't know much about M.E. I have many other illnesses on top also."**



**"Prejudice against my diagnosis. Disbelief. Minimising severity."**

Straight refusals to make referrals to specialist services were frequently cited.

**"GP surgery refused to refer me to a specialist for 3+ years."**

**"Refusal to refer by GP."**

UK-wide research<sup>5</sup> indicates that 39% of GPs find M.E. the most challenging condition for referral, while 42% think the NHS will no longer provide services for M.E. by 2015.

Frequently, health services were inflexible. Support one would expect for housebound and bedbound patients, such as home visits, is just not available,

**"Morning clinics – spend morning trying to sleep due to very bad insomnia. Phoning at 8am to make GP appointment is impossible."**

**"Wish GPs would do home visits, prescriptions over the phone."**

The NICE guideline for M.E.<sup>6</sup> acknowledges the importance of a flexible, regularly reviewed care plan for people with severe M.E., noting that management of it is difficult, complex and requires specialist expertise.

However, Action for M.E.'s survey<sup>1</sup> found that more than half of respondents with severe M.E. (53%) had not visited a specialist NHS M.E. 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).

Unfortunately, the inflexibility of health services can lead to a dismissive and unhelpful attitude on the part of other staff.

**"I find nurses especially to be extremely dismissive of me when they find out I have M.E."**

There was also frustration at the lack of specialist services and at the difficulty in accessing them.

**"If there was an M.E. specialist willing to hold clinics at local community hospital and willing to take longer term M.E. patients I might make an appointment via GP."**



**"Total refusal to refer to NHS specialists."**



**"There is no help for bedbound or housebound people with M.E."**

**Action for M.E. asks:** "How can we work towards personalised healthcare that takes into account the specific needs and complex symptom presentation of those with the most severe form of M.E.?"

# Welfare benefits and severe M.E.

There was a mixed response to experiences of the welfare benefit system. In some cases respondents had had positive experiences, though it must be noted that these were mostly tentative and rarely enthusiastic.

"I have been one of the lucky ones I think, I've always had very helpful people when I speak to them.

On the other hand, the number of people reporting negative experiences were numerous and these were dominantly very, very unhappy experiences.

"Hell on earth"

"Harrowing"

"Tiresome"

"Not very helpful"

"Hell"

"Abysmal"

"Very, very difficult"

"Terrible"

"Awful... extremely stressful"

"Awful"

"Terrifying and awful"

"Very negative"

"Abysmal, degrading and de-humanising"

"Extremely stressful. Extreme energy needed over very long periods."

"Kafkaesque, bizarre. Impossible to anticipate what either will or won't do next. DLA staff to my questions: 'We can do what we want'."

The Department for Work and Pensions (DWP), which has ultimate responsibility for welfare, received mixed reviews.

"DWP fine, helpful, even reassuring at times. Atos: words fail me. Whoever processed my claim didn't read anything I'd written, never had face to face interview."

"All individual staff at DWP been very helpful but process very very slow and complicated and too exhausting for me to deal with. Unable to face going through appeal process – saved by Stockport M.E. Group benefit adviser doing it for me – successfully!"

There were many comments about the apparent inefficiencies in the system.

"Very poor – all supporting medical information routinely ignored. Only when I approached my GP were the six medical reports previously submitted actually reviewed and assessed."

"Horrendous. Felt like I was a criminal."



"DWP OK mainly but pestering. Atos incompetent and clueless on M.E. Trying to catch you out."



Action for M.E.'s survey<sup>1</sup> showed that 18% of people with severe M.E. had applied for Personal Independence Payment in the past 12 months, but more than three-quarters (77%) were still having their applications processed.

It is unacceptable that this vulnerable group are placed under this financial and emotional pressure while they await the outcome.



**“Traumatic in the extreme, my parents tried to reason with Atos that I was too ill to attend assessment and were told that if I did not attend I would get no money. My specialist at M.E. clinic wrote a letter explaining I was too ill but they took no notice. I passed out at assessment and was wheeled out on an office chair. I went on to be bedbound for 12 months and am still trying to recover.”**

The system was also found to be difficult to navigate and its requirements stressful to complete.

**“Process is very lengthy. I avoid phoning as I struggle to keep up due to brain fog.”**

**“Because of my M.E. took two months to fill forms, which I had great help with.”**

The strongest area for dissatisfaction was the role, attitude and performance of Atos Healthcare, the company contracted by the DWP to assess claimants for welfare benefits. There were more negative comments about this organisation than anything else in the survey responses, many of them quite vituperative. Common themes were prevailing disbelief about the claimant's condition and the very existence of M.E.

Even where respondents had not had a bad experience in claiming welfare benefits, they expressed a sustained level of anxiety about it. Overall, the whole system was experienced as extremely stressful.

**“Had to appeal and go to tribunal, which I won. Personally it was very, very stressful.”**

One in five (21%) people with severe M.E. told Action for M.E. that their GP had not been helpful when it came to providing supporting evidence for their welfare benefit claim or appeal.

Support, where available, was critical.

**“In the past with filling out the forms myself I didn't get Disability Living Allowance (DLA), but after getting an agency to help me I have so far had no problems. I was extremely worried about my Employment and Support Allowance claim, but I received it without even having to have a medical so was very relieved.”**

**“In my earlier attempts to claim Income Support, I was treated poorly. It took six or seven attempts to get DLA. Action for M.E. factsheets have helped me recently get into the Support Group, thank you. I have gained confidence and dignity through the many years of dealing with dispassionate doctors and officials, and now I am empowered, partly due to Action for M.E. and their support, and my own awakening to the general political abuse levelled at the vulnerable.”**

**Action for M.E. asks:** “How can those most severely affected by M.E., including carers, be supported to access the welfare benefits they are entitled to?”

# Useful resources

As outlined in this report, there is a lack of resources available to support those with the most severe form of M.E. and the people who care for them. However, we can recommend the following resources.

## InterAction articles

Articles from our membership magazine *InterAction* on severe M.E. include:

- *The art of communication* (*InterAction* 82, Christmas 2012), about speaking, listening and writing aids
- *Coping with personal care* (*InterAction* 81, autumn 2012), including washing, haircare and toileting
- *Express yourself* (*InterAction* 80, summer 2012), about coping with the emotional impact of the most severe form of M.E.

These can be read and/or downloaded from the Severe M.E. section at [www.actionforme.org.uk/get-informed/publications/interaction-magazine/read-selected-ia-articles](http://www.actionforme.org.uk/get-informed/publications/interaction-magazine/read-selected-ia-articles)

Or contact us (see back cover for details) for paper copies.

## Severe M.E./CFS: a guide to living

With permission from the author and her family, each of the articles above quote from Emily Collingridge's book, *Severe M.E./CFS: a guide to living*.

The book is available for £5.99 from the Association of Young People with M.E. on 0845 123 2389 or online at [www.severeme.info](http://www.severeme.info)

## M.E. Friends Online

For those able to use a computer, tablet or smartphone, our peer support forum M.E. Friends Online offers the opportunity to share experience, advice and support.

[www.actionforme.org.uk/me-friends-online](http://www.actionforme.org.uk/me-friends-online)

## Services directory

Some local support groups offer services for those who are severely affected, and most welcome carers to their meetings and social events. You can find your local support group in our services directory.

[www.actionforme.org.uk/get-help/services-directory](http://www.actionforme.org.uk/get-help/services-directory)

## References

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- 6 National Institute for Health and Care Excellence (2007) *NICE clinical guideline 53: diagnosis and management of CFS/M.E. in adults and children*. [www.guidance.nice.org.uk/cg53](http://www.guidance.nice.org.uk/cg53)



**"I think convincing myself that, if everyone was as sick as me, they'd do exactly the same (in other words, stay in bed and get help with everything), has taken a lot of the 'I'm a failure' thoughts off my shoulders."**

Person with severe M.E. quoted in our *Express yourself* article in *InterAction* 80

“I have gone from a fit, healthy and active 37 year old with a job that I loved and a toddler I adored and done everything with, to being bed bound/housebound most days and completely reliant on my mum and husband should I wish to leave the house as I have to use a wheelchair. I’m about to lose my job. My daughter, who will be three in April, can’t ever remember her mummy being well. I require a great deal of help and support around the house and to help me care for my daughter. My journey so far with M.E. has been soul destroying/heartbreaking/devastating. I’d give anything to have my life back.”



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