

Facts and Figures



more than you know

A word from our President – Clare Francis MBE

Action for M.E. has an established tradition of listening to, and relating the experiences of people with M.E. In Spring 2006, we undertook a major survey of over 2,000 people with this serious, incapacitating illness, and commissioned an Ipsos MORI poll to determine public understanding of M.E.*



This booklet, which provides a range of often shocking information on the illness, arose from the research Action for M.E. developed as part of our 2006 'More Than You Know' campaign. I believe the information we have gathered will help readers gain a greater understanding of the nature of M.E., and the devastating impact it can have on people's lives. We also hope it will encourage the government, the Medical Research Council, and others, to undertake much needed research and health and social care.

A handwritten signature in cursive script that reads "Clare Francis". The signature is written in black ink and is underlined with a single horizontal stroke.

Clare Francis MBE
President, Action for M.E.

*Action for M.E. would like to express grateful thanks to Robert and Lizzie Cathery for supporting this research and the publication of these reports

Introduction

M.E. is a chronic, disabling illness that affects over 250,000 people in the UK, and has a devastating impact on millions more through its effects on families and friends. M.E. (Myalgic Encephalomyelitis/Encephalopathy), which is sometimes called Chronic Fatigue Syndrome, can affect anyone, at any age, and from any ethnic group. It appears most commonly, however, amongst the 25-50 age group. Children are more likely to suffer more severely than adults (although they have a better chance of recovery), and it can run in families. There also appears to be a gender bias, with two thirds of those affected being women.

M.E. disturbs many body systems and their functions, particularly the nervous and immune systems – the World Health Organisation recognises it as a neurological condition – and **it has no cure and no diagnostic test**. It can be triggered by a multitude of things, from organophosphates and pesticides to vaccinations or viruses, and an estimated one in ten people with glandular fever going on to develop M.E.

Up to 25% of people with M.E. are severely affected, either house or bed-bound, and unable to look after themselves. Many require wheelchairs and some need to be tube-fed. While our research shows that the speed of diagnosis has improved, many still suffer from considerable delays, which can increase the severity of the illness.

The illness can fluctuate wildly in intensity, with people living on a rollercoaster of good and bad days. Recovery is patchy although, over time, most can expect to substantially improve.

In 2002, the Chief Medical Officer's Report recommended that a specialist service for M.E. be developed. A fledgling service, in England only, has now been established with £8.5M of Government funding.

More Than You Know Survey

As part of Action for M.E.'s 2006 campaign, 'More Than You Know', we undertook a major survey of over 2,000 people with M.E. The majority (68%) of respondents were aged between 30-59, with the age profile peaking in the 50-59 age group. Most (74%) had suffered from M.E. for five years or more, with around half (49%) having M.E. for over ten years. Over four-fifths of the respondents were female.

Severity and Symptoms

At its worst, M.E. can leave an individual house and/or bed-bound, sometimes having to be tube-fed, and even unable to use a wheelchair. Often, M.E. is regarded as 'just' fatigue. What is not common knowledge, however, is how extreme M.E. fatigue can be. And how it can be accompanied by an array of symptoms, ranging from frightening cognitive dysfunction to harrowing, chronic pain.

"I didn't know M.E. caused pain', said the lovely, experienced, NHS nurse – until we met in 2005 and she saw how it was for me. Some perhaps experience little pain; others are far worse than me. It can be a dull ache, or like pins and needles, or, at its worst, burning, searing like someone's pressing a hot iron up and down your spine. A slight movement of my wrist provokes an 'electric' shock of pain that leaves me shaking. At times it's impossible to rest my feet even against a pillow. The worst pain, however, is emotional."

Severity

- **24%** described their current symptoms as severe.
- This increases to **74%** when respondents described their illness at its worst
- Those who have had M.E. the longest tended to describe it as currently severe

The most common daily symptoms experienced when the M.E. was at its worst were:

- Flu-like malaise (**86%**)
- Muscle pain (**83%**)
- Wildly fluctuating body temperature (**85%**)
- Digestive problems, e.g. constipation or diarrhoea (**69%**)

Overall

- **97%** have experienced muscle pain; **29%** severely
- **95%** reported a flu-like malaise, **33%** described it as severe
- **87%** reported problems with body temperature control; **66%** reported these as severe
- **87%** reported digestive problems (e.g. constipation or diarrhoea); **24%** describing it as severe

Other common symptoms

Figures given below show other common symptoms currently experienced by our survey respondents (figures tend to increase when the illness is at its worst).

Of all survey respondents:

- **85%** experience vertigo and/or dizziness; **30%** experience it daily; and **13%** describe it as severe
- **75%** get cramps; **24%** experience them daily; and **16%** describe them as severe
- **55%** get tinnitus; **25%** have it daily; and **9%** experience it severely
- **90%** report headaches; **35%** on a daily basis; and **20%** report them as being severe
- **52%** develop migraines; **4%** have them daily; and **17%** describe them as severe
- **80%** experience 'pins and needles'; **35%** get them daily; and **11%** severely
- **78%** experience nausea; **21%** suffer from it daily; and **10%** describe it as severe

Allergies and Sensitivities

- **97%** experience an allergic or sensitised reaction to anything from noise or light, to food, chemicals and even touch.
- **53%** have severe allergic reactions to at least one irritant

Of these, the following have experienced a severely increased sensitivity to:

- Noise (**33%**)
- Medications (**27%**)
- Food (**25%**)
- Chemicals (**24%**)
- Light (**21%**)
- Touch (**11%**)

"I was in my late 30s when I was stricken with M.E. I was lucky in some ways because I had a good doctor. I thought the worst thing was not knowing what was wrong but it didn't really help when I was diagnosed. My life was my bedroom, outside of which I knew of the changing seasons by the tree I could see from my window. Now 56, I use a wheelchair most of the time."

“When I tell people I have M.E. they often think that it means I get a bit tired, lethargic and low-spirited. If they have no experience of the illness, they can only compare it to their feeling tired after a long day’s work; but that is like comparing a kitten with a tiger – they are not in the same league.”

Fatigue and Sleep

- **97%** have disturbed sleep, **59%** on a daily basis
- **79%** describe this as severe when the M.E. was at its worst
- **71%** report that even if they do sleep they do not wake refreshed
- This increased to **88%**, when the M.E. was at its most severe

Cognitive Dysfunction

- **89%** have difficulty learning new things since they have developed M.E.
- This rose to **94%** for those with severe M.E.
- **79%** said that their everyday ability to concentrate had been reduced
- **73%** reported increased loss of short-term memory on a daily basis
- **38%** reported that they are now unable to drive as a result of their M.E.
- **81%** reported severe loss of concentration when the M.E. was at its worst
- **59%** were unable to drive when the M.E. was at its worst.

“I got a place at Oxford University and spent a horrendous three years. On top of the usual issues of that age, my health was steadily going downhill. I went to the college doctor, told them I had been previously diagnosed with Glandular Fever and Post Viral Fatigue Syndrome [which are often triggers for M.E.] and explained that I felt it was linked. The doctor said it was homesickness and I was prescribed Prozac. The tablets did strange things to my thought processes. I ended up in hospital after an attempted suicide. This just seemed to convince the doctors and everyone else that I was depressed. I struggled on but it was hard. I don’t know how I did it. Those three years are a total daze to me now, it all seemed unreal.”

Diagnosis

Some research suggests a link between the time taken to diagnose M.E. and its severity. Diagnosis of M.E. is still slow, although our survey shows that the speed of diagnosis has improved.

“Diagnosis is vital. Few people have the same symptoms. I was lucky; my GP already had a patient who had been quite ill with M.E. That patient and I are good friends now, as sharing experiences is invaluable. The hardest, cruellest part of this illness is ignorance, lack of support and the shock of being treated differently by many of my friends and family. I was ill with a disease I learnt has no cure.”

- **25%** had their M.E. diagnosed within 6 months...
- ...but **37%** said it took over 18 months
- **2%** were still not ‘officially’ diagnosed
- **66%** of those with M.E. for less than five years were diagnosed within 12 months...
- ...but for those who have had M.E. for ten years or more, just **38%** were diagnosed within a year
- There was some regional variation in speed of diagnosis
- **45%** of those diagnosed within a year came from Wales/South West...
- ...but this rose to **58%** in Scotland and Northern Ireland
- **43%** had their M.E. diagnosed by a GP
- **35%** were diagnosed by a consultant
- **11%** were self-diagnosed
- **5%** were diagnosed by an alternative practitioner

“It took three years to get a diagnosis and I have since had to sell my bungalow because of no financial benefits and help. Recently, though, I have received my teacher’s pension on ill health grounds and have had a lot of support from the medical profession.”

Economic Impact

A recent report by Sheffield Hallam University's Survey and Statistical Research Centre estimated M.E.'s cost to the UK at £6.4billion per annum. But the cost in terms of personal loss – both financial and emotional – is incalculable. The effects of this debilitating illness aren't limited to the individual experiencing it – it affects the person who cares for them (usually parents or a partner), their families and their friends.

"My employers were far from sympathetic. For the first month I had phone calls a few times a week, asking me when I would be back at work and warning me that my job would not be kept open. I returned to work but after a month collapsed with exhaustion. To stop the bullying and harassment I took out an official grievance against my employers. I managed to keep my job and was moved to a new team. After six months I returned to work part-time. I had to overcome much discrimination, judgments and assumptions. My employers were then taken over and I was transferred to a lower grade job and then, finally, made redundant."

- **77%** felt that they had lost their job because of the illness. Of these, **28%** were either forced to resign or were dismissed
- **93%** of respondents felt that their employment opportunities had deteriorated
- **74%** felt their educational opportunities had been limited or reduced
- Before developing M.E., **63%** of respondents worked full time. This drops to just **6%** after developing the illness
- **39%** saw a reduction in the employment opportunities of their carer

"I used to work as a freelance IT consultant, play in a band, go rock climbing and travelling. In November 1997, a sore throat reduced me to a person who could not talk for more than 10 minutes, walk 100 yards, read a book, watch a film or cope with visitors. I was ill for five years. It took my career, most of my friends, my sport, and left me devastated. I found, on recovery, that the world of work doesn't welcome you back with open arms. I now earn less than £15K per year.

Emotional and Relationship Impact

Any form of disability can push a person – and their family – onto the outskirts of society, where they are disempowered and isolated. To gain a better understanding of the effects of M.E., our More Than You Know survey asked respondents to comment on both their own emotional losses and on those of the people who cared for them.

“Twelve years ago my husband became ill with M.E. It is like having a third person in our marriage.”

- **77%** said their level of social contact had decreased significantly since they developed M.E.
- This figure increases to **94%** when their M.E. was at its worst
- **40%** felt that their close relationships had got worse since developing M.E.
- **80%** felt that their emotional development had been limited by the illness
- The same figure – **80%** – thought that the emotional development of carers had also been affected
- **44%** said their carer’s friendships had deteriorated
- **35%** stated carer’s close relationships had been adversely affected
- **25%** believed that the educational opportunities for their carer had been adversely affected.

“I have been ill with M.E. since I was 12 years old – I am now 31. One of the many distressing things is the fact that I have not had a life and do not know if I will ever have a chance to have one. I have been bed-bound for the 19 years I have been ill. I am kept prisoner in one small room while my body tortures me with pain and illness every single day, year upon year, with no end in sight. On top of this it is soul destroying to have so little understanding.”

Perceptions and Understanding

M.E. is now recognised as a neurological illness by the World Health Organisation and by the UK government as a serious national health problem. But on a day-to-day basis, people with M.E. continue to battle with ignorance and prejudice in all areas of their lives. And the impact of being disbelieved when suffering can only exacerbate an individual's sense of isolation and pain.

“Relapsing with M.E., I had progressively lost my ability to swallow for a fortnight, I was unable to eat and barely able to drink. Doctors told me I was not an emergency. In hospital the consultant shouted at me that I had ‘globus hystericus’. He removed my liquid food and refused to help. Following this my husband treated me with contempt, friends vanished: one told me I’d be better off dead than ruining my family’s life. Pulling something constructive from the wreckage of this devastating illness is familiar – restoring my faith in human nature still feels impossible.”

- The majority of respondents (**63%**) felt that health professionals believe that M.E. is a physical illness
- **60%** felt that their immediate family understood the impact of M.E...
- ...but only **29%** felt that health professionals understood the severity of the illness
- This figure dropped to **23%** for those with severe M.E.
- **74%** felt that their friends did not understand the real impact of M.E.

“My wife had M.E. seventeen years ago. I thought our lives had ended! She lost weight, couldn’t see well, couldn’t walk, developed food allergies and bruised spontaneously. She spent six months in bed and I thought she would die. With constant nursing and help from our fantastic GP – who visited three times a week for many months – she gradually got better. Early support from Action for M.E. helped save our lives.”

"It's the loneliness and utter frustration that I feel while having this invisible illness that affects me every single day. My family ignoring it because they don't see my bad times, or strangers who say 'you look alright', and friends who gradually drift away because it's all gone on too long and they have run out of understanding. Luckily, my husband and daughters do believe and help me through this."

Public Awareness

Action for M.E. commissioned a nationally representative, GB-wide survey by Ipsos MORI, of 2,084 people aged 15 and over, to determine the general public's perception of M.E.

- Just **5%** are roughly aware of how prevalent M.E. really is
- Over one third (**35%**) have never heard of M.E.
- The severity of M.E. is still not generally recognised
- Over half of respondents (**51%**) were unaware that M.E. can lead to people becoming house-bound
- While **65%** had heard of M.E., their understanding of it is extremely limited
- **18%** of this group thought it was most like flu
- Most respondents (**58%**) recognised fatigue as a symptom of M.E.
- **14%** were aware that it caused muscle or joint pain
- The full impact of any other symptom is, however, simply not recognised.
- **21%** of respondents overall could not name any symptoms of M.E.

"It's not the fatigue, the migraines, the nausea and stomach cramps. It's not the fact that I've lost my career, my independence and my social life. Most of all it is the dearth of support and kindness from other people. Instead, I am treated at best with disapproval and at worst with utter contempt. This is because they perceive my illness to be mental rather than physical – though surely a degree of depression is normal in such circumstances. All this shows me is how society treats those it deems to be mentally ill, and that is the most shocking of all."

Action for M.E. is a campaigning charity founded and led by people with M.E. for people with M.E. This chronic and disabling illness affects almost 250,000 people in the UK and has a devastating impact on many more through its effect on family and friends.

action for **M·E**

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