

nerve & pain

get informed · get diagnosed · get help

action for **ME**

A word from our President – Clare Francis MBE



M.E. can affect anyone, at any age, and from any ethnic group, though available studies suggest that women are more susceptible to it than men. Perhaps because of this it is often seen, quite wrongly, as a female illness. Yet it is estimated that at least 80,000 men in Britain have M.E.

When Action for M.E. commissioned a major study of over 2,000 people with M.E.,¹ we found that a significant proportion of men had more difficulty than women in obtaining an official diagnosis.

Early identification of M.E. is critical in aiding a quicker recovery, and can prevent the condition from becoming severe. Figures indicate that 16,000 men in Britain are currently living with M.E. that is undiagnosed and unsupported, and our in-depth research² suggests that for 62% it takes over a year to be diagnosed, whilst for 25% it takes over two and a half years. It was the discovery of this gender difference, and our understanding that men also have specific issues in relation to health and identity, that made us look more closely at men and M.E. – the theme for our 2007 campaign. It's a well-known fact that men are less likely than women to go to the doctor, hoping their problem will go away of its own accord. But with this illness that's the worst thing you can do. Being a man with M.E. is not about soldiering on and pretending you're not ill. It's about getting informed, getting diagnosed and getting help.

We hope this booklet will encourage men to seek help earlier; and give men with M.E., their partners, and friends, a greater understanding of the illness. And we hope it will encourage all those who can help – government, NHS, and researchers – to undertake and promote the research, health, and social care, so desperately needed by those with this chronic illness.

Clare Francis MBE, President, Action for M.E.

Introduction

M.E. is a painful and debilitating illness, affecting many aspects of body functioning, particularly the nervous and immune systems. It affects over 250,000 people in the UK and has a devastating impact on millions more through its effects on families and friends. In its most severe form, it can leave people house-bound or bed-bound for decades, with many needing wheelchairs and some having to be tube-fed.

Typical symptoms include overwhelming exhaustion, sleep problems and joint and muscle pain. Other symptoms can range from digestive and bowel problems, to difficulty with body temperature control and cognitive dysfunction or 'brain fog' – a disturbing and often frightening inability to understand, focus, or concentrate. M.E., which stands for Myalgic Encephalomyelitis/Encephalopathy, is also known as Chronic Fatigue Syndrome and is sometimes diagnosed as Post-Viral Fatigue Syndrome.

M.E. can fluctuate wildly in intensity, creating a rollercoaster of 'good' or 'bad' days. It often appears to be triggered by a viral infection – an estimated one in ten develop M.E. following a bout of glandular fever – but it can also be instigated by organophosphates, pesticides and vaccinations.

Recognised by the World Health Organisation as a neurological illness, M.E. has no diagnostic test and no cure. Action for M.E. has continuously campaigned for increased biomedical research into this illness. **We believe that if just one percent of the cost of M.E. to the nation – an estimated £6.4b³ – were used to discover causes and treatments, we would see significant benefits and breakthroughs.**

In 2002, the Chief Medical Officer's Report recommended that a specialist service for M.E. be developed, and a fledgling service (in England) has now been instituted. Despite the advances that have been made, too often people with M.E. still struggle to access appropriate medical care and we continue to lobby for specialist services to meet need throughout the UK.

1 More Than You Know Survey, Action for M.E., April 2006

2 Men & M.E. Survey, Action for M.E., March 2007

3 Sheffield Hallam University, Survey & Statistical Research Centre 2006

Men & M.E.

Our recent large-scale survey¹ of over 2,000 respondents provided a wealth of detail about M.E. But when we began to do some further data mining, we were surprised to discover a gender difference in terms of time taken to get a diagnosis. We found that approximately 20% of men had more difficulty than women in obtaining an official diagnosis – and that this can seriously damage their health. Various studies⁴ show that delayed diagnosis increases the severity of the illness, while early identification can help speed recovery⁴.

We undertook further in-depth research with over 200 men with M.E., combining survey questionnaires and telephone interviews, the outcomes of which we present here. The largest group (33%) of respondents was 40-49 years of age and 12.2% were under 30. The majority (62%) believed their M.E. was triggered by an infection.

Speed of Diagnosis

"I first became ill in 1989. I finally received a diagnosis of M.E. earlier this year."

D.I. Cornwall

"In all, I saw 16 consultants trying to find out what was wrong with me. As a former nurse, I knew that what was happening was not 'all in my head'."

A.B. Walsall

- An estimated **80,000** men in the UK have M.E.
- At least **16,000** are still waiting for a diagnosis
- For **62%** of men it takes over a year to get an official diagnosis
- For **25%** it takes 2½ years to obtain an official diagnosis

"It took about 6 years for me to get a diagnosis. I only realised what my 'mystery illness' was after seeing Clare Francis [author and President of Action for M.E.] being interviewed on TV."

C.B. Brighton

1 More Than You Know Survey, Action for M.E. April 2006

4 Wenham W, Pheby D, Saffron L, Journal of Chronic Fatigue Syndrome 2006

4 The M.E. Alliance Report – M.E. Diagnosis: Delay Harms Health, 2005

Diagnosis and Gender

In our survey of over 2,000 people with M.E.¹, more men (53.7%) than women (47.9%) reported being ill with M.E. for over a decade. Our depth research canvassed 200 men with M.E. and asked them if they thought that their gender delayed diagnosis.

"Although my GP is a nice enough guy, he made it clear that he didn't believe in M.E. and implied that, if it did exist, it was probably a female illness."

C.E. Sheffield

"As a man, you feel guilty about being ill, anyway..."

K.O. Lincs

- **15.9%** thought their gender affected the speed of diagnosis
- **37.8%** were unsure or didn't know
- But **28%** thought more men than women reported being ill for over 10 years because it took men longer to be diagnosed
- And **18%** thought health professionals see M.E. as a female illness

Healthcare and Self-care

According to the media, changing gender roles have created new stereotypes, from the new man to the metro-sexual. But, as a range of men's health campaigns have shown, there is still a difference in the way men and women understand, approach and deal with illness. For men with M.E., part of the problem could be a reluctance to visit a doctor. We asked the men we surveyed how long it took them to go to their GP after first getting symptoms of M.E.

"I fell ill with M.E. 'properly' in 2001, and was diagnosed three years later. My symptoms had been apparent for over a decade but, like a typical man, I did not go to the doctor until I had no alternative."

A.J. Nottingham

"My GP openly admits that he does not have the answers."

C.L. Bucks

- **14.6%** took over 6 months to visit a GP
- **42.7%** took over a month
- **19.6%** took between 2 weeks and a month
- **37.7%** went within the first 2 weeks
- **46%** thought men are less likely than women to know about M.E.

71% of our respondents thought men were less likely than women to go to their GP. **Of these:**

- **80%** thought it was because men find it harder to acknowledge they are ill
- **74%** thought there was still the perception that 'real' men don't get ill.
- **60%** thought men know less about healthcare than women
- **57%** thought that men get more nervous than women about visiting the doctor.

"Everything went: my wife, children, home, career and most of my friends, because of M.E. Everyone needs to learn about the reality of this illness. Only then can we start to improve the situation for those of us who have to live with it."

K.O. Lancs

"I think there is a real issue about men 'owning' our illness – simply acknowledging it. And then, of course, we tend to have enormous difficulties talking about it. We don't like to admit to something that makes us seem weak."

R.B. Somerset

Economic Impact

The annual cost of M.E. to the nation has been estimated at **£6.4b³** but there is little, if any, research into M.E.'s economic impact on the individual. The vast majority of men we questioned saw their income plummet as a result of this illness, often with devastating effects.

"I lost my home, a good income, and the job I loved – which involved a lot of travel. I am now virtually house-bound and sometimes I don't see anyone outside my immediate family for months."

K.S. Glos

- **27.7%** reported that the financial impact of M.E. led to them losing their home
- Before developing M.E., only **10%** had an annual income of under £10k
- Since developing M.E., **62.4%** now have less than £10k per annum
- The majority of respondents (**27.2%**) originally had an income of £20-30k
- Once their illness had taken hold, only **11.9%** reported this level of income

"My wife is having to work, instead of taking retirement, to support us financially. She also has to cope with my depression about my illness. I just feel that we have been robbed."

P.L. Cheshire

"I am working at a lower grade job than I had previously and am really struggling to maintain my productivity. Fortunately, my employer is very understanding, allowing me to take regular breaks and more sick leave than average. However, I have consistently been passed over for promotions."

J.L. Glos

Other Losses – Emotional Impact and Relationships

As we have shown, the financial consequences of getting M.E are severe. But no price can be put on the personal losses incurred by the illness.

“This lack of human contact, of interaction and exchange, the loss of valued relationships and good friends, far surpassed the physical debility of the illness itself.”

M.P. London

“M.E. has had an enormous effect on my life. I’ve had to forget a proper relationship as I no longer have any libido.”

C.E. Sheffield

- Over half (**51.8%**) reported a divorce or relationship breakdown
- **52.1%** reported a severe impact on immediate family or carer

We also asked the men in our survey what happened to their friendships once they developed M.E.

- **80.7%** saw a strong and negative impact on close friendships

Of these:

- The majority (**72%**), thought it was due to men having greater difficulty than women in dealing with illness
- But **53.6%** also said their loss of friends occurred because male bonding is often linked to sport or physical activity
- **36.7%** linked it to weaker friendship networks among men compared to women

“My relationships with male friends suffered as a result of my M.E. as I wasn’t able to participate in the usual activities... and finding they weren’t interested in hearing about me and my illness, I trivialised it to make something they couldn’t feel threatened or confused by.”

R.C. London

Identity and Illness

All health problems impinge on our sense of who we are and remind us of our own mortality. But living with a chronic illness – especially M.E., which has no diagnostic test and no cure – can be particularly difficult. And the problem can be compounded when you look well on the outside. The men we researched were asked to tell us what effect M.E. had on their sense of masculinity and self-identity.

“I couldn’t be the father I wanted to be.”

S.C. Sheffield

“I don’t tell new people when I meet them that I have M.E. – I’m embarrassed.”

R.B. Brighton

- **88%** said M.E. had a strong impact on their sense of identity
- **95.3%** said it had an impact

Of these:

- **70%** felt that M.E. was often seen as ‘just psychological’
- **70%** felt that it was often seen as an excuse for not working

And more than a third of respondents overall (**37.2%**) felt that there was more of a stigma being a man, rather than a woman, with M.E.

“The look in my kids’ eyes because I can’t do things is one of the most difficult things to deal with. They couldn’t understand that if I walked upstairs twice in one hour, I would collapse. Now, if they see me attempting to make a cup of tea and my hands are shaking, they will take over. It’s a strange situation with my children starting to look after me: that wasn’t supposed to happen for some years.”

P.G. Staffs

“There is no question that M.E. had an impact on my identity as a man. To a greater or lesser extent, my identity was bound up in what I did – my work, my role as a father and husband. My illness has forced me to look deeply at what and who I think I am...”

D.B. Southampton

Speaking Out

The World Health Organisation recognises M.E. as a neurological illness and the government's funding of specialist M.E. clinics is an acknowledgement that it is a serious health problem. On a day-to-day basis, however, many people with M.E. still face prejudice and misunderstanding. And the impact of being disbelieved when suffering can only exacerbate a sense of isolation and pain. So it isn't surprising that some are cautious about disclosing their condition. In our research on men and M.E. we asked our respondents about 'going public'.

"I've only recently started telling employers about M.E. as I worried that it would affect my work opportunities. And I didn't tell my friends or family for a number of years, as I wasn't sure how they would react."

C.S. Sussex

- When first diagnosed, almost a third (**30.3%**) chose not to disclose their illness to their employers

Of these:

- **53.7%** chose not to tell because they feared losing their job
- And **74.1%** felt the severity of the illness would not be recognised

But it is not just in the work place that people fear prejudice.

- **88.5%** of all respondents chose not to disclose their illness to their friends when first diagnosed
- And **39.1%** didn't tell their family or friends

When asked why they hadn't told family or friends:

- **79.2%** thought they wouldn't understand the severity of the illness
- **49.9%** thought they would not believe the diagnosis of M.E.
- And **28.6%** felt ashamed of having being diagnosed with M.E.

"Being a big chap – I'm 6'5" and shave my head – and not looking particularly ill doesn't help in terms of perceptions. People don't know that, for example, if I walk for over 10 minutes I feel as if my joints are on fire."

P.G. Staffs

Our Men & M.E. campaign has been endorsed by the following organisations:

Action on Pain
The Association of Teachers and Lecturers
BECTU
The British Home
Carers UK
Community Service Volunteers
Contact A Family
Counsel & Care
Crossroads Caring For Carers
DIAL UK
Disability Alliance
Family Welfare Association
Fibromyalgia Association
NACODS
NUS
Nationwide
Northwest Development Agency
Pain Concern
Princess Royal Trust For Carers
Professional Association Of Teachers
RADAR
Royal & Sun Alliance
Shaw Trust
Society of Merchant Venturers
United Road Transport Union

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 approximately 250,000 people in the UK and has a devastating impact on many more through its effect on family and friends.



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