

# Severely neglected



Membership survey  
March 2001



incorporating  
WESTCARE UK

M.E. in the UK

# M.E. in the UK – the reality

It is widely estimated that at least 240,000 people in the UK have M.E.

Despite its prevalence, there continue to be reports of severely ill people being unable to access the most basic services; services that people who have other chronic illnesses more widely recognised than M.E. can access as a matter of course.

It is in this climate that Action for M.E. conducted a major study of its members, in order to establish what their experiences were in the fields of health and social services and to assess what the ramifications were for the wider M.E. community throughout the UK.

Surveys were distributed to AfME's 7,529 members in August 2000 of whom 2,338 responded (31%), making it the biggest survey ever done of M.E. in the UK.

As the report shows, the findings were profoundly disturbing. They reveal a catalogue of failure and discrimination. Perhaps the most disturbing fact that emerges from the report is that those who are most severely ill get the least support and care.

## **In summary, the conclusions are:**

- 77% experienced severe pain because of the illness
- Over 50% had felt suicidal as a result of the illness
- 33% received a diagnosis only after 18 months and 52% reported that this had made "a huge difference" to the severity of their illness
- Nearly 2 out of 3 had received no advice from their GP on managing the illness
- 70% are either never able, or are sometimes too unwell to attend a doctor's clinic
- 80% of those who are currently bedridden by M.E. report that a request for a home visit by a doctor has been refused
- Many people do not receive state benefits to which they are clearly entitled and desperately in need of to survive

**Action for M.E. believes that this report should act as a wake-up call to the statutory agencies which are presently failing a great many people with M.E. We have made a number of recommendations which are at the end of the report.**

# Severity and Impact

M.E. is described by the World Health Organisation as a disease of the nervous system. For some the illness is manageable, allowing the continuation of a fairly normal life. However, many are so severely affected that they are bed-ridden for months, even years, on end.

Participants were asked about their level of severity:

1. 2,076 (89%) of the respondents (28% of those mailed) replied that they are or have been severely affected (i.e. either bed-ridden or house-bound).
2. Of the 2,338 respondents, 710 (30.4%) are currently severely affected.
3. 110 (4.7%) are very severely affected i.e. "bedridden – totally reliant on others for care".
4. 957 (41%) reported having been bedridden now or in the past.
5. 1,211 (58%) experienced this level of disability for over a year and 495 (24%) were at this level for over four years.
6. 1,176 (50.3%) replied "yes" to the question "Have you ever felt suicidal as a result of your illness".
7. Those who have had the illness worse, with the most severe pain, and who have had late diagnosis and management, are the most likely to have considered suicide.
8. 35% of respondents use a wheelchair.
9. 14% described themselves as deteriorating while 25% were improving.
10. 4 out of 5 suffered severe pain as a result of their illness. 29% reported experiencing severe pain much of the time.

*89% replied that they are or have been severely affected*

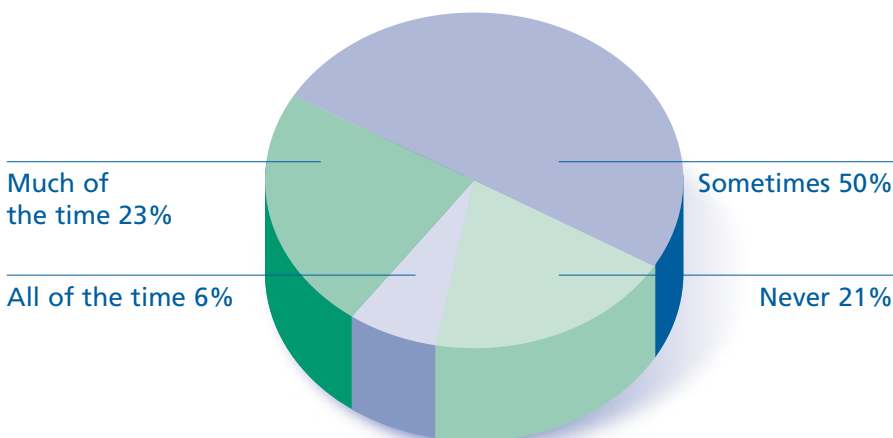
**Deteriorating 14%**

**Not improving or deteriorating 60%**

**Improving 25%**

**Other 1%**

## Are you in severe pain?



Note: Fluctuations in each of these groups are common

*33% waited more than 18 months for a diagnosis*

## Diagnosis

There is no definitive test to diagnose M.E. so the illness is identified by a process of elimination. Action for M.E. believes that early diagnosis, coupled with sound advice on management can help prevent the illness becoming severe.

Participants were asked about the diagnosis of their illness:

1. Whilst 30% were diagnosed within six months, 33% waited more than 18 months and 6% were diagnosed only after ten years.
2. 42% were diagnosed by their GP, 39% by a consultant and 19% by an M.E. specialist.
3. Participants were asked what difference an earlier diagnosis would have made to the severity and/or chronicity:

**The effect that an earlier diagnosis would have made**

**no difference 26%**

**a little difference 22%**

**a huge difference 52%**

*65% did not receive advice on managing their illness*

## Management & Advice

Sensible advice on managing M.E. early in the course of the illness can, in many cases, encourage recovery. It is important that doctor and patient work in partnership to establish the best method of recovery.

Participants were asked about their experiences of management and advice:

1. The question was posed "Did you receive advice from your GP on managing your illness – within six months of onset / after six months of onset / Not at all".
2. 41% felt that this lack of advice contributed to their illness becoming more severe or chronic.

**Did you receive GP advice on managing your illness?**

**before 6 months 19%**

**after 6 months 17%**

**not at all 65%**

# Accessibility to Healthcare Services

Action for M.E. believes that it is a basic right that those who are ill are given access to healthcare. The survey revealed that, in fact, the most severely affected M.E. patients receive the worst level of support.

Participants were asked about their access to healthcare since developing M.E.:

1. Participants were asked whether their condition was regularly monitored, and if so, by whom. Only 47% reported that their condition was monitored. In only 16% of cases was a specialist involved.

*only 47% reported that their condition was monitored*

## Is your condition regularly monitored by an NHS practitioner?

No **53%**

GP **31%**

Consultant **3%**

Psychiatrist **1%**

ME/ CFS specialist **6%**

Combination (e.g. GP and specialist) **6%**

2. Of the 110 currently bedridden, only 50 report that they are monitored.
3. 53% of those who have considered suicide at some point are not monitored by their doctors.
4. 8% reported that they were never well enough, and 62% were sometimes too unwell to attend a doctor's clinic.
5. 935 had requested a home visit by a doctor, 17% reporting that their request had been refused.
6. Of the 110 who are currently bedridden, 88 (80%) have been refused a request for a home visit by a doctor.
7. 240 had requested a home visit by a nurse, 13% reporting that their request had been refused.
8. 334 are visited by members of community teams.

Occupational therapists **182**

District Nurses **92**

Physiotherapists **90**

9. Of the 110 currently bedridden, only 60 report that they are visited by members of their community NHS teams.

*of those admitted to hospital more said they had been made worse*

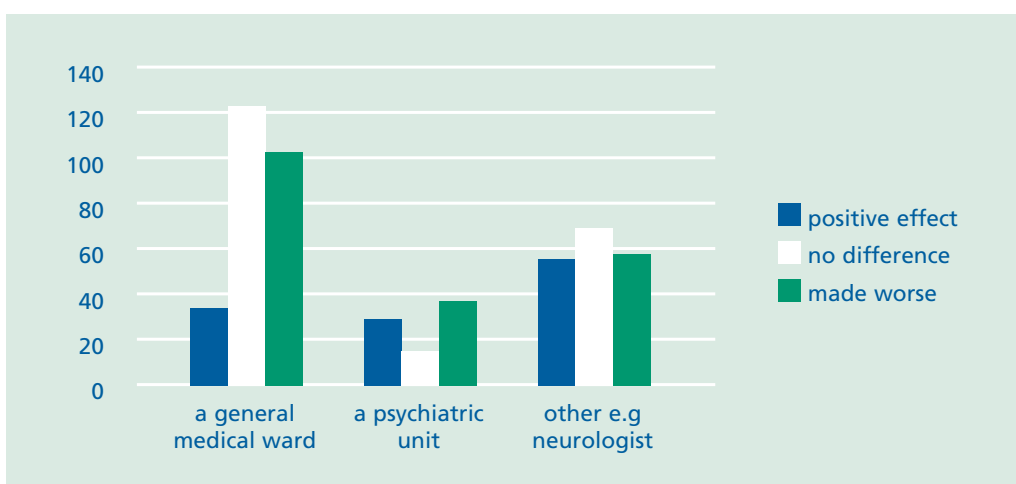
## In-patient care

There is an enormous gap between the number of people severely affected by M.E. and specialist in-patient provision for the illness in the UK.

The most severely affected M.E. patients frequently have painful sensitivities to light, noise and chemicals. The survey revealed that, where patients have been admitted to general wards, many report being made worse because of the environment or treatment they received for their illness.

Participants were asked about their experience of in-patient care:

1. Of those who had been admitted to hospital, more reported having been made worse than better.



Note: Some also reported mixed results

## Benefits

Like all seriously ill people, M.E. patients are entitled to state benefits.

However, there has been repeated evidence that many M.E. sufferers have been refused benefits to which their level of disability would seem to entitle them.

Participants were asked about their experiences of accessing benefits.

1. 64% of respondents (1,490) received state benefits.
2. 44% of respondents (1,039) had applied for Disability Living Allowance (DLA).
3. 44% of those who applied for DLA had to go to appeal.
4. Of those who applied for DLA, 25% were rejected (with or without appeal).

Notes to the survey

1. 2,338 replies to the survey were received – a response rate of 31%.
2. 10% were aged under 18.
3. 81% of respondents were female.
4. 39% were aged between 26 and 40 at the time of onset of M.E. 38% were aged between 41 and 65 at time of onset.
5. 15% had more than one family member who had had ME and 4% had two or more affected.

*44% who applied for DLA had to go to appeal*

# Management and Treatment

Pacing and rest were reported to have been most beneficial and graded exercise was reported to be the treatment that had made most people worse.

	Helpful	No Change	Made Worse
Drug medication for pain	61%	28%	11%
Drug medication for sleep	67%	17%	16%
Pacing your activities	89%	9%	2%
Graded exercise	34%	16%	50%
Diet changes	65%	32%	3%
Nutritional supplements	62%	36%	3%
Rest, including bed rest	91%	8%	1%
Cognitive Behavioural Therapy	7%	67%	26%
Other	75%	11%	14%

## Private Practitioners

There was evidence of extensive use of non-NHS practitioners, with only homeopaths and herbalists receiving a less than 50% response of having proved beneficial.

	Helpful	No Change	Made Worse
Doctor	50%	39%	11%
Counsellor/psychotherapist	52%	36%	12%
Osteopath/chiropractor	58%	29%	13%
Homeopath	44%	45%	11%
Herbalist	41%	46%	13%
Nutritional therapist	60%	33%	7%
Healer	51%	44%	5%
Complementary therapist/ other e.g. acupuncture, aromatherapy, massage, reflexology, yoga	61%	29%	10%

# Action is urgently needed

It would be disingenuous to claim that this report details the experiences of every single M.E. patient in the UK. On the other hand it would be absurd to suggest that it is only Action for M.E. members who will have experienced an NHS which fails them and a social services system which seems to discriminate against them.

Rather, it would be reasonable to assert that this report typifies the terrible struggle that many M.E. sufferers have to endure just to get the most basic level of care and support. It also indicates that the thousands of people who are most severely affected by M.E., who are bed-ridden and cut-off from society, receive the worst level of treatment from the NHS and Benefits Agency.

## Action for M.E. makes the following recommendations to address the issues raised in this report:

1. Establishment of community services, including monitoring of severely ill patients.
2. Establishment of specialist services including appropriate in-patient care and specialist out-reach services aimed at those who are bed-ridden by M.E.
3. Guidelines on early diagnosis and prompt information issued to all doctors.
4. Government sponsored research into the cause and management of M.E.
5. Education and training for all health professionals on M.E.
6. Education and training for Benefits Agency staff on the impact of M.E.

It is clearly a misconception to think of M.E. as a "mild" illness. It is neither mild for the people who have it, nor is the impact on the wider community mild. The loss to the economy is substantial, in terms of both lost revenue and social costs. A large portion of the M.E. community is, at one level invisible, but we should be under no illusions that the impact of this illness affects far more than the 150,000 people who actually have it.

**This report clearly demonstrates the level of isolation and exclusion suffered by thousands of M.E. patients.**

**It is time that those who have M.E. are given the type of treatment and services that the illness so clearly deserves.**



incorporating  
WESTCARE UK

Action for M.E.  
73 Watling Street  
London EC4M 9BL

**tel:** 020 7329 2299  
**fax:** 020 7329 3600  
**website:** [www.afme.org.uk](http://www.afme.org.uk)  
**e-mail:** [london@afme.org.uk](mailto:london@afme.org.uk)

Registered charity number: 1036419