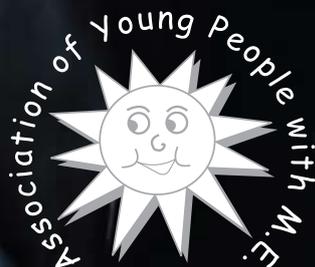


M.E. 2008: What progress?

Initial findings of a national survey of over 2,760 people with M.E. focusing on their health and welfare

M.E. Awareness Week
11-17 May 2008

action for 



What is M.E.?

M.E. (Myalgic Encephalomyelitis/Encephalopathy) is a chronic, fluctuating illness, also known as Chronic Fatigue Syndrome (CFS) and sometimes diagnosed as Post Viral Fatigue Syndrome (PVFS).

It affects over 250,000¹ people in the UK.

Common symptoms include persistent exhaustion, un-refreshing sleep, poor concentration and memory, headache, muscle pain and digestive problems.

Patient surveys indicate that 25% of people with the illness are so severely affected that they become housebound or bedbound, some for many years.

M.E. can affect anyone, at any age and from any ethnic group.

Action for M.E. and AYME

Action for M.E. and the Association of Young People with M.E. (AYME) are two of the UK's leading charities dedicated to improving the lives of people with M.E.

Action for M.E. (www.afme.org.uk) provides information and support to people affected by M.E. and their carers and campaigns for more research and better treatments and services for them. The charity has a volunteer support line, welfare rights line and a range of helpful booklets and leaflets.

AYME (www.ayme.org.uk) is the largest charity for children and young people with M.E., providing information and support to children and young people with M.E./CFS, their families, carers and professionals. AYME raises the awareness and understanding of the impact of this condition on young people. The charity's membership services, run by young people with M.E. aged under 26, focus on reducing the isolation felt by young people.

On the cover: Robert Kaye, aged 27, who has had M.E. for seven years.

(Photo: Martin Bennett)

Contents

Executive summary	3
The context	5
Introduction	6
– Purpose	
– Response	
Severity of illness	7
Diagnosis	8
GPs and M.E.	9
Specialist health services	10
Treatments / symptom management	12
Welfare benefits and social support	15
What has changed since 2002?	16
Conclusion and recommendations	17
Acknowledgements	19

Executive summary

"I do not feel that my GP believes in M.E."
(Respondent from Devon)

The results show that there have been significant improvements in many aspects of health service provision since 2001. However, there are also areas of persistent concern.

Respondents

2763 surveys were completed, 1799 in hard copy and 964 online. Four out of five respondents were female. Respondents ranged in age from under 11 to over 66 years but the majority (over 54%) were aged 41-65.

Over 20% had had M.E. since childhood or their teens (6% before they were 12). The majority (65%) had first become ill after the age of 25, 34% between the ages of 26 and 40 and just over 30% when they were aged 41-65. Less than 1% came down with M.E. over the age of 66.

Virtually all the respondents (97%) described themselves as white British and most (76%) lived in England. Of the remainder, just under 5% lived in Scotland, 3% in Wales and less than 1% in Northern Ireland.

Severity of illness

Nearly 29% of respondents were so severely affected that they were generally housebound and a further 4% were bedbound. At their worst, 36% had been bedbound and a further 52% had been housebound.

While just over 12% had been this bad for less than three months, 18% had been at their worst for up to two years, 18% for 2-4 years and nearly 6.5% for over 10 years.

Diagnosis

Nearly 60% of respondents were diagnosed within a year and the number waiting more than 18 months has decreased from 33% in 2001 to 29% in 2008.

However, 40% – two respondents in five – waited a year or more for a diagnosis and one in five people, including more than one in four children under 12, waited more than two years to get a diagnosis.

As some research suggests a link between time taken to diagnose M.E. and the subsequent severity of the illness, early diagnosis is important – particularly in children, where the prognosis becomes more optimistic, especially if specialist help is given.

GPs and M.E.

Respondents reported that 40% of GPs were supportive and a further 23% were very supportive but only 2% felt their GP was well informed. One in three people who responded to the survey said that their GP was either unsupportive or less informed than he or she should be about the illness. Most (24%) rated their GP's level of service as fair, some (20%) as best possible, given that there's no cure but 35% described their GP's service as poor (18%) or very poor (17%).

24% of respondents who were housebound or bedbound by M.E. no longer saw their GP.

Specialists

It is not always clear what is meant by an NHS specialist eg. a person with M.E. might see a specialist in immunology but that immunologist may or may not be a specialist in M.E. Specialist NHS CFS/M.E. multi-disciplinary services have been set up in some areas of England but most respondents from England (48%) did not know if they were receiving their specialist treatment from one of them or not.

When asked about the problems they experienced in seeing an NHS specialist, the lack of a local NHS specialist was the most common reason given (805 respondents).

516 people were too ill to see a specialist. Of these, 91 were children and young people.

Two were children aged under 11 years, 25 were aged 12-17 and 64 were aged between 18-25 years old.

Treatments / symptom management

All but two of the interventions listed were found to be helpful by more than 60% of the respondents, which is encouraging but there is still no cure for M.E.

Pacing was found to be the most helpful intervention – 82% of respondents found it helpful.

50% of respondents said they found cognitive behaviour therapy (CBT) helpful compared to 7% in 2001. 45% of patients who said they had received graded exercise therapy (GET) or graded activity found it beneficial compared to 34% in 2001.

However, 34% of patients who said they had received GET or graded activity and 12% of those who said they had received CBT reported that they felt worse after these treatments.

Welfare benefits and social support

Of the 1015 people receiving Disability Living Allowance, 37% (376) had to go to appeal but 72% won their appeal. This would seem to indicate that far too many people are turned down inappropriately when they first apply.

86% of respondents relied on carers within the family. The majority of carers (1266) were aged 36-65 but 312 relied on someone aged 66 or over. Older carers will increasingly have their own health and support needs.

More research needs to be done to establish how many people who are affected by M.E. are entitled to support from the Department for Work and Pensions and local social services and how many are/are not receiving it.

Gaps in services – geographical trends

The initial results of this survey did not indicate any statistically significant geographical trends. However, more detailed analysis is to follow. Responses from Northern Ireland, Scotland and Wales were small.

Summary of recommendations

- improve the speed of diagnosis
- address the lack of local M.E. services
- ensure the provision of individualised, person-centred care plans, including regular structured reviews, as recommended by the National Institute of Health and Clinical Excellence (NICE)
- identify the number of people with M.E. who are housebound or bedbound, dependent upon aging carers and/or who live alone, who need further support from health and/or social services
- GPs to offer M.E. patients an annual health review as a minimum standard, including patients no longer receiving active treatment
- establish why a significant proportion of the survey respondents who said they had received GET and CBT said it made them worse and determine how this issue is to be addressed
- ensure that only suitably trained health professionals, with sufficient knowledge of M.E., deliver GET
- ensure that healthcare professionals, including GPs, receive adequate training as recommended by the NICE guideline
- work with the Department for Work and Pensions to undertake a systematic analysis of the application processes and decision-making procedures for Disability Living Allowance, in order to establish why so many people have to go to appeal.

The context

"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."

(M.E. in the UK: Severely Neglected report, 2001)

In 2001, Action for M.E. published M.E. in the UK: Severely Neglected, which described the severity of the illness and the healthcare available as experienced by 2,338 of the charity's members. The charity found that:

- 77% of its members experienced severe pain because of the illness
- of the 2338 respondents, 710 were either bedbound or housebound
- 33% had received a diagnosis only after 18 months
- 80% of those who were bedridden by M.E. had been refused a request for a home visit by a doctor
- 89% had found pacing – an approach which balances activity and rest – to be the most successful treatment
- 34% had said that GET had been helpful, 50% felt that it had made them worse.
- only 7% had felt that CBT had been helpful while 26% felt it made them worse.
- 44% had applied for Disability Living Allowance and 44% had had to go to appeal. Of those who applied, 25% were rejected (with or without appeal).

In 2002 a milestone report about M.E. was produced by an independent working group set up by the UK's Chief Medical Officer (CMO).

The CMO's report said that people with M.E. and their carers often encountered a lack of understanding from healthcare professionals and that this seemed to be associated with inadequate awareness and understanding of the illness among many health professionals and in the wider public. It also said that many patients complained of difficulty in obtaining a diagnosis.

"There is evidence of under-provision of treatment and care, with patchy and inconsistent service delivery and planning across the country," the working group reported. There was also: "A paucity of good research evidence and very little research investment for a serious clinical problem that in likelihood has a pervasive impact on the individual and the community.

"Insufficient attention has been paid to differential outcomes and treatment responses in children and young adults, the severely affected, cultural, ethnic and social class groupings."

The Department of Health responded by endorsing the need for more research and agreeing that health and social care professionals should provide appropriate treatment and care, recognising that knowledge and skills needed to be improved.

In 2003 the government announced £8.5 million ring-fenced funding over two years (2004-06) to set up specialist multi-disciplinary services for M.E./CFS in England. From 08/09 onwards, £6.5 million per annum has been put into host Primary Care Trust budgets there. In August 2007 NICE produced guidance for healthcare professionals on the diagnosis and management of the illness in adults and children.

While Action for M.E. and AYME welcomed them as landmarks in the campaign to speed up diagnosis and improve health services for people with the illness, there have been concerns about the emphasis placed on CBT and GET – and doubts about the ability of NHS budget-holders to enable local health services to meet the needs of people with M.E. in the holistic and patient-centred way recommended by NICE.

Without doubt, there are some healthcare professionals and specialist services whose care and support have been the best possible, given that there is as yet no cure for M.E. The establishment of multi-disciplinary services for M.E. in England has made NHS specialists more accessible in many parts of the country. At the same time, health services for people with M.E. across the UK remain piecemeal, some children's services have closed and some people who are too ill to travel are still expected to travel too far.

Progress has been made but there are doubts about the capacity of the NHS, with its limited resources, to meet the needs of those who are most vulnerable and who need help most – children and the long-term severely affected.

Introduction

"I first had the symptoms and was bedridden in 1983. The GPs test each new flare up of symptoms, and medicate as they can. But I've been told I get referred to hospital 'too often.' I have been discouraged from taking up doctors' time. The locums are the most help now."

(Respondent from Midlothian)

In March 2008, Action for M.E. and the Association of Young People with M.E. (AYME) distributed 10,000 surveys to people with M.E. through their membership magazines, *InterAction* and *Cheers*, and other outlets. An online version of the survey was also available on the charities' websites and the link was circulated widely.

Purpose

The purpose of the survey was to collect data in a structured and comparable way, to help us to identify:

- any gaps or differences in health services and benefits experiences which exist across the country
- areas of good practice, to use as a benchmark for improvement elsewhere
- whether changes have taken place in health care and welfare services since a similar survey was undertaken by Action for M.E. in 2001
- how many people with M.E. have to go to appeal before they are awarded the welfare benefits to which they are entitled.

Response

The total number of surveys returned by the deadline and in time to be included in the analysis was 2763, the biggest response ever received by Action for M.E. and AYME.

Of these 2763, 1799 were hard copy surveys and 964 were completed online.

Just under 82% of respondents were female and just over 18% were male, a slightly higher female preponderance than is suggested by most epidemiological studies.

The age range of respondents was as follows (not everyone indicated their age range):

Age	Percentage	Responses
0-11 years	1%	22
12-17 years	6%	163
18-25 years	11%	291
26-40 years	21%	535
41-65 years	54%	1406
Over 66 years	7%	185

Their age at onset of illness was:

Age	Percentage	Responses
0-11 years	6%	161
12-17 years	15%	396
18-25 years	14%	379
26-40 years	34%	918
41-65 years	30%	807
Over 66 years	1%	22

The majority (97%) of respondents were white British, so the survey does not capture the experiences of people within black and minority ethnic communities although efforts had been made to target this group.

Most of the surveys came from people in England (76% or 2100 responses). Scotland accounted for 5% (132 responses), Wales 3% (87) and Northern Ireland 1% (24). A further 15% (420) could not be matched to a country as no postcode or address was given.

Notes on survey

This document reports the initial findings of the survey. Detailed analysis is still underway.

As with any survey of this type, respondents were self-selecting, therefore they cannot be assumed to be representative without systematic sampling to avoid intrinsic bias. The number of respondents from black and minority ethnic communities is very low, which may reflect the charities' membership profiles. In addition, over 59% of respondents have had the illness for more than five years and of those, 34% have been ill for over 10 years, so the sample could be skewed to reflect the experiences of people who have been ill for a long time.

NB. Not all respondents answered all the questions. Some questions could be answered by ticking more than one response. Percentages in this report reflect the proportion of responses, rather than the proportion of respondents. Percentages of .5+ have been rounded up to the nearest whole number and percentages of .01-.5 have been rounded down in this report (not in the online presentation), simply for ease of reading.

Severity of illness

"I am remarkably lucky to have people working here with 20+ years experience of M.E. I know other areas of the country are not as well served."

(Respondent from Sheffield).

Nearly 60% of respondents had been living with M.E for in excess of six years (the period of time elapsed since diagnosis).

Of the 155 matched people² who were under 12 at age of onset, 22 were still under 12 when they completed the survey in March 2008, 47 were aged 12-17 and 49 were aged 18-25.

22 were aged 26-40, 12 were 41-65 years old and three were aged over 66 years, demonstrating the long-term nature of the illness in some people.

Of the 378 matched people³ who were aged 12-17 at age of onset, 116 were still in that age range when they completed the survey, 168 were now aged 18-25, 70 were aged 26-40, 22 were aged 41-65 and two were over 66 years of age.

Most respondents (875 matched⁴) were aged between 26 and 40 when their illness started and the majority of these (614) were aged 41-65 when they completed the survey.

22 people developed M.E. when they were over 66 years old.

Common symptoms

Common daily symptoms were poor concentration or memory (84%), overwhelming exhaustion (83%), muscle pain (71%), abnormal sleep (70%), fluctuating body temperature (63%), flu-like malaise (54%), headache (53%), dizziness (46%), constipation or diarrhoea (42%), burning/shooting pain/fibromyalgia (36%) and nausea (32%).

On average, people were experiencing six out of the eleven symptoms listed. Other symptoms included anxiety, depression, joint pain, various sensitivities (eg. to light, noise, different foods or chemicals), tinnitus and visual problems.

Levels of severity

At the time when they completed the survey, 23% of respondents were able to lead a near-normal life and 44% were mobile over short distances. 29% were housebound and 4% were bedbound/totally reliant on others for care.

At their worst, 88% were either bedbound (36%) or housebound (52%), typically unable to walk for 15 minutes, prepare meals, do light housework or drive a car. 41% were unable to shower, bathe or wash themselves and 15% were unable to eat unaided.

While just over 12% had 'only' been this bad for less than three months, 18% had been at their worst for up to two years, 18% for 2-4 years and nearly 6.5% for over 10 years.

Most (63%) described their current condition as fluctuating, in relapse or deteriorating. Only 15% felt that they were getting better and only one in five could lead a near-normal life.

Severity and time since diagnosis

Of those who were bedbound, 43% had been diagnosed over 10 years ago, 28% between six and ten years ago, 21% two to five years ago and 8% within the past two years.

Of those who were housebound, 36% had been diagnosed over 10 years ago, 26% between six and ten years ago, 25% two to five years ago and 13% within the past two years.

31% of those who were living a near-normal life were diagnosed over ten years ago, 23% between six and ten years ago, 29% between two and five years ago and 16% in the past two years.

Diagnosis

“Before being diagnosed by a consultant in 2006 I had numerous visits to doctors and emergency doctors when I felt so ill. The lengthy (time until) diagnosis I believe made me worse as I did not know to rest etc.”

(Respondent from Cornwall)

There is no definitive test to diagnose M.E. so the illness is diagnosed on the basis of characteristic features and by ruling out other conditions which seem similar. Some research indicates that early diagnosis, coupled with sound advice on management, can help prevent the illness becoming severe.

Over 14% of our survey respondents had been diagnosed within the last two years. 27% were diagnosed between two and five years ago, 25% between six and ten years ago and the majority, 34%, more than 10 years ago.

How long did it take to be diagnosed?

Just over 30% were diagnosed within six months, 59% within a year, over 29% waited more than 18 months and of these, 20% waited more than two years.

Although it is encouraging to see that nearly 60% were diagnosed within a year, and the number waiting more than 18 months has decreased from 33% in 2001 to 29% in 2008, **40% – two people in five – waited a year or more for a diagnosis.**

Of the 154⁵ people, including adults, who were aged 0-11 at age of onset, most 34% (52 children) were diagnosed within six months and another 27% (42 children) were diagnosed within seven to 12 months. However, another 27% (42) took more than two years to get a diagnosis.

33% (124) of the 373 people⁶ aged 12-17 at age of onset were diagnosed within six months, and 30% (113) at between seven and 12 months. Over 16% (60 people) took more than two years.

Overall, children under 12 benefited from a slightly better rate of early diagnosis than adults but nevertheless, more than one in four had to wait over two years for a diagnosis.

Most people (857⁷) experienced the onset of their illness between the ages of 26-40 and 30% of these (257) received a diagnosis within six months and 29% (250) within seven and 12 months. Although 10% (89) waited 13-18 months to obtain a diagnosis and 9% (78) waited 19 months to two years, over 21% (183) people waited over two years.

In both adults and children, delays in diagnosis could adversely affect their prognosis.

Who provided the diagnosis?

42% (1098 people) were diagnosed by their GP and a further 37% (973) by an NHS consultant. 13% were diagnosed by a private consultant, 5% (139) were self diagnosed and 3% (67) indicated some other route to diagnosis, eg. rheumatologist, neurologist, paediatrician, occupational therapist.

Between six and ten years ago, a person was more likely to be diagnosed by a GP (45%) than an NHS consultant (34%) or a private consultant (13%). In the past two years, the diagnosis is more likely to come from an NHS consultant (45%) than the GP (38%) or private consultant (9%). Just over 3% of people were self-diagnosed six to ten years ago and that has not changed much; just under 4% self-diagnosed in the past two years.

GPs and M.E.

“There are three GPs in my practice. Sadly my own GP retired at the end of March. He has been enormously supportive. Another practitioner is also extremely good but she too is leaving. The third GP does not seem to believe in M.E.”

(Respondent from Lincolnshire).

GPs play a vital role as the gatekeepers to diagnosis, treatment and specialist referrals.

Over 22% (598) of respondents said that they had seen their GP in the last month with a further 28% having seen their GP in the previous two to six months. However, over 30% (815) no longer saw their GP about their M.E. – a significant minority.

Of the 761⁸ people who were housebound when they completed the survey, 24% (183 people) had seen their GP in the last month, 31% (234 people) had seen him or her in the last two to six months and 17% (130 people) in the last six to twelve months. However, **25% (189 people) no longer saw their GP at all and almost 2% (13 people) were not registered with a GP.**

Of the 110⁹ people who were currently bedbound, 27% (30 people) had seen their GP in the last month, 25% (27 people) had seen him or her in the last two to six months and 21% (23 people) in the last six to twelve months. However, 18% (20 people) no longer saw their GP at all and 8% (9 people) were not registered with a GP.

24% of people who were housebound or bedbound by M.E. at the time they completed the survey, no longer saw their GP at all, indicating a hidden burden of illness.

Information and support

Respondents reported that 40% of GPs were supportive and 23% very supportive but **only 2% (49 people) felt their GP was well informed.** 18% (482 people) said that their GP was less informed than s/he could be. 11% said their GP was unsupportive.

This means that overall, although two thirds of GPs are supportive, one in three is less informed or supportive than their patients think they should be.

When asked, “How do you rate the service your GP has provided in recent years (since 2005)?” most (24%) said fair. Nearly 20% ticked “best possible, given there’s no cure” and over 21% said good but a significant minority of 35% said poor (18%) or very poor (17%).

Treatment options

GPs were most frequently reported to be discussing (and providing) medication for pain, sleep and mood problems with respondents, (1229, 1099 and 1128 responses respectively).

GPs’ provision of pacing was relatively low (only 489 said their GP discussed it with them and 178 said that their GP provided this treatment since 2005), although **respondents found pacing by far the most helpful treatment** (1461 responses). By comparison, 891 NHS specialists and 638 NHS therapists discussed pacing with respondents while 721 (combined) provided this as a treatment.

323 GPs discussed complementary therapies, compared to 163 NHS specialists and 80 NHS therapists.

Home visits

200 respondents said that they had asked their GP for a home visit but been refused. 389 indicated that they had requested and received a home visit. A significant minority said that they had also been refused a home visit by a specialist doctor, a nurse, occupational therapist or physiotherapist.

These results are hard to interpret in today’s NHS, especially as it is unclear when respondents requested a home visit and how ill people were when their request for a home visit was denied. Nevertheless, it does indicate that a significant minority might not be receiving the domiciliary care they need.

Specialist health services

"I was very lucky to have a specialist consultant at the local hospital who knew all about me and designed a programme for me to follow. It was a relief to be diagnosed as people thought I was faking it. I am fully recovered now after following the help from my consultant. I am back at school almost full time and doing my GCSEs. I also now have a social life and go out with friends for the first time in two years!"
(Respondent from Brighton)

It is not always clear what is meant by an NHS specialist eg. a person with M.E. might see a specialist in immunology but that immunologist may or may not be a specialist in M.E.

Specialist NHS CFS/M.E. multi-disciplinary services have been set up in some areas of England but most respondents from England (48%) did not know if they were receiving their specialist treatment from one of them or not.

Range of specialisms

Of those who had seen a specialist, most (just over 50%) had seen a physician such as an immunologist, rheumatologist or endocrinologist (other physicians were also listed under 'Other'). A further 11% had seen a paediatrician, 6% an occupational therapist, 6% a psychiatrist, 4% a specialist M.E. nurse, 4% a clinical psychologist, 2% a physiotherapist and 17% indicated 'Other.'

Within the 'Other' category, specialists typically included: neurologist, GP, M.E. specialist, infectious diseases consultant, virologist, homeopath, immunologist or a named professional.

Overall, a broad range of professional expertise was represented amongst the specialist teams. The assertion by some patients that the provision of specialist services is dominated by psychiatrists or psychologists was not supported by respondents.

Specialists seen

30% of people in England said they were receiving their specialist treatment from one of the new services and 22% said they were not.

Almost 73% of respondents had seen an NHS specialist and 61% of respondents waited less than six months to do so. Although the survey was UK wide, these figures probably reflect the benefits of investment in M.E. services in England in recent years. Implementation of the NICE guideline should see further improvements as long as further resources are made available by care commissioners.

However, 26% people had not seen an NHS specialist and 59% had not seen an NHS specialist in the last year.

More detailed geographical analysis is required to establish whether or not there are particular problems in different health authority areas.

2% had not seen an NHS specialist but had an upcoming appointment. 12% of those who had seen a specialist indicated that they had seen one within the last month. Just under 20% had seen a specialist two to six months ago, almost 10% had seen one between seven and twelve months ago.

Children and young people

Just under 69% of children under 12 and just under 68% of young people aged 12-17 saw a specialist within six months, and a further 6% of children and 13% of young people saw one within a year. We do not know at what age they saw the specialist.

However, some are not receiving specialist help for much longer, which could severely affect their chances of recovery. **Eight 12-17 year olds were not seen for 18 months to two years and five children under the age of 11 were not seen for over two years.**

Further referral

Following their initial assessment by an NHS specialist, the most common referral was to an occupational therapist (450 people).

361 people were referred to a physiotherapist, 241 to a clinical psychologist, 200 to a physician such as an immunologist, rheumatologist or endocrinologist, 190 to a psychiatrist, 157 to a dietician, 148 to a specialist M.E. nurse, 93 to a counsellor and 38 to a paediatrician.

Over 400 indicated that they had been referred to someone else. Common examples included CBT specialist, ear nose and throat specialist, haematologist, homeopath, neurologist, pain clinic.

Nearly 29% of respondents had had one or two appointments with NHS specialists overall. Over 26% had had three to six appointments, 11% had had seven to eight and 20% had had thirteen or more.

30% of people who had been diagnosed over 10 years ago had only had one or two appointments with NHS specialists and 28% had had between three and six appointments.

Barriers to accessing services

Overall, **the lack of a local NHS specialist was the most commonly cited reason given by respondents experiencing a problem seeing an NHS specialist** (805 responses)¹⁰, even for people who were well enough to lead a near normal life. Distance/travel time was an issue for 550 respondents.

Of the 805 people who lacked a local NHS specialist, at least 134 were children and young people. Of these, five were aged 11 or under, 34 were aged 12-17 and 95 were 18-25 years old. Three children under 11 indicated that distance/travel time was a problem, as did 26 of the 12-17 year olds and 72 of those aged 18-25.

135 people (all ages) had travelled over 100 miles to access NHS treatment, 204 had travelled 51-100 miles, 405 had traveled 26-50 miles and 560 had traveled 11-25 miles. 764 had been able to access NHS services within 0-5 miles and 481 within 6-10 miles.

Long waiting times for treatment or referral and a lack of information were also barriers (438 and 428 responses respectively). One respondent from Suffolk said: "When I finally got referred to a specialist clinic I received a letter saying that I could not even be put on the waiting list until the next financial year. The only emotion I can describe feeling when reading that letter is heartbreak."

73 young people ticked "lack of information," most (54) aged 18-25 years.

Too ill to see a health specialist

516 people were simply too ill to see a specialist, including 74 who were currently bedbound, 248 who were housebound and 147 who were mobile over short distances.

These results would indicate a serious mismatch between the pattern of NHS provision and the needs of the patient group.

Of the 516 people who were too ill to see a specialist, at least **91 were children and young people**. Two were children under 11, 25 were aged 12-17 and 64 were between 18-25 years old.

Long waiting times were an issue for 98 children and young people – for three of the under 11s, 24 of the 12-17 year olds and 71 of those aged 18-25.

A number of 'other' problems in seeing an NHS specialist were given. Comments included: "Didn't know there was one," "Doctor not referring," "Funding refused," "Never offered" and "PCT not funding."

Satisfaction rates

25% felt that their NHS specialist provided the best possible service, given that there is no cure for M.E. and a further 26% said their service was good. 19% rated it fair.

However, 13% rated their NHS specialist as poor and 17% as very poor.

Treatments / symptom management

"She told me that the only treatment available for me is graded exercise or CBT."

(Anonymous respondent)

People were asked which treatments they had tried since 2005. Although all but two of the interventions listed were found to be helpful by more than 60% of the respondents, there is still no 'cure' for M.E.

NICE recommends that healthcare professionals should offer GET and/or CBT to people with mild or moderate M.E. and to draw on the principles of CBT and GET when treating the severely affected.

Figures for CBT have shown significant improvement. 50% had found CBT helpful in recent years, compared to 7% in 2001. 12% still felt that CBT made them worse, compared to 26% in 2001.

Nearly 45% of respondents said that they had found GET beneficial, compared to 34% in 2001. In that year, 50% said that GET had made their M.E. worse, compared to 34% in 2008.

Of the 722 who said that they had tried GET, 467 (65%) had been treated by a GP or NHS specialist or therapist and 255 (35%) indicated that their treatment had been managed by someone else.

The comments under 'other' included NHS staff (eg. "NHS nurse," "pain clinic," "psychologist attached to GP's surgery," a named NHS hospital or unit and "hospital doctor"), private consultants including occupational therapists, physiotherapists, an osteopath, neurologist and psychologist and healthcare professionals not identified as either NHS or private (eg. "physio," nutritional therapist, dietician, counsellor.) Some said "self taught." Some people were advised by relatives ("My sister who has M.E.," "Mother is occupational therapist"). One said, "I know what to do having been trained by NHS specialist in 1992-2001."

The figures in the table overleaf indicate that improvements are taking place but the fact that 34% of respondents who said that they received GET or graded activity and 12% of those who said they received CBT perceived themselves to be worse after these treatments is a cause for concern. It will be important to establish why this happened and to determine how this issue is to be addressed.

It is vital that health professionals and patient groups work in partnership to ensure that only properly trained and experienced therapists deliver treatment to people with M.E.

The concern that treatment options are being heavily dominated by CBT and GET is not supported by the survey results.

Healthcare professionals, especially NHS specialists and therapists, were reported to have discussed pacing more often with patients (2018 responses) than GET (1191) and CBT (1198). Medication to ease pain, aid sleep and help mood were the most common treatments discussed, primarily with GPs.

Medication to improve mood helped 64% but it also made a significant minority (14%) feel worse. It is not clear from the survey if this reflects known side-effects, transitory or longer-lasting, or discontinuation/withdrawal symptoms.

Pacing

Both NHS specialists and therapists were reported to be discussing pacing with respondents more frequently than any other intervention. This was reflected as well in the treatment actually provided by NHS specialists and therapists since 2005. Pacing was the treatment that over 80% of respondents reported to be helpful.

Pacing remains the most helpful intervention.

Complementary therapy

1436 respondents had tried some kind of complementary therapy at some time. Of the options listed, 614 had tried acupuncture, 651 herbal remedies, 344 reiki, 100 lightning therapy, 103 reverse therapy or Mickel therapy.

616 respondents had tried other complementary therapies: the qualitative data on this is yet to be analysed.

It is clear that many people felt that they had benefited from complementary therapies but as with orthodox treatments, a significant minority made people worse. The charity's policy remains unchanged when it comes to therapies which claim to offer a cure, have not been subject to research published in respected peer-reviewed journals and require the payment of large sums of money. Whilst we understand people's desire to try therapies in their desperation to get well again, we strongly advise people to examine any claim with scepticism.

Results on treatment in 2008 (compared to 2001)

Treatment	Helpful	No change	Made worse
	2008 (2001)	2008 (2001)	2008 (2001)
GET	45% (34%)	21% (16%)	34% (50%)
CBT	50% (7%)	38 % (67%)	12% (26%)
Pacing	82% (89%)	15% (9%)	3% (2%)
Rest inc. bed rest	86% (91%)	13% (8%)	1% (1%)
Pain medication	74% (61%)	22% (28%)	4% (11%)
Sleep medication	76% (67%)	17% (17%)	7% (16%)
Dietary changes	68% (65%)	30% (32%)	2% (3%)
Supplements	61% (62%)	37% (36%)	2% (3%)
Extra questions 2008			
Medication to help mood	64% (n/a)	22% (n/a)	14% (n/a)
Other medication Eg. for nausea	71% (n/a)	23% (n/a)	6% (n/a)

Who provided the GET?

	Helpful	No change	Made worse
GP	43%	11%	45%
NHS specialist	46%	23%	31%
Other	57%	14%	29%

Complementary therapy

	Helpful	No change	Made worse
Acupuncture	56%	34%	10%
Herbal remedies	58%	36%	6%
Reiki	63%	32%	5%
Lightning therapy	53%	31%	16%
Reverse/ Mickel therapy	45%	34%	21%

Ongoing support

Participants were asked, "What ongoing support was offered to you from the NHS during treatment?" 1298 said "None." 603 had been offered one to one support, 396 had been offered group therapy, 203 had been offered a home visit, 146 had been offered referral to an Expert Patient Programme and 115 had been offered email support.

309 people ticked "other." Comments varied widely. Examples included: "Recommended for CFS/M.E. pacing programme but funding ran out so no programme available," "I was offered a place on their research programme but distance made it impossible," "Occasional visit from GP when requested," "Was not offered treatment, was told hopefully it will fizzle out," "Constant one to one homeopathy appointments and monthly GP," "Since 2005 I was seen once and no further help could be given," "Didn't want any," "Treated like a time waster – they don't listen," "What I want is help cleaning and cooking etc."

Although M.E. is often a long-term condition, 1557 were offered no support after treatment. 59 were offered referral to an Expert Patient Programme, 80 were offered a home visit, 85 were offered e-mail support, 93 were offered group therapy, 183 were offered one to one support, 265 were offered telephone support, 268 were offered some other kind of support.

Welfare benefits and social support

"I need DLA but the process of applying would make my symptoms worse so I can't apply. It's bad enough having to jump through the various Incapacity Benefit hoops every year or so; that makes my condition worse for months afterwards."

(Respondent from Hertfordshire)

The survey asked: "If you receive care from someone to help you with daily activities, what is their relationship to you?"

Some people ticked more than one response. Of the 1951 respondents who said they had a carer, 1673 people said that their carer was a family member, 214 had a friend as their carer, 115 received care from social services and 170 paid for private care.

763¹¹ people did not reply to the question about care. Of those who did not answer, nine were bedbound, 109 were housebound, 330 were mobile over short distances and 315 were living near-normal lives. Follow-up work needs to be done to establish if and how those who are not living near-normal lives are managing without care.

Of the 1673 people whose primary carer was a family member, a tiny but heart-wrenching number (4) relied on a child aged under 11. A further 14 received their care from a teenager aged 12-17 and 65 from a carer aged 18-25.

The majority (1266 people) received care from a person aged 36-65, presumably from partners or parents. 312 relied upon someone aged 66 or over.

627 respondents used a wheelchair. Of these, 336 had had their wheelchair prescribed for them.

M.E. is a long-term illness. An aging cohort of people with M.E. is dependent on an aging group of carers who will increasingly have their own medical needs and experience increased frailness.

Social services

114 respondents described themselves as bedbound and 776 as generally housebound, with a further 1195 mobile only over short distances, yet only 115 people received care from social services – a surprisingly low level of support for what is a disabling long-term condition.

Welfare benefits

1683 of the 2763 respondents were in receipt of at least one of the benefits listed (Incapacity Benefit, Severe Disablement Allowance, Income Support and Disability Living Allowance).

1080 people did not answer this question, so it is possible that 1080 are not on benefits. However, only 861 ticked "no" to all four though so this figure is inconclusive.

Of those who were receiving benefit, some were receiving more than one.

1133 people were receiving Incapacity Benefit (IB), just over 106 were receiving Severe Disablement Allowance, 320 were receiving Income Support and 1015 were receiving Disability Living Allowance (DLA).

15% (169) of people receiving IB had gone to appeal/tribunal in the last three years. 81% had succeeded at that stage, strongly suggesting that they should have been awarded the benefit initially.

Even more significantly, 376 (37%) of people applying for DLA had had to go to appeal during the previous three years and 72% (274) had won their appeal. M.E. is a complex fluctuating illness which may make assessment difficult. Nevertheless, **too many people who need and are entitled to DLA are being turned down inappropriately when first they apply.**

In reality, more than 37% of people with M.E. who are receiving DLA have had to go to tribunal, as the question was limited to appeals made in the past three years.

What has changed since 2002?

"I can't believe that we had to sell our home and move to an area where the PCT would fund a child to be seen by a specialist."

(Respondent from Worcestershire)

In 2002 the CMO's report said that many patients complained of difficulty in obtaining a diagnosis. At that time, 30% of Action for M.E. members were diagnosed within six months and 33% waited more than 18 months, some much longer.

In 2008, of the people responding to the Action for M.E. and AYME survey, 30% were diagnosed within six months, 29% between seven and twelve months, 12% waited 13-18 months, 10% waited 19-24 months and 20% waited more than two years.

Of those people diagnosed in the last two years, 39% were diagnosed within six months compared to 31% diagnosed between two and five years ago. 26% were diagnosed six to ten years ago and 29% diagnosed more than 10 years ago. This would seem to indicate that there has been a gradual improvement in early diagnosis results over time.

Nevertheless, too many people, including children and young people, are still waiting too long for a diagnosis which could prevent them from becoming severely affected.

Severity and support

In 2001, 35% of respondents were either bedbound or housebound and the charity called for the establishment of specialist services which included appropriate in-patient care and specialist outreach services, backed by community services, to support and monitor severely ill patients.

In 2008, 33% of respondents were severely affected when they completed the survey 36% had been bedbound and a further 51% had been housebound at some point.

Specialist services have been established in England but the level of domiciliary and/or ongoing support the NHS offers is limited. 18% of survey respondents (516 people) said they were 'too ill' to see a specialist, including 74 who were currently bedbound, 248 who were housebound and 147 who were mobile over short distances. The majority of all respondents had been offered no on-going support during or after receiving NHS treatment.

In addition, 24% of survey respondents who were housebound or bedbound no longer see their GP and social services seem to be providing very little care. For those people with M.E. who are lucky enough to have family, a family member continues to carry the burden of care.

How long did it take to get a diagnosis?

How long ago were you diagnosed?	Under 2 yrs	2-5yrs	6-10yrs	10+yrs	Total
Less than 6 months	39% (140)	31% (203)	26% (154)	29% (240)	737
7-12 months	32% (114)	29% (188)	31% (181)	26% (213)	696
13-18 months	10% (36)	12% (82)	12% (72)	11% (93)	283
19 months-2yrs	4% (14)	10% (64)	12% (70)	11% (89)	237
Over 2 yrs	15% (52)	18% (117)	19% (113)	24% (199)	481
Total	356	654	590	834	2434

The CMO's report said that people with M.E. and their carers often encountered a lack of understanding from healthcare professionals and that this seemed to be associated with inadequate awareness and understanding of the illness among many health professionals and in the wider public.

Respondents reported that 40% of GPs were supportive and 23% very supportive but only 2% felt their GP was well informed. One in three people who responded to the 2008 survey said that their GP was either unsupportive or uninformed about the illness.

In addition to healthcare, a supportive GP or consultant is essential to a person with M.E. for the provision of the medical evidence required for a successful benefits application or appeal.

Treatment

In 2001, 89% had found pacing to be the most helpful treatment. 34% had said that GET had been helpful, 50% felt that it had made them worse. Only 7% had felt that CBT had been helpful while 26% felt it made them worse.

In 2008, the results show signs of improvement but some serious concerns remain. 34% of respondents who said that they had received GET and 12% of those who said that they had received CBT felt worse after these treatments. Does this reflect the age or severity of illness in this particular sample, or the long-term nature of their illness – or the way in which GET and CBT are being administered and by whom?

Welfare benefits

In 2001, 44% had applied for DLA and of these, 44% had had to go to appeal. Of those who applied, 25% were rejected (with or without appeal).

In 2008, 37% had had to go to appeal but 72% won, suggesting that they should have been awarded the benefit in the first place.

Conclusion and recommendations

"Action for M.E. and AYME have elected to be critical partners with the NHS and to work together for the greater benefit of all people with M.E. The word critical here is as important as the word partner."

Peter Spencer, RSM conference, 28 April 2008

M.E. can have a very severe and long-term affect on people's lives. NICE recognised this in 2007 in its guideline for healthcare professionals on the diagnosis and management of the illness in adults and children. It stated, as its first key principle, the importance of "shared decision-making between the person with M.E. and healthcare professionals during diagnosis and all phases of care" and that "the healthcare professional should acknowledge the reality and impact of the condition and the symptoms."

It also said, under provision of care, that every person diagnosed with M.E. should be offered:

- acceptance and understanding
- help negotiating the healthcare, benefits and social care systems.

M.E. and the NHS

For local health care commissioners, not planning or providing any services for people with M.E. within their area should no longer be an acceptable option.

Current treatments may be beneficial to a significant proportion but they are far from curative, leaving many patients enduring years of significant disability.

Although M.E. is often a long-term condition, many respondents were not offered any kind of support (one to one, group therapy, telephone support, e-mail support, home visit or referral to an Expert Patient Programme) after treatment. Many were not offered any ongoing support during treatment.

The NHS provides care for many respondents with M.E., but more needs to be done to:

- improve the speed of diagnosis
- ensure adequate funding is available to:
 - address the lack of local M.E. services
 - properly implement NICE recommendations on providing individualised, person-centred care plans with regular structured reviews
 - increase and maintain adequate levels of support for people who are housebound or bedbound

- offer M.E. patients an annual health review as a minimum standard, including former patients no longer receiving active treatment, to encourage people to stay in touch with their GP, have their condition monitored, enable access to new treatments as they develop and improve chances of obtaining appropriate medical evidence to support applications for welfare benefits
- establish why a significant proportion of the survey respondents who said they had received GET and CBT said it made them worse and determine how this issue is to be addressed
- ensure that only suitably trained health professionals, with sufficient knowledge of M.E., deliver GET
- ensure that healthcare professionals, including GPs, receive adequate training about the impact of the illness and all the treatment options

The chronic disabling and fluctuating nature of the illness is very apparent and improved access to specialist services and treatments may not automatically lead to a rapid or full recovery. The need for long-term support, both by the NHS and by social services, needs to be addressed.

More research is needed, both to deepen understanding of the condition and to identify how to successfully rehabilitate a greater proportion of people with M.E. who are desperate to return to a near-normal life.

Welfare benefits

Currently, too many people of working age who have M.E. face the bleak prospect of spending the remainder of their circumscribed lives on benefits, 'proving' to the authorities how ill they are.

A systematic analysis of DLA processes and procedures is needed in order to establish why so many people have to go to appeal. The forms are burdensome for applicants and clinicians and clearly do not elicit the information needed to align against the criteria for award. The guidance document for decision makers, published in July 2007, was rejected by all the M.E. charities, including Action for M.E., which will monitor its impact.

Social support

The survey highlighted that there is an aging cohort of people with M.E. who are dependent on an aging group of carers who will increasingly have their own medical needs and experience increased frailness.

Older people with M.E. who live alone and do not receive help from social services may be particularly vulnerable.

Access to social care is linked to the eligibility criteria used by local authorities, and how these are applied to people with M.E. Different authorities may offer care at different levels of need. The question is, does the nature of M.E. lead to any widespread injustice in the allocation of social care or support offered to people with the condition, when compared to people with other chronic illnesses or disabilities? And if they are discriminated against, do people with M.E. lack the energy to complain through the official channels set up for this purpose?

More research needs to be done to address these fundamental questions.

It is important to identify the number of people with M.E. who are housebound or bedbound, dependent upon aging carers and/or who live alone, who need further support from both health and/or social services.

The role of the voluntary sector

For their part, Action for M.E. and AYME will endeavour to:

- provide information and helplines, to which healthcare professionals can signpost patients, including details of local support groups
- answer any questions which arise from these survey results to support the development of services and treatments for people with M.E., which can reasonably be asked within the limits of the survey and abilities of the staff available
- undertake further statistical analysis of these survey results to identify any potential geographical inequalities in access to specialist care
- undertake a further survey in 2008/9 to explore in more depth the issues relating to welfare benefits and social services support.

This report provides a summary of findings available by 1 May 2008. The analysis of results is ongoing. The latest version of the full results may be accessed via the websites of Action for M.E. and AYME at www.afme.org.uk and www.ayme.org.uk.

The need for more biomedical research

In 2002 the CMO's report on M.E. identified: "A paucity of good research evidence and very little research investment for a serious clinical problem (that in likelihood has a pervasive impact on the individual and the community.)"

Following the report, the Medical Research Council (MRC) was charged with developing a broad strategy for advancing biomedical and health services research on the illness.

In 2003 the MRC issued a 'highlight notice' for M.E./CFS, to flag up that it would welcome high quality research proposals in the field. Although it has invested in two large-scale trials (PACE and FINE), an epidemiological feasibility study of chronic fatigue, irritable bowel syndrome and chronic widespread pain and a study which looked at chronic fatigue and ethnicity, there is a desperate need for more high quality proposals in the area.

The Gibson Inquiry report into progress in research found that the research areas defined by the CMO Report in 2002 had not been addressed. It said:

"Although some interesting biomedical research has been done in the UK precedence has been given to psychological research and definitions. The UK should take this opportunity to lead the way in encouraging biomedical research into the potential causes of CFS/M.E. Further research is the single most important area in this field."

Acknowledgements

A number of people provided invaluable help in the drafting of the survey and this report, in distributing the survey and in providing feedback on the initial results.

Action for M.E. and AYME would like to thank the following people in particular, without forgetting those who preferred to offer their advice anonymously.

Mark Seymour for his many hours of statistical analysis.

Members of the M.E. Research Observatory Reference Group.

Trustees, representatives of the healthcare profession and people with M.E. who provided comments.

The young people of AYME.

Those support groups, NHS M.E. Coordinating Centres and individuals who promoted the survey to their members and patients.

Ninepoint, for questionnaire and report design.

Data input by www.dataimage.uk.com

Footnotes

- 1 Estimates of incidence based on a research paper by Gallagher et al in the Journal of the Royal Society of Medicine, December 2004, indicated a prevalence of 240,000 people with M.E./CFS in the UK and an incidence of 25,000 ie. a further 25,000 are affected per annum.
- 2 When two questions have been 'matched' or cross referenced – eg. "What is your age now?" and "What was your age at onset?" – the total number of matched responses is often different from the total number of responses overall, because not everyone answered every question. In this example, although we received 161 responses overall from people who were under 12 at age of onset, only 155 of these answered the question about their age now.
- 3 378 matched of 396 overall
- 4 Of 918 overall
- 5 Matched people, of 161 overall
- 6 Matched people, of 396 overall
- 7 Matched people, of 918 overall
- 8 Matched people, of 776 overall
- 9 Matched people, of 114 overall
- 10 Percentages for Northern Ireland, Wales and Scotland were higher than England but the number of responses overall for this question from these countries was too low to extrapolate.
- 11 763 matched people of 812 overall

"I found it very difficult as a medical practitioner to believe that I could be so ill and that no one was interested."

(Respondent from Northern Ireland)

Contact



Action for M.E.
PO Box 2778
Bristol
BS1 9DJ

Tel: 0845 123 2380
E-mail: admin@afme.org.uk
www.afme.org.uk

Registered charity no: 1036419



Association of Young People with M.E.
9a Vermont Place
Tongwell
Milton Keynes
MK15 8JA

Tel: 08451 23 23 89
E-mail: info@ayme.org.uk
www.ayme.org.uk

Registered charity no: 1082059