



Managing my M.E.

What people with ME/CFS and their carers want from the UK's health and social services

**THE RESULTS OF THE ME ASSOCIATION'S MAJOR
SURVEY OF ILLNESS MANAGEMENT REQUIREMENTS**

Published by The ME Association, May 2010

OUR AMBITION?

A comprehensive management programme welcomed by the vast majority of people with ME/CFS – and an NHS willing to embrace it

During a period of over four months, which ended in September 2008, The ME Association conducted a comprehensive questionnaire survey involving all aspects of ME/CFS management. A paper version of the questionnaire was sent out to ME Association members in our *ME Essential* magazine. An on-line version was made available to a much wider audience through the MEA website.

Overall, 4,217 people took part – making this the largest ever survey of patient and carer evidence on issues relating to ME/CFS management. A total of 3,494 people took part using the on-line version. Another 723 completed the paper version. Almost all of those completing the paper version (97%) were members of The ME Association. Most people who completed the on-line version (77%) were non-members.

The aim of the survey was to gather a wide range of patient and carer experience and evidence relating to all aspects of management. The survey also asked people what sort of services they wanted, which health professionals they wanted to see involved in their care, and where they wanted referral services to operate from. There was a separate section for carers.

Much of the feedback – especially in relation to approaches such as pacing, cognitive behaviour therapy (CBT) and graded exercise therapy (GET) – is in line with what we already know from previous questionnaires and anecdotal feedback. But some of the feedback is not. This obviously raises questions as to whether some of the generally accepted conclusions about management options, often based on less robust patient evidence, are correct.

The results of the survey are set out in detail in this report. A preliminary report was sent to the All Party Parliamentary Group on ME to assist them with their Inquiry into NHS Service Provision and part of the final MEA report has been inserted into the APPG report.

The information in this final report will form an important part of our submission to NICE when, as is scheduled for later in 2010, they review their current guideline on ME/CFS. If we are going to send patient evidence to NICE that presents alternatives to CBT and GET, then we require good quality evidence on the use of these approaches, and the more acceptable alternatives, upon which to base our case.

So the aim will be to use all this information to develop a comprehensive MEA management programme that would be welcomed by the vast majority of people with ME/CFS. This will also offer a real challenge to some of the unpopular recommendations contained in the NICE guideline.

Funding for this research came from The ME Association's Ramsay Research Fund.

The ME Association wishes to thank co-opted trustee Janet Thomas for devising the questionnaire and Dr John Bottone FORS for doing the statistical analysis.

Dr Charles Shepherd wrote the discussion segments that accompany the results to each question.

A more detailed statistical analysis of the results, including cross-referencing, has also been carried out. These results can be obtained as a separate summary, which is available on request from The ME Association.

This report has also been made available for open access at The ME Association website:
www.meassociation.org.uk

© The ME Association, 2010

Section for people with ME/CFS

Question 1

Are you a member of The ME Association?

Overall, only 37% were members.

Of the respondents to the online questionnaire, the majority (77%) were not members – whereas for the print version, distributed with our *ME Essential* magazine, the majority (97%) were members.

MEA member?

Yes	37%
No	63%
Answered question:	
3875	

Question 2

Which area of the country do you live in?

In terms of regional population statistics, respondents in Scotland, Wales and the Midlands are under-represented in this survey.

Where do you live?

England (SE)	22%
England (Midlands)	13%
England (SW)	10%
England (NW)	10%
England (NE)	9%
Elsewhere	7%
Scotland (S & Mid)	7%
England (E)	7%
England (S)	5%
Wales (S)	3%
Ireland (N)	2%
Scotland (Highlands)	2%
Wales (N)	1%
England (W)	1%
Eire	1%
Answered question:	
3875	

Question 3

What is your age?

Research evidence from published epidemiological studies indicates that most people with ME/CFS are between 20 and 50, certainly at the start of their illness. This is similar to the findings reported here. However, the percentage in the 51-60 age group in The ME Association survey is significantly higher than reported in research evidence. The fact that those answering the printed version were older may reflect the probability that people using The ME Association website are more likely to be newly diagnosed and patient support charities have a membership that is biased towards people who have become more chronic or severely affected and are therefore older.

The ME Association survey under-estimated the number of children and adolescents with ME/CFS. This is probably because The ME Association does not focus on this age range and there are two separate charities that do. Children and adolescents are obviously less likely to be using a medical charity website, although their parents may well be doing so.

Age

Combined		Printed Form		Online	
5-10 years	0%	5-10 years	0%	5-10 years	0%
11-20 years	5%	11-20 years	1%	11-20 years	6%
21-35 years	24%	21-35 years	6%	21-35 years	28%
36-50 years	35%	36-50 years	24%	36-50 years	37%
51-65 years	30%	51-65 years	47%	51-65 years	26%
66+ years	6%	66+ years	22%	66+ years	3%
Answered question:		Answered question:		Answered question:	
3859		719		3140	

Question 4

What is your gender?

In line with all the current epidemiological evidence, the survey found a significantly higher proportion of female sufferers – which may be partly explained by various predisposing vulnerabilities. Research studies suggest a female:male ratio of around 70:30. The 78:22 split in The ME Association survey might reflect an increased willingness by females to engage with this type of survey and be members of a patient support group.

Gender

Female	78%
Male	22%
Answered question:	3834

Questions 4 and 5

Age breakdown by Gender

There was very little difference between the age ranges of the female and male respondents.

Age breakdown by Gender

	FEMALE		MALE	
	Percent	Number	Percent	Number
5 - 10 years	0%	2	0%	1
11-20 years	5%	164	4%	36
21-35 years	25%	747	19%	164
35-50 years	36%	1063	33%	278
51-65 years	28%	846	36%	301

Question 5

Has the diagnosis of ME/CFS been confirmed?

88% of respondents had had their diagnosis confirmed.

Confirmed diagnosis?

Yes	88%
No	12%
Answered question:	3854

Question 6

Who made the diagnosis of your illness as ME/CFS?

82% of diagnoses were made by a doctor.

Who diagnosed?

Doctor	82%
Other person	15%
Yourself	3%
Complementary therapist	1%
Answered question:	3350

Question 7

Indicate the duration of your illness from the onset of symptoms.

The majority of respondents had been ill for more than 10 years. So the results of this survey are significantly biased towards people with experience of a more long-term chronic illness and may not adequately reflect experiences and problems relating to the early stages of ME/CFS.

How long ill?

Less than a year	8%
2-5 years	28%
6-10 years	20%
More than 10 years	44%
Answered question:	
3781	

Question 8

How long did it take to reach a diagnosis in your case?

Delay in making a diagnosis of ME/CFS is a major issue that has been highlighted in both the 2002 Chief Medical Officer's report into ME/CFS and the 2005 report from the ME Alliance: *ME Diagnosis – Delay Harms Health*. The latter report found that around 25% of adults were diagnosed within six months; 22% were diagnosed between six months and a year; and 53% took over a year to get a diagnosis. The figures in this survey indicate that many people still face an unacceptable delay when it comes to obtaining an early and accurate diagnosis along with appropriate forms of management.

We currently have no sound research evidence relating to the proportion of people who fit into the approximate definitions of mild, moderate or severe ME/CFS. It has been widely suggested that around 25% of people have a severe form of ME/CFS at some stage in their illness. The figure of 15% in a severe category in The ME Association survey is likely to be an under-estimate given the fact that people with severe ME/CFS may have found the completion of the lengthy questionnaire to be difficult or impossible – even though it could have been completed in stages.

Time to diagnosis

Less than 6 months	18%
6-12 months	28%
More than a year	53%
Answered question:	
3768	

Question 9

How does the illness affect your current state of health?

The majority of respondents were “moderately” affected by their illness.

Effect of illness on health

Mildly	28%
Moderately	57%
Severely	15%
Answered question:	
3,722	

Question 10

There are five symptoms commonly associated with ME/CFS. Tick these symptoms in the order of severity for yourself (ie grade them).

Muscle Fatigue was ranked as the symptom that affected respondents the most. This was followed by cognitive dysfunction, then pain, then sleep problems. The least troublesome was mobility problems.

Eighteen people said they had none of the key features of ME/CFS. This suggests that they either do not have ME/CFS or had recovered, or they had misunderstood the question.

These results are very much in line with what has already been reported in the medical literature and used in various clinical definitions of what constitutes ME/CFS.

Cognitive dysfunction refers to problems with short-term memory, concentration, information processing and attention span.

Your five most severe symptoms

	1st	2nd	3rd	4th	5th	Rating Average
Muscle Fatigue	1730	815	457	248	85	0.771
Cognitive Dysfunction	548	956	836	679	277	0.596
Pain (esp in muscles & joints)	504	737	771	775	357	0.539
Sleep Problems	461	617	893	842	507	0.537
Mobility Problems	197	278	385	577	1519	0.330
None of these apply	18	3	4	6	51	0.010

Answered Question: 3594

Question 11 (see table on opposite page)

This question presented a list of other common symptoms found in ME/CFS. Respondents were asked to select all that had ever applied to them – choosing whether they were a ‘major’ or a ‘minor’ problem.

All respondents listed more than 66% of these symptoms as either major or minor problems and most reported more than 80% of them.

These results are again very much in line with what we already know about what are often termed ‘secondary symptoms’. A finding of 70% experiencing pain emphasises the fact that pain, although often occurring in ME/CFS, is not always present.

The most common symptoms – were they MAJOR or MINOR to you?

	Major problem	Minor problem	Rating average of combined Major and Minor
Feeling tired on waking up	91%	7%	0.95
Feeling ill for several days after minor exertion	88%	9%	0.93
General malaise that varies through day	82%	13%	0.88
Poor concentration and short-term memory	73%	24%	0.85
Muscle pain	70%	25%	0.82
Severe muscle weakness after minor exertion	72%	21%	0.82
Inability to cope with temperature changes (or night sweats)	63%	28%	0.76
Aching joints without swelling or redness	60%	28%	0.74
Increased sensitivity to light and/or sound	54%	35%	0.71
Problems remembering names of people and objects	52%	38%	0.71
Headaches of type not previously experienced	51%	35%	0.69
Irritable bowel problems	52%	32%	0.68
Dizziness or feeling faint on standing (postural hypotension)	45%	42%	0.66
Problems with balance	38%	48%	0.61
Recurrent sore throats and enlarged glands	37%	48%	0.61
Sleeping in the day rather than at night	40%	40%	0.60
Alcohol intolerance	38%	38%	0.57
Sensory changes, eg tingling or abnormal skin sensations	33%	46%	0.56
Twitching of muscles or eyelids	28%	54%	0.55
New allergies	30%	40%	0.50
Difficulty in finding way about	17%	50%	0.42
Other	10%	4%	0.12

Answered Question: 3663

Questions 12 and 13

There were two questions about mental health. One asked whether respondents had been told that their ME/CFS was a psychological illness. The other asked respondents if they had been diagnosed with any of three mental health problems as part of their illness.

A diagnosis of depression, anxiety, panic attacks or mood swings had been given to between 72% and 86% of respondents. These were equally described as a 'major' or 'minor' problem.

The figures here are higher than previous reporting but may reflect the wording of the question which referred to whether a doctor had made a diagnosis of a mental health problem. Unfortunately, we are still in a situation where some doctors still regard ME/CFS as a form of atypical depression or anxiety and diagnose it as such.

Have you been told your ME/CFS is psychological?

No	48%
Yes	28%
Uncertain	23%
Answered question: 3609	

Any mental health diagnosis as part of your illness?

	Major problem	Minor problem	Rating Average
Depression	46%	40%	0.66
Anxiety and/or panic attacks	38%	38%	0.57
Mood swings or emotional lability	37%	35%	0.55

Answered Question: 2477

Questions 14 – 16

These questions were about the effect of general therapies on the illness. Respondents were invited to answer questions for any they had tried.

When looking at the techniques that made respondents slightly worse or much worse, Graded Exercise Therapy was specified by 56%, followed by physiotherapy, the drug modafinil, yoga and physiotherapy. It appears that any "physical" type of therapy has the potential to make many patients worse. Lightning Process made 20% worse. Cognitive Behaviour Therapy only made 19% worse, but it also produced 'no change' in 54%.

The fact that pacing is rated very strongly as the most effective form of management is consistent with several other surveys of patient opinion and a large amount of anecdotal feedback. The findings relating to the two very controversial treatments recommended by the National Institute for Health and Clinical Excellence (NICE) – ie cognitive behaviour treatment (CBT) and graded exercise therapy (GET) – are again in line with previous surveys of patient opinion, which have found CBT to be ineffective in a high proportion of people (55% in the MEA survey; 67% in the Chief Medical Officer's report) and GET to be unhelpful (21% in the MEA survey; 15% in the CMO's report) or even harmful (in around 50% of cases in both the MEA survey and the CMO's report).

Results relating to other forms of treatment, where the survey numbers involved may be small and assessment in properly controlled clinical trials is either poor or non-existent, obviously have to be viewed with considerable caution. However, it is interesting to note that some of the more popular drugs and supplements used by people with ME/CFS – eg carnitine, evening primrose oil, and Immunovir – end up in the bottom half of this table.

Affects on symptoms of 25 therapies tried by respondents – sorted by the percentage of people who IMPROVED

	Responses	Greatly improved	Improved	No change	Slightly worse	Much worse	Total improved
PACING	2137	11.6%	59.6%	24.1%	3.5%	1.2%	71.2%
MEDITATION OR RELAXATION TECHNIQUES	1675	6.1%	47.6%	44.3%	1.6%	0.4%	53.7%
PERRIN TECHNIQUE	115	13.9%	37.4%	37.4%	7.0%	4.3%	51.3%
ALLERGY TREATMENTS	686	9.5%	41.7%	45.2%	2.2%	1.5%	51.2%
OSTEOPATHY/ CHIROPRACTIC	774	9.8%	41.1%	33.3%	10.1%	5.7%	50.9%
MASSAGE	1037	5.4%	43.9%	31.3%	12.7%	6.7%	49.3%
LIGHTNING PROCESS	101	25.7%	18.8%	34.7%	7.9%	12.9%	44.6%
CORTICOSTEROID eg HYDROCORTISONE	323	10.5%	32.5%	35.3%	10.8%	10.8%	43.0%
ADVICE (to help to cope)	2147	3.3%	39.5%	50.9%	3.7%	2.6%	42.8%
HYDROTHERAPY	275	4.0%	37.5%	32.0%	13.5%	13.1%	41.5%
THYROXINE	414	8.7%	30.4%	50.0%	6.0%	4.8%	39.1%
YOGA	812	4.2%	34.9%	32.9%	20.8%	7.3%	39.0%
MODAFINIL/PROVIGIL	81	14.8%	22.2%	33.3%	16.0%	13.6%	37.0%
EICOSAPENTAENOIC AID (EPA) OMEGA 3 OIL	1217	3.2%	33.1%	59.7%	2.9%	1.1%	36.3%
VITAMINS AND SUPPLEMENTS	2370	3.7%	31.9%	61.9%	1.8%	0.8%	35.5%
L CARNITINE	318	2.8%	28.0%	62.9%	3.8%	2.5%	30.8%
PHYSIOTHERAPY	862	3.5%	27.0%	36.7%	17.2%	15.7%	30.5%
REVERSE THERAPY	107	8.4%	21.5%	45.8%	16.8%	7.5%	29.9%
HOMEOPATHY	1100	5.5%	24.4%	59.9%	7.1%	3.2%	29.8%
COUNSELLING (other than CBT)	984	2.6%	26.8%	60.1%	6.1%	4.4%	29.5%
EVENING PRIMROSE OIL	1231	2.6%	25.8%	66.3%	3.7%	1.5%	28.4%
COGNITIVE BEHAVIOUR THERAPY (CBT)	997	2.8%	23.1%	54.6%	11.6%	7.9%	25.9%
INOSINE PRANOBEX/ IMUNOVIR	62	8.1%	17.7%	50.0%	16.1%	8.1%	25.8%
GRADED EXERCISE THERAPY (GET)	906	3.4%	18.7%	21.4%	23.4%	33.1%	22.1%
ENADA/NADH	358	3.4%	16.5%	63.4%	12.3%	4.5%	19.8%

Affects on symptoms of 25 therapies tried by respondents – sorted by the percentage of people who were made WORSE

	Responses	Greatly improved	Improved	No change	Slightly worse	Much worse	Total worse
GRADED EXERCISE THERAPY (GET)	906	3.4%	18.7%	21.4%	23.4%	33.1%	56.5%
PHYSIOTHERAPY	862	3.5%	27.0%	36.7%	17.2%	15.7%	32.8%
MODAFINIL/PROVIGIL	81	14.8%	22.2%	33.3%	16.0%	13.6%	29.6%
YOGA	812	4.2%	34.9%	32.9%	20.8%	7.3%	28.1%
HYDROTHERAPY	275	4.0%	37.5%	32.0%	13.5%	13.1%	26.5%
REVERSE THERAPY	107	8.4%	21.5%	45.8%	16.8%	7.5%	24.3%
INOSINE PRANOBEX/ IMUNOVIR	62	8.1%	17.7%	50.0%	16.1%	8.1%	24.2%
CORTICOSTEROID eg HYDROCORTISONE	323	10.5%	32.5%	35.3%	10.8%	10.8%	21.7%
LIGHTNING PROCESS	101	25.7%	18.8%	34.7%	7.9%	12.9%	20.8%
COGNITIVE BEHAVIOUR THERAPY (CBT)	997	2.8%	23.1%	54.6%	11.6%	7.9%	19.6%
MASSAGE	1037	5.4%	43.9%	31.3%	12.7%	6.7%	19.4%
ENADA/NADH	358	3.4%	16.5%	63.4%	12.3%	4.5%	16.8%
OSTEOPATHY/ CHIROPRACTIC	774	9.8%	41.1%	33.3%	10.1%	5.7%	15.8%
PERRIN TECHNIQUE	115	13.9%	37.4%	37.4%	7.0%	4.3%	11.3%
THYROXINE	414	8.7%	30.4%	50.0%	6.0%	4.8%	10.9%
COUNSELLING (other than CBT)	984	2.6%	26.8%	60.1%	6.1%	4.4%	10.5%
HOMEOPATHY	1100	5.5%	24.4%	59.9%	7.1%	3.2%	10.3%
L CARNITINE	318	2.8%	28.0%	62.9%	3.8%	2.5%	6.3%
ADVICE (to help to cope)	2147	3.3%	39.5%	50.9%	3.7%	2.6%	6.3%
EVENING PRIMROSE OIL	1231	2.6%	25.8%	66.3%	3.7%	1.5%	5.4%
PACING	2137	11.6%	59.6%	24.1%	3.5%	1.2%	4.7%
EICOSAPENTAENOIC AID (EPA) OMEGA 3 OIL	1217	3.2%	33.1%	59.7%	2.9%	1.1%	3.9%
ALLERGY TREATMENTS	686	9.5%	41.7%	45.2%	2.2%	1.5%	3.6%
VITAMINS AND SUPPLEMENTS	2370	3.7%	31.9%	61.9%	1.8%	0.8%	2.5%
MEDITATION OR RELAXATION TECHNIQUES	1675	6.1%	47.6%	44.3%	1.6%	0.4%	2.0%

Acceptability

Of the therapies that caused the most improvement, the top six were all satisfactory for 78% to 89% of respondents. The most unacceptable were Graded Exercise Therapy (53%), Reverse Therapy (47%), Lightning Process (41%), the drug modafinil (38%), Cognitive Behavioural Therapy (38%) and Physiotherapy (37%).

Acceptability			
	Responses	Satisfactory	Not acceptable
PACING	2047	88%	12%
MEDITATION OR RELAXATION TECHNIQUES	1525	89%	11%
PERRIN TECHNIQUE	107	78%	22%
ALLERGY TREATMENTS	646	79%	21%
OSTEOPATHY / CHIROPRACTIC MASSAGE	720	80%	20%
987	987	83%	17%
LIGHTING PROCESS	106	59%	41%
CORTICOSTEROID, eg HYDROCORTISONE	293	66%	34%
ADVICE (to help me to cope)	2090	79%	21%
HYDROTHERAPY	261	69%	31%
THYROXINE	383	82%	18%
YOGA	743	78%	22%
MODAFINIL / PROVIGIL	73	62%	38%
EICOSAPENTAENOIC ACID (EPA) Omega 3 oil	1075	87%	13%
VITAMINS AND SUPPLEMENTS	2081	82%	18%
L CARNITINE	276	84%	16%
PHYSIOTHERAPY	818	63%	37%
REVERSE THERAPY	102	53%	47%
HOMEOPATHY	1014	74%	26%
COUNSELLING (other than CBT)	940	73%	27%
EVENING PRIMROSE OIL - Omega 6 oil	1095	81%	19%
COGNITIVE BEHAVIOUR THERAPY	976	62%	38%
INOSINE PRANOBEX / IMUNOVIR	54	74%	26%
GRADED EXERCISE THERAPY	888	47%	53%
ENADA/NADH	322	65%	35%

Where carried out

Of the six techniques that caused the most improvement, pacing and meditation/relaxation techniques were mostly done at home, Perrin Technique and osteopathy/chiropractic were mostly done at a private clinic whereas allergy treatments and massage were mostly done at either home or at a private clinic.

Graded Exercise Therapy was carried out at a specialist ME centre, at a local hospital or at home and Cognitive Behaviour Therapy was carried out at either a specialist ME centre or at a local hospital. GP surgeries were mostly used for drug therapies, advice, allergy treatments and for counselling.

Where carried out						
	Responses	Specialist ME centre	At home	GP surgery	Local hospital	Private clinic
PACING	1909	21%	59%	7%	10%	3%
MEDITATION OR RELAXATION TECHNIQUES	1496	8%	71%	2%	7%	12%
PERRIN TECHNIQUE	97	3%	9%	0%	1%	87%
ALLERGY TREATMENTS	616	3%	29%	19%	12%	37%
OSTEOPATHY / CHIROPRACTIC	722	0%	3%	2%	3%	92%
MASSAGE	836	1%	31%	2%	3%	63%
LIGHTNING PROCESS	86	5%	22%	0%	1%	72%
CORTICOSTEROID, eg HYDROCORTISONE	289	2%	29%	33%	26%	10%
ADVICE (to help me to cope)	1915	26%	24%	26%	18%	6%
HYDROTHERAPY	205	3%	17%	2%	59%	18%
THYROXINE	373	2%	29%	50%	6%	12%
YOGA	554	1%	69%	1%	1%	28%
MODAFINIL/PROVIGIL	63	5%	43%	29%	11%	13%
EICOSAPENTAENOIC ACID (EPA) Omega 3 oil	1087	2%	92%	2%	1%	3%
VITAMINS AND SUPPLEMENTS	2047	2%	87%	4%	1%	7%
L CARNITINE	281	2%	85%	3%	1%	8%
PHYSIOTHERAPY	792	5%	10%	12%	55%	18%
REVERSE THERAPY	91	1%	24%	1%	7%	67%
HOMEOPATHY	988	1%	26%	6%	7%	59%
COUNSELLING (other than CBT)	825	8%	16%	28%	20%	29%
EVENING PRIMROSE OIL - Omega 6 oil	1066	2%	90%	5%	1%	2%
COGNITIVE BEHAVIOUR THERAPY	902	25%	14%	11%	37%	13%
INOSINE PRANOBEX / IMUNOVIR	47	19%	36%	21%	15%	9%
GRADED EXERCISE THERAPY	794	21%	33%	8%	32%	6%
ENADA/NADH	306	8%	82%	4%	1%	5%

Source of Advice and Supply

	Responses	Allcomp therapist	Consultant neurologist	Consultant Psychiatrist	Counsellor	General Physician	GP	MC charity	Nurse	Occupational therapist	Other therapist	Over the counter	Physiotherapist	Private doctor	Psychologist	Self-help book	Social worker
PACING	1871	2.0%	4.4%	1.6%	1.7%	4.2%	13.8%	9.6%	2.9%	17.3%	3.3%	0.1%	5.5%	2.7%	2.6%	28.0%	0.2%
MEDITATION OR RELAXATION TECHNIQUES	1455	20.1%	1.0%	1.8%	3.9%	1.2%	4.0%	3.1%	2.8%	10.2%	9.1%	1.7%	2.7%	1.1%	3.8%	33.3%	0.3%
PERRIN TECHNIQUE	92	53.3%	0.0%	0.0%	0.0%	0.0%	2.2%	0.0%	0.0%	0.0%	30.4%	0.0%	4.3%	3.3%	0.0%	6.5%	0.0%
ALLERGY TREATMENTS OSTEOPATHY /	613	21.5%	1.1%	0.2%	0.0%	9.8%	29.9%	0.8%	1.8%	0.2%	5.4%	6.9%	0.2%	16.6%	0.0%	5.7%	0.0%
CHIROPRACTIC	668	51.5%	0.4%	0.1%	0.1%	0.7%	4.0%	0.1%	0.1%	1.3%	27.2%	0.3%	3.6%	5.4%	0.0%	4.8%	0.0%
MASSAGE	916	60.3%	0.2%	0.1%	0.1%	0.7%	1.9%	0.2%	1.0%	1.2%	18.4%	0.7%	8.6%	0.9%	0.1%	5.7%	0.0%
LIGHTNING PROCESS	90	41.1%	1.1%	0.0%	3.3%	0.0%	3.3%	1.1%	0.0%	22.2%	18.9%	1.1%	0.0%	2.2%	5.6%	20.0%	0.0%
CORTICOSTEROID, eg HYDROCORTISONE	279	0.4%	3.2%	0.0%	0.4%	20.8%	48.7%	0.4%	0.7%	0.0%	1.8%	1.4%	0.0%	21.1%	0.0%	1.1%	0.0%
ADVICE (to help me to cope)	1952	4.8%	6.7%	4.1%	3.7%	8.2%	25.2%	7.5%	2.9%	14.0%	3.0%	0.2%	3.0%	3.9%	4.0%	8.5%	0.3%
HYDROTHERAPY	227	7.9%	2.2%	0.0%	0.0%	5.7%	12.8%	2.2%	2.2%	4.8%	7.5%	0.9%	38.3%	0.9%	0.0%	14.5%	0.0%
THYROXINE	381	1.8%	1.3%	1.3%	0.0%	13.1%	58.5%	0.0%	0.0%	0.3%	0.8%	1.8%	0.0%	19.4%	0.0%	1.6%	0.0%
YOGA	639	32.9%	0.3%	0.5%	0.2%	0.9%	2.3%	3.4%	0.5%	1.6%	16.3%	1.9%	1.3%	0.0%	0.0%	37.9%	0.2%
MODAFINIL/PROVIGIL	64	0.0%	18.8%	3.1%	0.0%	12.5%	34.4%	3.1%	0.0%	0.0%	1.6%	6.3%	0.0%	15.6%	1.6%	3.1%	0.0%
EICOSAPENTAENOIC ACID (EPA) Omega 3 oil	1061	12.9%	3.2%	0.2%	0.0%	2.7%	5.6%	11.2%	0.4%	0.6%	1.9%	26.9%	0.1%	5.2%	0.0%	29.2%	0.0%
VITAMINS AND SUPPLEMENTS	2036	15.9%	1.4%	0.2%	0.0%	2.5%	8.7%	3.0%	0.6%	0.2%	3.3%	29.9%	0.2%	7.3%	0.0%	26.6%	0.0%
L CARNITINE	280	10.7%	1.1%	0.0%	0.4%	3.9%	3.9%	4.6%	0.4%	0.0%	0.4%	22.1%	0.0%	25.7%	0.7%	26.1%	0.0%
PHYSIOTHERAPY	798	1.4%	1.5%	0.5%	0.3%	2.9%	12.2%	0.3%	0.4%	3.0%	2.4%	0.0%	72.2%	1.3%	1.3%	0.5%	0.1%
REVERSE THERAPY	95	34.7%	0.0%	1.1%	5.3%	0.0%	5.3%	0.0%	0.0%	2.1%	20.0%	0.0%	1.1%	7.4%	5.3%	17.9%	0.0%
HOMEOPATHY	998	61.4%	0.3%	0.4%	0.3%	6.0%	7.8%	0.7%	0.2%	0.8%	5.4%	3.3%	0.0%	8.0%	0.1%	5.2%	0.0%
COUNSELLING (other than CBT)	898	4.5%	0.7%	5.9%	47.2%	0.8%	7.5%	1.3%	2.0%	3.7%	6.8%	0.2%	1.0%	1.3%	14.3%	1.3%	1.6%
EVENING PRIMROSE OIL -Omega 6 oil	1056	10.2%	2.7%	0.4%	0.0%	2.7%	8.5%	8.9%	0.2%	0.1%	1.4%	29.3%	0.0%	3.7%	0.2%	31.7%	0.1%
COGNITIVE BEHAVIOUR THERAPY	907	2.1%	2.8%	12.2%	11.6%	2.0%	6.3%	0.3%	4.9%	15.4%	8.5%	0.1%	2.4%	1.8%	25.1%	3.6%	0.9%
INOSINE PRANOBEX / IMUNOVIR	48	2.1%	12.5%	0.0%	0.0%	14.6%	27.1%	2.1%	0.0%	0.0%	6.3%	4.2%	0.0%	25.0%	0.0%	6.3%	0.0%
GRADED EXERCISE THERAPY	827	0.7%	4.7%	4.2%	1.0%	6.5%	17.0%	0.6%	2.8%	13.4%	6.3%	0.1%	27.7%	2.9%	3.4%	8.2%	0.4%
ENADA/NADH	313	9.9%	9.3%	0.0%	0.0%	4.2%	5.4%	11.2%	0.0%	1.3%	1.0%	28.1%	0.0%	10.2%	0.0%	19.5%	0.0%

Question 17

Respondents were asked to rate nine therapies for pain. They were asked questions about their treatment experience for any they had used.

Effect on Symptoms

The best response was to opiate analgesics (63%). NSAIDs, aspirin, paracetamol and acupuncture all helped around 50% of respondents. Amitriptyline, pregabalin and gabapentin all made around 30% of respondents worse. Aspirin and paracetamol had the fewest adverse effects (3%).

Pain can be a major problem with ME/CFS and may involve muscles, joints and/or nerves ('neuropathic pain'). Most doctors prescribe pain relief in a step-like fashion, starting with simple over-the-counter painkillers such as paracetamol or NSAIDs (non-steroidal anti-inflammatory drugs) such as ibuprofen/Brufen.

This process progresses through the use of prescription-only drugs, including low-dose amitriptyline, and then possibly trying approaches such as gabapentin/Neurontin or pregabalin/Lyrica for more severe pain. It is interesting to note that, while around 38% reported good or moderate responses to gabapentin and pregabalin, around 28% felt these drugs had made them feel worse. The use of morphine-containing (opiate) drugs is normally restricted by doctors to severe or terminal pain and, while it is not surprising to find that these drugs are rated as very effective by people with ME/CFS, the significant dangers of using stronger opiate drugs have to be very carefully balanced against the possible benefits. It was disturbing to find the very low rating given for pain relief clinics – something that may reflect the inexperience of staff involved in dealing with ME/CFS.

The ME Association has a leaflet providing detailed information on the management of all aspects of pain relief.

Sorted according to the percentage of those who reported a good or moderate effect

	Responses	Good	Moderate	Poor	No change	Worse	Good//moderate
Drug - opiate analgesics (eg tramadol)	618	20%	43%	8%	12%	16%	63%
Drug - NSAIDs (eg. ibuprofen/Brufen)	1612	8%	45%	14%	23%	11%	53%
Drug - aspirin or paracetamol	2045	5%	43%	18%	31%	3%	48%
Acupuncture	1036	16%	32%	5%	34%	13%	48%
Drug - amitriptyline	1196	11%	31%	9%	19%	31%	41%
TENS	521	7%	33%	11%	35%	15%	40%
Drug - pregabalin/Lyrica	146	16%	22%	10%	23%	29%	38%
Drug - gabapentin/Neurontin	248	11%	27%	11%	25%	27%	38%
Referral to a pain clinic	338	8%	25%	9%	45%	13%	33%

Sorted according to the percentage of those who reported feeling worse

	Responses	Good	Moderate	Poor	No change	Worse
Drug - amitriptyline	1196	11%	31%	9%	19%	31%
Drug - pregabalin/Lyrica	146	16%	22%	10%	23%	29%
Drug - gabapentin/Neurontin	248	11%	27%	11%	25%	27%
Drug - opiate analgesics (eg tramadol)	618	20%	43%	8%	12%	16%
TENS	521	7%	33%	11%	35%	15%
Referral to a pain clinic	338	8%	25%	9%	45%	13%
Acupuncture	1036	16%	32%	5%	34%	13%
Drug - NSAIDS (eg. ibuprofen/Brufen)	1612	8%	45%	14%	23%	11%
Drug - aspirin or paracetamol	2045	5%	43%	18%	31%	3%

Acceptability

	Responses	Satisfactory	Not acceptable
Drug - opiate analgesics (eg. tramadol)	566	71%	29%
Drug - NSAIDS (eg. ibuprofen/Brufen)	1463	69%	31%
Drug - aspirin or paracetamol	1854	74%	26%
Acupuncture	968	75%	25%
Drug - amitriptyline	1110	57%	43%
TENS	471	67%	33%
Drug - pregabalin/Lyrica	134	61%	39%
Drug - gabapentin/Neurontin	228	56%	44%
Referral to a pain clinic	326	60%	40%

Where Carried Out

	Responses	Specialist ME centre	At home	GP surgery	Local hospital	Comp health clinic
Drug - opiate analgesics (eg. tramadol)	556	1%	45%	41%	11%	2%
Drug - NSAIDS (eg. ibuprofen/Brufen)	1428	1%	74%	23%	2%	1%
Drug - aspirin or paracetamol	1822	1%	80%	18%	1%	0%
Acupuncture	958	1%	4%	9%	12%	74%
Drug - amitriptyline	1110	4%	37%	48%	9%	1%
TENS	481	1%	75%	3%	16%	5%
Drug - pregabalin/Lyrica	130	3%	33%	23%	30%	11%
Drug - gabapentin/Neurontin	211	10%	41%	27%	19%	3%
Referral to a pain clinic	316	5%	1%	3%	84%	7%

Question 17 contd

Source of Advice and Supply		Responses	All/comp therapist	Consultant neurologist	Consultant psychiatrist	Counsellor	General physician	GP	ME charity	Nurse	Occupational therapist	Other therapist	Over the counter	Physiotherapist	Private doctor	Psychologist	Self-help book	Social worker
Drug - opiate analgesics (eg. tramadol)	542	0%	0%	5%	0%	0%	13%	73%	0%	1%	0%	1%	2%	0%	4%	0%	0%	0%
Drug - NSAIDS (eg. ibuprofen/Brufen)	1345	0%	0%	1%	0%	0%	6%	52%	0%	1%	0%	0%	31%	0%	2%	0%	6%	0%
Drug - aspirin or paracetamol	1674	0%	0%	0%	0%	0%	5%	45%	0%	0%	0%	0%	38%	0%	1%	0%	8%	0%
Acupuncture	947	57%	0%	0%	0%	0%	3%	9%	0%	2%	1%	8%	0%	8%	6%	0%	5%	0%
Drug - amitriptyline	1098	0%	10%	3%	0%	0%	11%	71%	1%	0%	0%	1%	0%	0%	3%	0%	1%	0%
TENS	438	4%	3%	0%	0%	0%	6%	13%	1%	3%	3%	2%	27%	18%	2%	0%	18%	0%
Drug - pregabalin/Lyrica	124	0%	16%	2%	0%	0%	22%	37%	1%	2%	0%	3%	1%	1%	14%	2%	1%	0%
Drug - gabapentin/ Neurontin	218	0%	25%	2%	0%	0%	17%	43%	0%	0%	1%	2%	1%	0%	7%	0%	1%	0%
Referral to a pain clinic	304	2%	11%	1%	0%	0%	30%	26%	0%	3%	4%	8%	0%	8%	4%	2%	0%	0%

Question 18

Respondents were asked to rate five therapies for sleep. They were asked questions about their treatment experience for any they had used.

Effect on Symptoms

Nearly 60% of respondents had a good response to short-acting sleeping drugs and to relaxation techniques. There was a less beneficial response to amitriptyline, melatonin and sleep hygiene advice. Amitriptyline also made the symptoms worse in 27% of respondents. Doctors, quite rightly, take a cautious approach to the use of drugs in any form of sleep disturbance. But where simple sleep hygiene measures fail, the use of short-acting hypnotics such as zopiclone/Zimovane (for initiating sleep), or a low dose of amitriptyline (for generally disturbed sleep), or melatonin (for more severe disturbance in sleep pattern) is worth considering. The results here suggest that all three approaches can sometimes be helpful – where appropriate.

The ME Association has a leaflet providing detailed information on all aspects of management of sleep disturbance, including the use of melatonin.

Sorted according to the percentage of those who reported a good or moderate effect

	Responses	Good	Moderate	Poor	No change	Worse	Good/moderate
Drug - short acting sleeping tablets (eg. zaleplon/Sonata, zolpidem/Stilnoct, zopiclone/Zimovane)	755	23.2%	35.0%	10.3%	14.4%	17.1%	58.1%
Relaxation techniques	1582	10.8%	47.0%	9.5%	31.8%	0.9%	57.8%
Drug - amitriptyline (low dose)	1122	13.1%	30.4%	10.7%	18.4%	27.5%	43.5%
Drug - melatonin	391	17.4%	24.8%	7.9%	36.8%	13.0%	42.2%
Sleep hygiene advice	687	5.5%	30.6%	11.5%	47.6%	4.8%	36.1%

Sorted according to the percentage of those who reported feeling worse

	Responses	Good	Moderate	Poor	No change	Worse
Drug - amitriptyline (low dose)	1122	13.1%	30.4%	10.7%	18.4%	27.5%
Drug - short acting sleeping tablets (eg. zaleplon/Sonata, zolpidem/Stilnoct, zopiclone/Zimovane)	755	23.2%	35.0%	10.3%	14.4%	17.1%
Drug - melatonin	391	17.4%	24.8%	7.9%	36.8%	13.0%
Sleep hygiene advice	687	5.5%	30.6%	11.5%	47.6%	4.8%
Relaxation techniques	1582	10.8%	47.0%	9.5%	31.8%	0.9%

Acceptability

	Responses	Satisfactory	Not acceptable
Drug - short acting sleeping tablets (eg. zaleplon/Sonata, zolpidem/Stilnoct, zopiclone/Zimovane)	706	70.0%	30.0%
Relaxation techniques	1458	87.7%	12.3%
Drug - amitriptyline (low dose)	1025	58.0%	42.0%
Drug - melatonin	346	71.4%	28.6%
Sleep hygiene advice	641	76.9%	23.1%

Where Carried Out

	Responses	Specialist ME centre	At home	GP surgery	Local hospital	Comp health clinic
Drug - short acting sleeping tablets (eg. zaleplon/Sonata, zolpidem/Stilnoct, zopiclone/Zimovane)	696	2.7%	54.0%	37.8%	3.2%	2.3%
Relaxation techniques	1436	7.9%	74.6%	1.5%	6.6%	9.4%
Drug - amitriptyline (low dose)	1032	4.6%	46.5%	38.9%	8.4%	1.6%
Drug - melatonin	347	5.8%	73.8%	8.4%	4.6%	7.5%
Sleep hygiene advice	604	19.4%	54.1%	10.4%	12.6%	3.5%

Source of Advice and Supply

	Responses	Alt/comp therapist	Consultant neurologist	Consultant psychiatrist	Counsellor	General physician	GP	ME charity Nurse	Occupational therapist	Other therapist	Overseas	
Drug - short acting sleeping tablets (eg. zaleplon/Sonata, zolpidem/Stilnoct, zopiclone/Zimovane)	705	0.1%	2.4%	3.5%	0.0%	7.0%	76.0%	0.4%	0.4%	0.4%	0.3%	1.1%
Relaxation techniques	1369	17.7%	0.9%	2.0%	4.4%	1.3%	4.3%	2.8%	3.1%	11.2%	7.6%	1.1%
Drug - amitriptyline (low dose)	1030	0.0%	9.3%	2.7%	0.1%	10.2%	70.4%	1.0%	0.2%	1.0%	0.9%	0.0%
Drug - melatonin	342	6.7%	6.4%	1.8%	0.3%	11.4%	10.8%	2.0%	0.9%	0.6%	0.6%	21.1%
Sleep hygiene advice	608	2.8%	3.5%	2.1%	2.6%	6.7%	18.3%	5.1%	3.5%	13.7%	5.6%	0.0%

Question 19

Respondents were asked to rate six therapies for depression. They were asked questions about their treatment experience for any they had used.

Effect on Symptoms

SSRI antidepressants, cognitive behaviour therapy (CBT), venlafaxine and tricyclic antidepressants were used by 35% to 40% of respondents. Monoamine oxidase inhibitors were less effective. However, SSRI antidepressants, venlafaxine, tricyclic antidepressants and monoamine oxidase inhibitors also made 30% to 38% worse.

Estimates of the incidence of true clinical depression in ME/CFS vary considerably but, when depression occurs, it may be due to a combination of both internal factors (ie changes in brain chemical transmitters) and external factors (ie problems with coping, benefits, doctors, employment, etc). The choice of antidepressant therapy should, to some extent, be related to ME/CFS symptoms – because some of the symptoms of ME/CFS can be very similar to side-effects of antidepressant drugs. Overall, the SSRIs (selective serotonin reuptake inhibitors – drugs that increase the level of serotonin in the brain) were preferred to the older tricyclic group of drugs in this survey. The less frequently used MAOI (monoamine oxidase inhibitors) drugs came last. The results also indicate that CBT and St John's Wort (the herb hypericum) can both be helpful in some cases for managing co-existent depression. The ME Association has a leaflet that provides detailed information on all aspects of managing depression.

Sorted according to the percentage of those who reported a good or moderate effect

Drug	Responses	Good	Moderate	Poor	No change	Worse	Good/moderate
Drug - SSRI antidepressants (eg. citalopram/Cipramil, fluoxetine/Prozac, paroxetine/Seroxat, sertraline/Lustral)	1529	13.0%	27.9%	8.7%	20.3%	30.0%	40.9%
Cognitive behavioural therapy (CBT)	686	12.2%	27.1%	7.7%	38.6%	14.3%	39.4%
Drug - venlafaxine/Efexor	276	13.8%	22.8%	8.0%	16.7%	38.8%	36.6%
Drug - tricyclic antidepressants (eg. full dose amitriptyline, imipramine, dothiepin/Prothiaden)	715	9.5%	26.2%	10.2%	18.3%	35.8%	35.7%
Herb - St John's Wort	668	6.0%	22.5%	8.5%	50.0%	13.0%	28.4%
Drug - monoamine oxidative inhibitor antidepressants (eg. phenelzine/Nardil, moclobemide/Manerix)	165	6.7%	16.4%	9.7%	29.7%	37.6%	23.0%

	er the counter	Physiotherapist	Private doctor	Psychologist	Self-help book	Social worker
	7%	0.0%	6.5%	0.3%	0.9%	0.0%
	4%	4.0%	1.4%	4.0%	33.5%	0.3%
	2%	0.4%	3.1%	0.0%	0.6%	0.0%
	9%	0.3%	18.1%	0.3%	17.8%	0.0%
	5%	3.6%	5.3%	4.6%	21.9%	0.3%

Sorted according to the percentage of those who reported feeling worse

	Responses	Good	Moderate	Poor	No change	Worse
Drug - venlafaxine/Efexor	276	14%	23%	8%	17%	39%
Drug - monoamine oxidative inhibitor antidepressants (eg. phenelzine/Nardil, moclobemide/Manerix)	165	7%	16%	10%	30%	38%
Drug - tricyclic antidepressants (eg. full dose amitriptyline, imipramine, dothiepin/Prothiaden)	715	10%	26%	10%	18%	36%
Drug - SSRI antidepressants (eg. citalopram/Cipramil, fluoxetine/Prozac, paroxetine/Seroxat, sertraline/Lustral)	1529	13%	28%	9%	20%	30%
Cognitive behavioural therapy (CBT)	686	12%	27%	8%	39%	14%

Acceptability

	Responses	Satisfactory	Not acceptable
Drug - SSRI antidepressants (eg. citalopram/Cipramil, fluoxetine/Prozac, paroxetine/Seroxat, sertraline/Lustral)	1433	57%	43%
Cognitive behavioural therapy (CBT)	650	65%	35%
Drug - venlafaxine/Efexor	262	52%	48%
Drug - tricyclic antidepressants (eg. full dose amitriptyline, imipramine, dothiepin/Prothiaden)	658	51%	49%
Herb - St John's Wort	595	64%	36%
Drug - monoamine oxidative inhibitor antidepressants (eg. phenelzine/Nardil, moclobemide/Manerix)	151	42%	58%

Where Carried Out

	Responses	Specialist ME centre	At home	GP surgery	Local hospital	Comp health clinic
Drug - SSRI antidepressants (eg. citalopram/Cipramil, fluoxetine/Prozac, paroxetine/Seroxat, sertraline/Lustral)	1426	2%	39%	50%	7%	2%
Cognitive behavioural therapy (CBT)	634	19%	15%	13%	37%	16%
Drug - venlafaxine/Efexor	258	2%	31%	47%	18%	2%
Drug - tricyclic antidepressants (eg. full dose amitriptyline, imipramine, dothiepin/Prothiaden)	656	3%	39%	46%	10%	2%
Herb - St John's Wort	561	1%	92%	4%	0%	3%
Drug - monoamine oxidative inhibitor antidepressants (eg. phenelzine/Nardil, moclobemide/Manerix)	143	5%	31%	42%	16%	6%

Question 19 contd

Source of Advice and Supply

	Responses	Alc/comp therapist	Consultant neurologist	Consultant psychiatrist	Counselor	General physician	Gp	ME charity	Nurse	Occupational therapist	Other therapist	Over the counter	Physiotherapist	Private doctor	Psychologist	Self-help book	Social worker
Drug - SSRI antidepressants (eg. citalopram/Cipramil, fluoxetine/Prozac, paroxetine/Seroxat, sertraline/Lustral)	1430	0%	2%	10%	0%	7%	77%	0%	0%	0%	0%	0%	2%	1%	0%	0%	0%
Cognitive behavioural therapy (CBT)	629	2%	3%	12%	13%	2%	11%	0%	4%	12%	8%	0%	2%	1%	25%	5%	1%
Drug - venlafaxine/ Efexor	261	0%	4%	23%	0%	9%	60%	0%	0%	0%	0%	0%	0%	3%	0%	0%	0%
Drug - tricyclic antidepressants (eg. full dose amitriptyline, imipramine, dothiepin/ Prothiaden)	651	0%	6%	10%	0%	9%	71%	0%	0%	0%	0%	0%	0%	2%	1%	0%	0%
Herb - St John's Wort	569	13%	0%	0%	0%	2%	9%	2%	0%	0%	1%	37%	0%	2%	0%	34%	0%
Drug - monoamine oxidative inhibitor antidepressants (eg. phenelzine/Nardil, moclobemide/Manerix)	147	0%	5%	20%	0%	10%	57%	1%	1%	0%	0%	0%	1%	3%	1%	0%	0%

Question 20

Respondents were asked to rate four therapies for bowel problems. They were asked questions about their treatment experience for any they had used.

Effect on Symptoms

Dietary modification was the most effective for bowel problems (69%). Antispasmodics were 58% effective, bulk laxatives 52% and increased dietary fibre 47%. Increased dietary fibre and bulk laxatives made 16% of respondents feel worse.

Symptoms of irritable bowel syndrome (IBS) – abdominal pain, bloating, changes in bowel habit – are very common in ME/CFS and were reported by just over 50% of respondents in this survey. Drug management should be symptom-related (ie antispasmodics for pain; bulk laxatives for constipation) and there are a number of other drug approaches that can be very effective. Dietary modification and food sensitivity avoidance is also a well accepted form of management that can sometimes be very helpful. As has been found elsewhere, some people with IBS are very sensitive to dietary change that involves increasing fibre – so this has to be carried out slowly and with care. Although not asked about in the questionnaire, it is extremely important that anyone with ME/CFS and IBS-type symptoms has a screening test for coeliac disease. This is because some of the symptoms of ME/CFS and coeliac disease overlap.

The ME Association has a leaflet that provides detailed information on all aspects of management of IBS-type symptoms, including screening for coeliac disease, and an additional leaflet on dietary approaches to IBS.

Sorted according to the percentage of those who reported a good or moderate effect

	Responses	Good	Moderate	Poor	No change	Worse	Good//moderate
Dietary modification	1599	23.1%	45.8%	7.8%	21.1%	2.1%	69.0%
Drug - antispasmodic (eg. mebeverine/Colofac, peppermint oil/Colpermin)	812	17.5%	41.0%	11.0%	23.4%	7.1%	58.5%
Bulk laxatives (eg. Fybogel, Isogel)	709	12.1%	40.6%	11.0%	20.2%	16.1%	52.8%
Increased dietary fibre intake	914	11.2%	36.4%	8.6%	27.2%	16.5%	47.6%

Source of Advice and Supply

	Responses	Alt/ the
Drug - antispasmodic (eg. mebeverine/Colofac, peppermint oil/Colpermin)	722	1.5
Bulk laxatives (eg. Fybogel, Isogel)	641	2.2
Increased dietary fibre intake	725	9.1
Dietary modification	1323	20.9

Sorted according to the percentage of those who reported feeling worse

	Responses	Good	Moderate	Poor	No change	Worse
Increased dietary fibre intake	914	11.2%	36.4%	8.6%	27.2%	16.5%
Bulk laxatives (eg. Fybogel, Isogel)	709	12.1%	40.6%	11.0%	20.2%	16.1%
Drug - antispasmodic (eg. mebeverine/Colofac, peppermint oil/Colpermin)	812	17.5%	41.0%	11.0%	23.4%	7.1%
Dietary modification	1599	23.1%	45.8%	7.8%	21.1%	2.1%

Acceptability

	Responses	Satisfactory	Not acceptable
Dietary modification	1474	86.6%	13.4%
Drug - antispasmodic (eg. mebeverine/Colofac, peppermint oil/Colpermin)	754	77.9%	22.1%
Bulk laxatives (eg. Fybogel, Isogel)	654	69.7%	30.3%
Increased dietary fibre intake	821	75.8%	24.2%

Where Carried Out

	Responses	Specialist ME centre	At home	GP surgery	Local hospital	Comp health clinic
Dietary modification	1465	2.1%	82.0%	3.5%	4.4%	7.8%
Drug - antispasmodic (eg. mebeverine/Colofac, peppermint oil/Colpermin)	739	0.8%	60.2%	34.1%	4.2%	0.7%
Bulk laxatives (eg. Fybogel, Isogel)	649	0.9%	67.8%	25.9%	5.1%	0.3%
Increased dietary fibre intake	809	1.2%	88.5%	5.6%	3.0%	1.7%

	Comp therapist	Consultant neurologist	Consultant psychiatrist	Counsellor	General physician	GP	ME charity	Nurse	Occupational therapist	Other therapist	Over the counter	Physiotherapist	Private doctor	Psychologist	Self-help book	Social worker
	5%	0.6%	0.1%	0.0%	8.2%	71.1%	0.0%	0.1%	0.0%	0.6%	9.6%	0.0%	1.4%	0.1%	6.8%	0.0%
	2%	0.5%	0.3%	0.2%	8.6%	64.6%	0.3%	1.1%	0.0%	1.1%	14.4%	0.0%	1.4%	0.0%	5.5%	0.0%
	1%	0.4%	0.0%	0.0%	5.4%	22.5%	1.5%	1.5%	0.7%	3.4%	11.0%	0.3%	3.3%	0.0%	40.8%	0.0%
	9%	0.5%	0.3%	0.0%	5.5%	13.3%	2.1%	1.0%	0.8%	6.7%	4.2%	0.2%	7.3%	0.1%	37.2%	0.0%

Questions 21 and 22

Respondents were asked whether there were any other treatments that they had found to be either helpful or unhelpful.

These were two open questions which allowed respondents to list their own choices.

Helpful treatments not already asked about in the questionnaire – with 30 or more mentions – were: acupuncture, antibiotics, Co-enzyme Q10, D-ribose, healing, herbal remedies, magnesium supplements, probiotics, reflexology, reiki and Vitamin B12.

Unhelpful treatments not already asked about in the questionnaire – with 15 or more mentions – were: acupuncture, Alexander Technique, antibiotics, aromatherapy, healing, herbal remedies, kinesiology, magnesium and reflexology.

With such small numbers, it is difficult to draw any firm conclusions. It is not surprising to note that several treatments that were found to be helpful by some were found to be unhelpful by others – a finding that is consistent with an illness where there is a wide variation in individual responses to almost any form of treatment.

A complete electronic list of these responses can be supplied by The ME Association on request.

Question 23

How would you rate your current standard of medical care?

The results – along with the answers to Questions 24 and 25 – are very disappointing. Overall, they indicate that knowledge about ME/CFS diagnosis and management among doctors and other health professionals is still seriously lacking. Equally disturbing is the finding that around 22% of people had apparently opted out of receiving medical care from conventional NHS sources – presumably because their doctor was either unsympathetic or felt unable to offer any meaningful management advice.

Rate current standard of medical care

Average	24.9%
Not receiving any	21.8%
Good	20.1%
Poor	16.3%
Very poor	11.3%
Excellent	5.8%

**Answered question:
2965**

Question 24

Do you think that your medical adviser is well enough informed about the diagnosis of ME/CFS?

Is your doctor well enough informed about diagnosis of ME/CFS?

No	38.9%
Partly	33.4%
Yes	27.7%

**Answered question:
3297**

Question 25

Do you think that your medical adviser is sufficiently aware of the range of therapies available for ME/CFS?

Is your doctor sufficiently aware of the range of therapies available?

No	52.7%
Partly	32.0%
Yes	15.3%

**Answered question:
3264**

Questions 26 to 28

In relation to your own illness, which of the aspects of management do you feel would be both helpful and acceptable and should therefore form part of a general management programme that The ME Association subsequently recommends for widespread use within the NHS?

Helpful therapies

Pacing and activity/energy management	81.7%
Dietary Advice	63.8%
Alternative therapies	59.6%
Counselling (other than CBT)	49.5%
Cognitive Behavioural Therapy (CBT)	27.7%
Graded Exercise Therapy (GET)	24.1%
Answered question: 3099	

Sources of assistance to do with help available in the community

Help with benefits	82.5%
Help with employment	60.2%
Help with provision of social care (eg. home helps)	59.4%
Help with disability and mobility aids	55.8%
Help with education	45.7%
Answered question: 2289	

Therapies to do with specific symptom areas

Help with sleep problems	77.4%
Help with pain control	68.9%
Help with stress management	63.6%
Help with depression	51.5%
Help with bowel symptoms	47.6%
Help with other symptoms	32.5%
Answered question: 3113	

Question 29

Who would you like to co-ordinate the management of your illness?

The GP, followed by a combination of GP and consultant physician, was the most preferred for co-ordination. A psychologist or psychiatrist was the least preferred.

The answers given to Questions 29-32 are fully consistent with ME Association policy, which is to recommend that multidisciplinary hospital-based referral services should be easily accessible throughout the whole of the UK and that a physician should be in overall charge of the service. The reality is that there are still significant parts of the UK where there are no services at all – especially in Northern Ireland, Scotland and Wales. Elsewhere there is a disturbing trend towards setting up services that are not physician-led. Similar points were made in the recent report from the All Party Parliamentary Group on ME Inquiry into NHS service provision. The lack of services for people with ME/CFS is currently the subject of political and medical initiatives in both Wales and Scotland, where The ME Association is playing an active role in the consultation and development process.

Extra suggestions regarding people who should be involved in the co-ordination of management included the patients themselves, a domiciliary nurse with good knowledge of ME and anyone who is local, sympathetic and has extensive and current knowledge of the illness. Overall, the strongly expressed view was that whoever co-ordinated management, it was essential that they were empathetic to the effects of ME/CFS on the patient and that their knowledge of ME was both extensive and current.

Who would you like to co-ordinate the management of your illness?

	Ist Choice	2nd Choice	3rd Choice	Rating Average
GP	794	428	313	0.38
Mixture of GP & Consultant Physician	751	382	196	0.35
Mixture of GP & Practice Nurse	270	330	287	0.19
Consultant Physician	291	272	182	0.17
Neurologist	301	250	172	0.17
Nurse Specialist	192	304	281	0.16
An alternative medicine therapist	144	201	321	0.12
Occupational Therapist	72	193	204	0.09
None of these	169	13	42	0.06
Practice Nurse	21	116	158	0.05

Question 30

Where do you think that future management should be co-ordinated for the majority of the time?

The first choice was at a specialist ME centre, closely followed by a GP surgery. A local NHS hospital was third.

The additional comments from people inferred that this question was being interpreted as asking about where people with ME/CFS should be treated as well as where their treatment should be co-ordinated. There were some very strong adverse comments about the way in which the current ME/CFS referral clinics operate, especially where the approach to management appears to be heavily influenced by the psychosocial model of ME/CFS.

Extra suggestions about where people thought management of their illness should take place included a centre also offering complementary medicine and a local GP surgery. A domiciliary (home visiting) service and a telephone and internet helpline were also mentioned.

Where should management be co-ordinated most of the time?

	Ist Choice	2nd Choice	3rd Choice	Rating Average
Specialist ME Centre	1735	704	404	0.74
Primary Care ie. GP surgery	1177	1125	562	0.67
Local NHS Hospital	155	865	1434	0.38
Other Centre	94	40	60	0.04

Question 31

Which health professionals and organisations do you want to be involved?

The GP was most favoured, then a consultant physician. A neurologist, a GP nurse, a dietician/nutritionist, an alternative medicine therapist, an occupational therapist, a counsellor and physiotherapist all were moderately favoured. A psychiatrist was least favoured.

Extra suggestions included an ME specialist, an ME nurse specialist, an immunologist, an endocrinologist and a support worker (presumably dealing with benefits, social services, etc).

Which health professionals and organisations do you want to be involved?

	Ist Choice	2nd Choice	3rd Choice	4th Choice	5th Choice	6th Choice	Rating Average
GP	1502	662	313	108	69	73	0.77
Consultant Physician	627	621	344	126	94	84	0.48
Neurologist	367	337	296	173	97	93	0.32
GP Nurse	70	449	295	228	150	157	0.27
Dietician / Nutritionalist	37	145	295	362	378	350	0.23
Alternative medicine therapist	124	165	227	292	274	205	0.22
Occupational Therapist	62	147	244	239	225	154	0.18
Counsellor	30	106	238	317	267	221	0.18
Physiotherapist	26	78	181	245	203	126	0.14
CBT Therapist	22	51	110	107	134	97	0.08
Psychologist	20	56	103	111	91	98	0.08
Other	117	19	24	14	9	36	0.05
Psychiatrist	15	36	47	55	41	47	0.04

Question 32

What sort of approach to management would you prefer?

Individual sessions with doctors and other health professionals was most favoured. This was followed by a mixture of individual and group sessions. Group sessions alone were the least favoured option.

Extra suggestions for approaches to management included a preference for one-to-one sessions, and the need for home visits, internet and home support. Group sessions were rated poorly by a number of people who felt they could be difficult to get to. They then had further difficulty in coping with all the information being given out during what can be quite long sessions.

What sort of approach to management would you prefer?

	Ist Choice	2nd Choice	3rd Choice	Rating Average
Individual sessions with doctors and other health professionals	2027	466	203	0.76
A mixture of both	941	846	428	0.52
Group sessions where a specific topic – eg. diet, pacing, sleep, etc – is covered in a series of presentations and discussions	104	637	1129	0.29

Section for Carers

Question 1

How many significant carers are involved with this person's management?

70% of patients only had one significant carer, 19% had two and 7% had three. Only 4% had more than three.

Number of significant carers are involved

One	70%
Two	19%
Three	7%
More than 3	4%
Answered question: 896	

Question 2

Are any of you members of The ME Association?

Only 18% of patients had a carer who was a member of The ME Association.

MEA members

No	82%
Yes	18%
Answered question: 892	

Question 3

Approximately how many hours each week is care from all sources required?

24% of Patients required less than 10 hours per week and the proportion generally decreased as more time was required. However, 27% of patients required virtually full time care, ie more than 40 hours per week.

Hours of care required each week

Less than 10 hrs	24%
10 hours	15%
20 hours	17%
30 hours	10%
40 hours	8%
Virtually full-time	27%
Answered question: 878	

Question 4

What are the relationship(s) between you, the carers and the person that you look after?

48% of patients were cared for by their spouse/partner and 80% of care came from within the family. Only 6% came from either social services or professional sources.

Relationships

Spouse/Partner	48%	542
Other family member	32%	358
Other	8%	84
Friend	6%	63
Social Service based	3%	31
Professional Carer (agency)	3%	29
Neighbour	1%	11
Answered question: 1118		

Question 6

What are the main roles required?

Help with daily living activities, shopping and accompanying to appointments was required by 91%, 86% and 78% of patients respectively. 60% required help with mobility outside the house. Fewer required help with personal care, mobility in the house or in other ways.

What are the main roles required?

Care with daily living activities (eg. cooking , cleaning)	91%	803
Shopping and running errands	86%	761
Accompanying to appointments	78%	687
Helping with mobility outside the house	60%	526
Help with personal care (eg. washing, dressing, feeding)	32%	280
Helping with mobility in the house	28%	245
Other	25%	216
Answered question: 880		

Question 7

As a carer, which of these options do you think would help you to provide better care for the person you look after?

Care with daily living activities, shopping and accompanying to appointments was required by 91%, 86% and 78% of patients respectively. 60% required help with mobility outside the house.

Which options would help provide better care for your patient?

Information about ME/CFS	58%	466
Advice about benefits available	55%	440
Visiting counsellor	38%	304
Carers' support group	34%	271
A visiting Occupational Therapist (OT)	32%	254
Access to hydrotherapy (physiotherapy in a warm pool)	31%	249
Advice about mobility aids	29%	234
Transport to specialist centres etc	27%	213
Respite care facility	23%	183
Other	21%	169
Training in patient handling etc	18%	147
Answered question: 799		

Further help required by carers

It is clear that carers require much more information about issues such as benefits, care options, respite care, etc. The ME Association publishes a wide range of leaflets covering all the main DWP benefits, along with social care, etc.

In the comment section, which allowed for additional observations to be made, carers listed items of both direct help for the carer and help for the patient that they felt would lead to improvements in their situation.

The most commonly requested forms of direct help related to:

- help in the home/garden
- help with filling in benefit forms
- increased public awareness of ME/CFS
- availability of pre-booked and emergency respite care
- greater financial benefits
- a local referral centre with a transport service

The most commonly requested forms of help for the person being cared for related to:

- medical support from empathetic personnel who are experienced in ME/CFS management
- better medical care
- regular GP visits
- wider range of approved NHS therapies, including alternative therapies
- better access to ME specialists
- educational help for younger patients

A full electronic list of these comments can be obtained from The ME Association.



**Published by The ME Association, 7 Apollo Office Court, Radclive Road,
Gawcott, Buckinghamshire MK18 4DF.
Tel: 01280 818964 Email: meconnect@meassociation.org.uk
Registered Charity Number 801279**