



# **Managing my M.E.**

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

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**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.

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**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](http://www.meassociation.org.uk)

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## 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?

<b>Yes</b>	<b>37%</b>
<b>No</b>	<b>63%</b>
<b>Answered question:</b>	
<b>3875</b>	

### 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?

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

### 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

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

## 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

<b>Female</b>	78%
<b>Male</b>	22%
<b>Answered question:</b>	<b>3834</b>

## 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
<b>5 - 10 years</b>	0%	2	0%	1
<b>11-20 years</b>	5%	164	4%	36
<b>21-35 years</b>	25%	747	19%	164
<b>35-50 years</b>	36%	1063	33%	278
<b>51-65 years</b>	28%	846	36%	301

## Question 5

### Has the diagnosis of ME/CFS been confirmed?

88% of respondents had had their diagnosis confirmed.

#### Confirmed diagnosis?

<b>Yes</b>	88%
<b>No</b>	12%
<b>Answered question:</b>	<b>3854</b>

## Question 6

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

82% of diagnoses were made by a doctor.

#### Who diagnosed?

<b>Doctor</b>	82%
<b>Other person</b>	15%
<b>Yourself</b>	3%
<b>Complementary therapist</b>	1%
<b>Answered question:</b>	<b>3350</b>

### 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?

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

### 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

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

### 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

<b>Mildly</b>	28%
<b>Moderately</b>	57%
<b>Severely</b>	15%
<b>Answered question:</b>	
<b>3,722</b>	

## 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
<b>Muscle Fatigue</b>	1730	815	457	248	85	0.771
<b>Cognitive Dysfunction</b>	548	956	836	679	277	0.596
<b>Pain (esp in muscles &amp; joints)</b>	504	737	771	775	357	0.539
<b>Sleep Problems</b>	461	617	893	842	507	0.537
<b>Mobility Problems</b>	197	278	385	577	1519	0.330
<b>None of these apply</b>	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
<b>PACING</b>	2137	11.6%	59.6%	24.1%	3.5%	1.2%	71.2%
<b>MEDITATION OR RELAXATION TECHNIQUES</b>	1675	6.1%	47.6%	44.3%	1.6%	0.4%	53.7%
<b>PERRIN TECHNIQUE</b>	115	13.9%	37.4%	37.4%	7.0%	4.3%	51.3%
<b>ALLERGY TREATMENTS</b>	686	9.5%	41.7%	45.2%	2.2%	1.5%	51.2%
<b>OSTEOPATHY/ CHIROPRACTIC</b>	774	9.8%	41.1%	33.3%	10.1%	5.7%	50.9%
<b>MASSAGE</b>	1037	5.4%	43.9%	31.3%	12.7%	6.7%	49.3%
<b>LIGHTNING PROCESS</b>	101	25.7%	18.8%	34.7%	7.9%	12.9%	44.6%
<b>CORTICOSTEROID eg HYDROCORTISONE</b>	323	10.5%	32.5%	35.3%	10.8%	10.8%	43.0%
<b>ADVICE (to help to cope)</b>	2147	3.3%	39.5%	50.9%	3.7%	2.6%	42.8%
<b>HYDROTHERAPY</b>	275	4.0%	37.5%	32.0%	13.5%	13.1%	41.5%
<b>THYROXINE</b>	414	8.7%	30.4%	50.0%	6.0%	4.8%	39.1%
<b>YOGA</b>	812	4.2%	34.9%	32.9%	20.8%	7.3%	39.0%
<b>MODAFINIL/PROVIGIL</b>	81	14.8%	22.2%	33.3%	16.0%	13.6%	37.0%
<b>EICOSAPENTAENOIC AID (EPA) OMEGA 3 OIL</b>	1217	3.2%	33.1%	59.7%	2.9%	1.1%	36.3%
<b>VITAMINS AND SUPPLEMENTS</b>	2370	3.7%	31.9%	61.9%	1.8%	0.8%	35.5%
<b>L CARNITINE</b>	318	2.8%	28.0%	62.9%	3.8%	2.5%	30.8%
<b>PHYSIOTHERAPY</b>	862	3.5%	27.0%	36.7%	17.2%	15.7%	30.5%
<b>REVERSE THERAPY</b>	107	8.4%	21.5%	45.8%	16.8%	7.5%	29.9%
<b>HOMEOPATHY</b>	1100	5.5%	24.4%	59.9%	7.1%	3.2%	29.8%
<b>COUNSELLING (other than CBT)</b>	984	2.6%	26.8%	60.1%	6.1%	4.4%	29.5%
<b>EVENING PRIMROSE OIL</b>	1231	2.6%	25.8%	66.3%	3.7%	1.5%	28.4%
<b>COGNITIVE BEHAVIOUR THERAPY (CBT)</b>	997	2.8%	23.1%	54.6%	11.6%	7.9%	25.9%
<b>INOSINE PRANOBEX/ IMUNOVIR</b>	62	8.1%	17.7%	50.0%	16.1%	8.1%	25.8%
<b>GRADED EXERCISE THERAPY (GET)</b>	906	3.4%	18.7%	21.4%	23.4%	33.1%	22.1%
<b>ENADA/NADH</b>	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
<b>GRADED EXERCISE THERAPY (GET)</b>	906	3.4%	18.7%	21.4%	23.4%	33.1%	56.5%
<b>PHYSIOTHERAPY</b>	862	3.5%	27.0%	36.7%	17.2%	15.7%	32.8%
<b>MODAFINIL/PROVIGIL</b>	81	14.8%	22.2%	33.3%	16.0%	13.6%	29.6%
<b>YOGA</b>	812	4.2%	34.9%	32.9%	20.8%	7.3%	28.1%
<b>HYDROTHERAPY</b>	275	4.0%	37.5%	32.0%	13.5%	13.1%	26.5%
<b>REVERSE THERAPY</b>	107	8.4%	21.5%	45.8%	16.8%	7.5%	24.3%
<b>INOSINE PRANOBEX/ IMUNOVIR</b>	62	8.1%	17.7%	50.0%	16.1%	8.1%	24.2%
<b>CORTICOSTEROID eg HYDROCORTISONE</b>	323	10.5%	32.5%	35.3%	10.8%	10.8%	21.7%
<b>LIGHTNING PROCESS</b>	101	25.7%	18.8%	34.7%	7.9%	12.9%	20.8%
<b>COGNITIVE BEHAVIOUR THERAPY (CBT)</b>	997	2.8%	23.1%	54.6%	11.6%	7.9%	19.6%
<b>MASSAGE</b>	1037	5.4%	43.9%	31.3%	12.7%	6.7%	19.4%
<b>ENADA/NADH</b>	358	3.4%	16.5%	63.4%	12.3%	4.5%	16.8%
<b>OSTEOPATHY/ CHIROPRACTIC</b>	774	9.8%	41.1%	33.3%	10.1%	5.7%	15.8%
<b>PERRIN TECHNIQUE</b>	115	13.9%	37.4%	37.4%	7.0%	4.3%	11.3%
<b>THYROXINE</b>	414	8.7%	30.4%	50.0%	6.0%	4.8%	10.9%
<b>COUNSELLING (other than CBT)</b>	984	2.6%	26.8%	60.1%	6.1%	4.4%	10.5%
<b>HOMEOPATHY</b>	1100	5.5%	24.4%	59.9%	7.1%	3.2%	10.3%
<b>L CARNITINE</b>	318	2.8%	28.0%	62.9%	3.8%	2.5%	6.3%
<b>ADVICE (to help to cope)</b>	2147	3.3%	39.5%	50.9%	3.7%	2.6%	6.3%
<b>EVENING PRIMROSE OIL</b>	1231	2.6%	25.8%	66.3%	3.7%	1.5%	5.4%
<b>PACING</b>	2137	11.6%	59.6%	24.1%	3.5%	1.2%	4.7%
<b>EICOSAPENTAENOIC AID (EPA) OMEGA 3 OIL</b>	1217	3.2%	33.1%	59.7%	2.9%	1.1%	3.9%
<b>ALLERGY TREATMENTS</b>	686	9.5%	41.7%	45.2%	2.2%	1.5%	3.6%
<b>VITAMINS AND SUPPLEMENTS</b>	2370	3.7%	31.9%	61.9%	1.8%	0.8%	2.5%
<b>MEDITATION OR RELAXATION TECHNIQUES</b>	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
<b>PACING</b>	2047	88%	12%
<b>MEDITATION OR RELAXATION TECHNIQUES</b>	1525	89%	11%
<b>PERRIN TECHNIQUE</b>	107	78%	22%
<b>ALLERGY TREATMENTS</b>	646	79%	21%
<b>OSTEOPATHY / CHIROPRACTIC MASSAGE</b>	720	80%	20%
<b>987</b>	987	83%	17%
<b>LIGHTING PROCESS</b>	106	59%	41%
<b>CORTICOSTEROID, eg HYDROCORTISONE</b>	293	66%	34%
<b>ADVICE (to help me to cope)</b>	2090	79%	21%
<b>HYDROTHERAPY</b>	261	69%	31%
<b>THYROXINE</b>	383	82%	18%
<b>YOGA</b>	743	78%	22%
<b>MODAFINIL / PROVIGIL</b>	73	62%	38%
<b>EICOSAPENTAENOIC ACID (EPA) Omega 3 oil</b>	1075	87%	13%
<b>VITAMINS AND SUPPLEMENTS</b>	2081	82%	18%
<b>L CARNITINE</b>	276	84%	16%
<b>PHYSIOTHERAPY</b>	818	63%	37%
<b>REVERSE THERAPY</b>	102	53%	47%
<b>HOMEOPATHY</b>	1014	74%	26%
<b>COUNSELLING (other than CBT)</b>	940	73%	27%
<b>EVENING PRIMROSE OIL - Omega 6 oil</b>	1095	81%	19%
<b>COGNITIVE BEHAVIOUR THERAPY</b>	976	62%	38%
<b>INOSINE PRANOBEX / IMUNOVIR</b>	54	74%	26%
<b>GRADED EXERCISE THERAPY</b>	888	47%	53%
<b>ENADA/NADH</b>	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
<b>PACING</b>	1909	21%	59%	7%	10%	3%
<b>MEDITATION OR RELAXATION TECHNIQUES</b>	1496	8%	71%	2%	7%	12%
<b>PERRIN TECHNIQUE</b>	97	3%	9%	0%	1%	87%
<b>ALLERGY TREATMENTS</b>	616	3%	29%	19%	12%	37%
<b>OSTEOPATHY / CHIROPRACTIC</b>	722	0%	3%	2%	3%	92%
<b>MASSAGE</b>	836	1%	31%	2%	3%	63%
<b>LIGHTNING PROCESS</b>	86	5%	22%	0%	1%	72%
<b>CORTICOSTEROID, eg HYDROCORTISONE</b>	289	2%	29%	33%	26%	10%
<b>ADVICE (to help me to cope)</b>	1915	26%	24%	26%	18%	6%
<b>HYDROTHERAPY</b>	205	3%	17%	2%	59%	18%
<b>THYROXINE</b>	373	2%	29%	50%	6%	12%
<b>YOGA</b>	554	1%	69%	1%	1%	28%
<b>MODAFINIL/PROVIGIL</b>	63	5%	43%	29%	11%	13%
<b>EICOSAPENTAENOIC ACID (EPA) Omega 3 oil</b>	1087	2%	92%	2%	1%	3%
<b>VITAMINS AND SUPPLEMENTS</b>	2047	2%	87%	4%	1%	7%
<b>L CARNITINE</b>	281	2%	85%	3%	1%	8%
<b>PHYSIOTHERAPY</b>	792	5%	10%	12%	55%	18%
<b>REVERSE THERAPY</b>	91	1%	24%	1%	7%	67%
<b>HOMEOPATHY</b>	988	1%	26%	6%	7%	59%
<b>COUNSELLING (other than CBT)</b>	825	8%	16%	28%	20%	29%
<b>EVENING PRIMROSE OIL - Omega 6 oil</b>	1066	2%	90%	5%	1%	2%
<b>COGNITIVE BEHAVIOUR THERAPY</b>	902	25%	14%	11%	37%	13%
<b>INOSINE PRANOBEX / IMUNOVIR</b>	47	19%	36%	21%	15%	9%
<b>GRADED EXERCISE THERAPY</b>	794	21%	33%	8%	32%	6%
<b>ENADA/NADH</b>	306	8%	82%	4%	1%	5%

## Source of Advice and Supply

	Responses	Allcomp 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
<b>PACING</b>	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%
<b>MEDITATION OR RELAXATION TECHNIQUES</b>	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%
<b>PERRIN TECHNIQUE</b>	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%
<b>ALLERGY TREATMENTS OSTEOPATHY /</b>	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%
<b>CHIROPRACTIC</b>	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%
<b>MASSAGE</b>	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%
<b>LIGHTNING PROCESS</b>	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%
<b>CORTICOSTEROID, eg HYDROCORTISONE</b>	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%
<b>ADVICE (to help me to cope)</b>	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%
<b>HYDROTHERAPY</b>	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%
<b>THYROXINE</b>	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%
<b>YOGA</b>	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%
<b>MODAFINIL/PROVIGIL</b>	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%
<b>EICOSAPENTAENOIC ACID (EPA) Omega 3 oil</b>	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%
<b>VITAMINS AND SUPPLEMENTS</b>	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%
<b>L CARNITINE</b>	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%
<b>PHYSIOTHERAPY</b>	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%
<b>REVERSE THERAPY</b>	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%
<b>HOMEOPATHY</b>	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%
<b>COUNSELLING (other than CBT)</b>	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%
<b>EVENING PRIMROSE OIL -Omega 6 oil</b>	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%
<b>COGNITIVE BEHAVIOUR THERAPY</b>	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%
<b>INOSINE PRANOBEX / IMUNOVIR</b>	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%
<b>GRADED EXERCISE THERAPY</b>	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%
<b>ENADA/NADH</b>	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

	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
<b>Drug - opiate analgesics (eg. tramadol)</b>	542	0%	5%	0%	0%	13%	73%	0%	1%	0%	1%	2%	0%	4%	0%	0%	0%
<b>Drug - NSAIDS (eg. ibuprofen/Brufen)</b>	1345	0%	1%	0%	0%	6%	52%	0%	1%	0%	0%	31%	0%	2%	0%	6%	0%
<b>Drug - aspirin or paracetamol</b>	1674	0%	0%	0%	0%	5%	45%	0%	0%	0%	0%	38%	0%	1%	0%	8%	0%
<b>Acupuncture</b>	947	57%	0%	0%	0%	3%	9%	0%	2%	1%	8%	0%	8%	6%	0%	5%	0%
<b>Drug - amitriptyline</b>	1098	0%	10%	3%	0%	11%	71%	1%	0%	0%	1%	0%	0%	3%	0%	1%	0%
<b>TENS</b>	438	4%	3%	0%	0%	6%	13%	1%	3%	3%	2%	27%	18%	2%	0%	18%	0%
<b>Drug - pregabalin/Lyrica</b>	124	0%	16%	2%	0%	22%	37%	1%	2%	0%	3%	1%	1%	14%	2%	1%	0%
<b>Drug - gabapentin/ Neurontin</b>	218	0%	25%	2%	0%	17%	43%	0%	0%	1%	2%	1%	0%	7%	0%	1%	0%
<b>Referral to a pain clinic</b>	304	2%	11%	1%	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
<b>Drug - short acting sleeping tablets (eg. zaleplon/Sonata, zolpidem/Stilnoct, zopiclone/Zimovane)</b>	755	23.2%	35.0%	10.3%	14.4%	17.1%	58.1%
<b>Relaxation techniques</b>	1582	10.8%	47.0%	9.5%	31.8%	0.9%	57.8%
<b>Drug - amitriptyline (low dose)</b>	1122	13.1%	30.4%	10.7%	18.4%	27.5%	43.5%
<b>Drug - melatonin</b>	391	17.4%	24.8%	7.9%	36.8%	13.0%	42.2%
<b>Sleep hygiene advice</b>	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
<b>Drug - amitriptyline (low dose)</b>	1122	13.1%	30.4%	10.7%	18.4%	27.5%
<b>Drug - short acting sleeping tablets (eg. zaleplon/Sonata, zolpidem/Stilnoct, zopiclone/Zimovane)</b>	755	23.2%	35.0%	10.3%	14.4%	17.1%
<b>Drug - melatonin</b>	391	17.4%	24.8%	7.9%	36.8%	13.0%
<b>Sleep hygiene advice</b>	687	5.5%	30.6%	11.5%	47.6%	4.8%
<b>Relaxation techniques</b>	1582	10.8%	47.0%	9.5%	31.8%	0.9%

## Acceptability

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

## Where Carried Out

	Responses	Specialist ME centre	At home	GP surgery	Local hospital	Comp health clinic
<b>Drug - short acting sleeping tablets</b> (eg. zaleplon/Sonata, zolpidem/Stilnoct, zopiclone/Zimovane)	696	2.7%	54.0%	37.8%	3.2%	2.3%
<b>Relaxation techniques</b>	1436	7.9%	74.6%	1.5%	6.6%	9.4%
<b>Drug - amitriptyline (low dose)</b>	1032	4.6%	46.5%	38.9%	8.4%	1.6%
<b>Drug - melatonin</b>	347	5.8%	73.8%	8.4%	4.6%	7.5%
<b>Sleep hygiene advice</b>	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	
<b>Drug - short acting sleeping tablets</b> (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%	1.0%
<b>Relaxation techniques</b>	1369	17.7%	0.9%	2.0%	4.4%	1.3%	4.3%	2.8%	3.1%	11.2%	7.6%	1.0%
<b>Drug - amitriptyline (low dose)</b>	1030	0.0%	9.3%	2.7%	0.1%	10.2%	70.4%	1.0%	0.2%	1.0%	0.9%	0.0%
<b>Drug - melatonin</b>	342	6.7%	6.4%	1.8%	0.3%	11.4%	10.8%	2.0%	0.9%	0.6%	0.6%	21.0%
<b>Sleep hygiene advice</b>	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
<b>Drug - SSRI antidepressants</b> (eg. citalopram/Cipramil, fluoxetine/Prozac, paroxetine/Seroxat, sertraline/Lustral)	1529	13.0%	27.9%	8.7%	20.3%	30.0%	40.9%
<b>Cognitive behavioural therapy (CBT)</b>	686	12.2%	27.1%	7.7%	38.6%	14.3%	39.4%
<b>Drug - venlafaxine/Efexor</b>	276	13.8%	22.8%	8.0%	16.7%	38.8%	36.6%
<b>Drug - tricyclic antidepressants</b> (eg. full dose amitriptyline, imipramine, dothiepin/Prothiaden)	715	9.5%	26.2%	10.2%	18.3%	35.8%	35.7%
<b>Herb - St John's Wort</b>	668	6.0%	22.5%	8.5%	50.0%	13.0%	28.4%
<b>Drug - monoamine oxidative inhibitor antidepressants</b> (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
<b>Drug - SSRI antidepressants</b> (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%
<b>Cognitive behavioural therapy (CBT)</b>	629	2%	3%	12%	13%	2%	11%	0%	4%	12%	8%	0%	2%	1%	25%	5%	1%
<b>Drug - venlafaxine/ Efexor</b>	261	0%	4%	23%	0%	9%	60%	0%	0%	0%	0%	0%	0%	3%	0%	0%	0%
<b>Drug - tricyclic antidepressants</b> (eg. full dose amitriptyline, imipramine, dothiepin/ Prothiaden)	651	0%	6%	10%	0%	9%	71%	0%	0%	0%	0%	0%	0%	2%	1%	0%	0%
<b>Herb - St John's Wort</b>	569	13%	0%	0%	0%	2%	9%	2%	0%	0%	1%	37%	0%	2%	0%	34%	0%
<b>Drug - monoamine oxidative inhibitor antidepressants</b> (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
<b>Dietary modification</b>	1599	23.1%	45.8%	7.8%	21.1%	2.1%	69.0%
<b>Drug - antispasmodic (eg. mebeverine/Colofac, peppermint oil/Colpermin)</b>	812	17.5%	41.0%	11.0%	23.4%	7.1%	58.5%
<b>Bulk laxatives (eg. Fybogel, Isogel)</b>	709	12.1%	40.6%	11.0%	20.2%	16.1%	52.8%
<b>Increased dietary fibre intake</b>	914	11.2%	36.4%	8.6%	27.2%	16.5%	47.6%

### Source of Advice and Supply

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

## Sorted according to the percentage of those who reported feeling worse

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

## Acceptability

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

## Where Carried Out

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

## Question 24

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

## Question 25

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

### Rate current standard of medical care

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

**Answered question:  
2965**

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

<b>No</b>	38.9%
<b>Partly</b>	33.4%
<b>Yes</b>	27.7%

**Answered question:  
3297**

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

<b>No</b>	52.7%
<b>Partly</b>	32.0%
<b>Yes</b>	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
<b>GP</b>	794	428	313	0.38
<b>Mixture of GP &amp; Consultant Physician</b>	751	382	196	0.35
<b>Mixture of GP &amp; Practice Nurse</b>	270	330	287	0.19
<b>Consultant Physician</b>	291	272	182	0.17
<b>Neurologist</b>	301	250	172	0.17
<b>Nurse Specialist</b>	192	304	281	0.16
<b>An alternative medicine therapist</b>	144	201	321	0.12
<b>Occupational Therapist</b>	72	193	204	0.09
<b>None of these</b>	169	13	42	0.06
<b>Practice Nurse</b>	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
<b>Specialist ME Centre</b>	1735	704	404	0.74
<b>Primary Care ie. GP surgery</b>	1177	1125	562	0.67
<b>Local NHS Hospital</b>	155	865	1434	0.38
<b>Other Centre</b>	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
<b>GP</b>	1502	662	313	108	69	73	0.77
<b>Consultant Physician</b>	627	621	344	126	94	84	0.48
<b>Neurologist</b>	367	337	296	173	97	93	0.32
<b>GP Nurse</b>	70	449	295	228	150	157	0.27
<b>Dietician / Nutritionalist</b>	37	145	295	362	378	350	0.23
<b>Alternative medicine therapist</b>	124	165	227	292	274	205	0.22
<b>Occupational Therapist</b>	62	147	244	239	225	154	0.18
<b>Counsellor</b>	30	106	238	317	267	221	0.18
<b>Physiotherapist</b>	26	78	181	245	203	126	0.14
<b>CBT Therapist</b>	22	51	110	107	134	97	0.08
<b>Psychologist</b>	20	56	103	111	91	98	0.08
<b>Other</b>	117	19	24	14	9	36	0.05
<b>Psychiatrist</b>	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
<b>Individual sessions with doctors and other health professionals</b>	2027	466	203	0.76
<b>A mixture of both</b>	941	846	428	0.52
<b>Group sessions where a specific topic – eg. diet, pacing, sleep, etc – is covered in a series of presentations and discussions</b>	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

<b>One</b>	<b>70%</b>
<b>Two</b>	<b>19%</b>
<b>Three</b>	<b>7%</b>
<b>More than 3</b>	<b>4%</b>
<b>Answered question: 896</b>	

### 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

<b>No</b>	<b>82%</b>
<b>Yes</b>	<b>18%</b>
<b>Answered question: 892</b>	

### 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

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

### 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

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

## 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.



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