**Report on Survey of Members of Local ME Groups**

**Author: Dr Lesley Cooper**

**Sponsors: Action for ME and the ME Association**

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**Abstract**

A postal survey of the members of local groups associated with either Action for ME or the ME Association was carried out between June and August 2000. A total of 730 questionnaires were finally distributed and 347 respondents replied (47% response rate). The main aims of the survey were to investigate the issues and concerns of ME sufferers as well as their experiences of services and treatments. The study found that many of the previously voiced concerns of ME patients were substantiated. Further studies might want to investigate these issues in more detail.

## 1. INTRODUCTION

### 1.1 Outline of Study

A postal survey of the members of local groups associated with either Action for ME or the ME Association was carried out between June and August 2000. Groups from different areas in England were sent questionnaires via the group organisers. These were returned by mid September 2000 and the final report was completed in November 2000.

### 1.2 Background to the Research

The impetus for this survey came from various sections of the ME population including the patient groups who felt that the needs and experiences of sufferers were being largely ignored. For instance the National Task Force Report published in 1998 concluded that there was a huge disparity in services for ME. Anecdotal evidence suggests that patients with ME/CFS experience problems in various areas of their lives. There is also evidence that some patients are concerned with the controversial issues surrounding ME/CFS such as the name of the illness and the proposed treatments that are available. Although the CMO's working group has completed a paper on benefits, which suggests that sufferers had been having problems with receiving social security benefits, there has been no methodical attempt to discover if this is actually the case.

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Nor has there been any systematic attempt to discover what their major concerns and experiences are. The survey was therefore initiated in order to provide some initial data. It is hoped that this report and further research will go some way towards rectifying this situation. The CMO's Working Group on ME/CFS recognised the need for such a survey but were unable to carry it out themselves, so this independent survey was suggested as a way of providing possible material for the Working Group, and of giving a clear picture of the problems and difficulties experienced by the ME sufferer. It is hoped that both patient groups will be able to draw on these findings.

This survey was conducted at the same time as a comparable one initiated by the '25% ME Group'[i] which was completed in July 2000. An attempt will be made to compare results where appropriate.

### 1.3 Aims of the survey

The primary aims of this survey are therefore to discover:

- The concerns that ME patients consider most pressing
- The problems that ME patients consider most pressing
- Whether NHS and patient group services are helpful
- Difficulties in obtaining benefits
- Experiences of treatments – what helps and what hinders

### Initial hypotheses

Due to anecdotal evidence several hypotheses were made at the start of this survey. These were:

- That CBT and graded exercise, having been criticised by sufferers and other medical critics, did not benefit ME sufferers and in some cases actually harmed them.
- That alternative medicine was of benefit to ME patients – again this hypothesis was based on anecdotal evidence.
- That ME patients experienced problems with medical services and private and public benefits.
- That ME sufferers were concerned not only about issues of diagnosis and treatment, but about the more contentious issues such as the name of the illness and the differences between CFS and ME'.
- That ME patients often found GPs and other medical professionals unhelpful and in some cases abusive and threatening. This hypothesis was based both

on my own previous work[ii] and on evidence gathered in the CMO's sounding board event.

## 2. SURVEY METHODOLOGY

### 2.1 Overview

The survey was conducted by means of a mailed self-administered questionnaire, which was sent to the members of local groups via the local groups' organiser. This method was chosen as the simplest and most economical method of discovering patients' views. The questionnaire was designed to enable easy input into the quantitative software program, SPSS[iii] for analysis of the data. Initial drafts of the questionnaire were sent out to Dr Charles Shepherd, Dr Derek Pheby, and the chief executives of the national patient groups. The questionnaire was also checked and validated by Dr Jonathan Scales of Essex University. Dr Scales has worked with quantitative analysis and SPSS for several years and is familiar with the type of questionnaire design that best suits SPSS.

### 2.2 Sample size and selection criteria

A sample of local groups was chosen according to their size (over 150 membership) and geographical location (This list is probably not totally representative of populations elsewhere and any location bias must be taken into consideration.[iv]). The membership of the groups that agreed to take part was then randomly sampled to include approximately one third of membership of the groups selected. The sampling was done either by myself or by the group organiser who was told how to select respondents according to simple random sampling criteria (i.e. every third member was selected). The groups that agreed to take part in this survey included Hampshire, Hereford, Worcester, Kent, Colchester, Leicestershire, Sussex, Hertfordshire, and a small group in London, Leeds and Swindon. A total of 730 questionnaires were finally distributed and 347 respondents replied. The response rate was therefore 47%. Any assessment of the validity and reliability of these findings must take into account the fact that this survey sample is small compared to the possible total number of ME/CFS sufferers in the United Kingdom alone. A larger and more comprehensive survey may or may not verify these results. This sample may under represent the severely affected as this sub group would find it much more difficult to fill in the questionnaire let alone belong to a local group. In choosing to seek respondents via groups, it is also acknowledged that they may not be representative of everyone with ME. Bias[v] is likely to be towards those from middle class backgrounds and those who have not recovered quickly. Those

responding are also likely to include those with most experience of using health practitioners and who have become more familiar with the issues.

### 2.3 Questionnaire design

The A 4 two-sided questionnaire consisted of 17 questions asking for single or multiple response answers. The questionnaire can be found in Appendix 1.

## 3. RESULTS

### 3.1& 2 Verification of Respondents

This question asked whether the respondent actually had the illness or was a carer who was filling out the questionnaire on behalf of someone. It was felt that many of the members of the local groups might not actually have the illness and so confirmation of their status as ME sufferers needed verifying. 328 had CFS or ME[vi], 21 were carers of someone who had the illness but this included several that also had ME. Carers usually filled in the form on behalf of their children. The 347 questionnaires were therefore representative of the experiences of ME sufferers even when they were not completed in person.

### 3.3 Male/female ratio

- 76% of the respondents were women
- 24 % were men

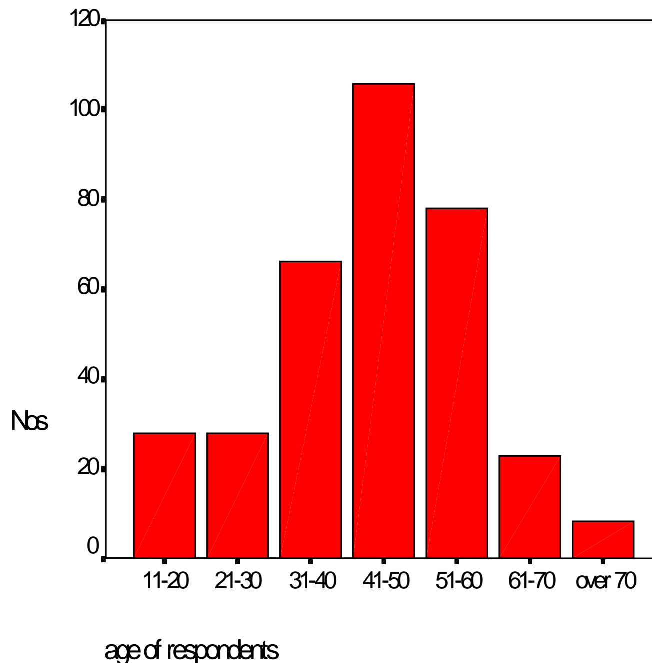
### 3.4 Age

The age range was spread from as young as eleven years of age upto the over 70s, but as can be seen in figure 1 there were more in the mid age range than at either end. The numbers of those with ME peak between the ages 30- 60 with the age group 40-50 having the highest number of sufferers.

Table 1 Age of respondents

| | | Frequency | Valid Percent |
|---|---|---|---|
| Valid | 11-20 | 28 | 8.3 |
| | 21-30 | 28 | 8.3 |
| | 31-40 | 66 | 19.6 |
| | 41-50 | 106 | 31.5 |
| | 51-60 | 78 | 23.1 |
| | 61-70 | 23 | 6.8 |
| | over 70 | 8 | 2.4 |
| | Total | 337 | 100.0 |
| Missing | -9.00 | 10 | |
| Total | | 347 | |

Figure 1: Age range of Respondents




**3.5 Occupation**

Occupations were coded according to simple categories: manual, professional, housewife, student and teacher. The reasoning behind this will be discussed in the next section. The professional category included all white-collar occupations such as secretarial, IT, administrative and managerial jobs. As can be seen from the chart there was a much higher percentage of people who had previously been in professional occupations than those who had been manually employed. This may however reflect a bias in having sought respondents via local groups.

There is nevertheless some anecdotal and epidemiological evidence that high numbers of teachers and health care workers have become ill with ME/CFS. Teachers, health care workers[vii] and students are more likely to encounter viral infections – it has been

argued that schools and hospitals tend to be places where people are more likely to catch colds and flu. In order to further test the hypothesis that these occupations are high-risk categories for ME/CFS these occupations were coded for separately as can be seen in figure and then aggregated in figure . This shows that a total of 125 people or 37 percent of the respondents were in these professions before they began to suffer from the illness.

**Table 2: Occupation Before Illness**

| | Occupation | Frequency | Valid Percent |
|---|---|---|---|
| Valid | student | 47 | 13.8 |
| | professional | 128 | 37.5 |
| | housewife | 18 | 5.3 |
| | teacher | 39 | 11.4 |
| | health care worker | 39 | 11.4 |
| | manual | 38 | 11.1 |
| | misc | 32 | 9.4 |
| | Total | 341 | 100.0 |
| Missing | missing | 6 | |
| Total | | 347 | |

**Figure 2: Occupation before illness**

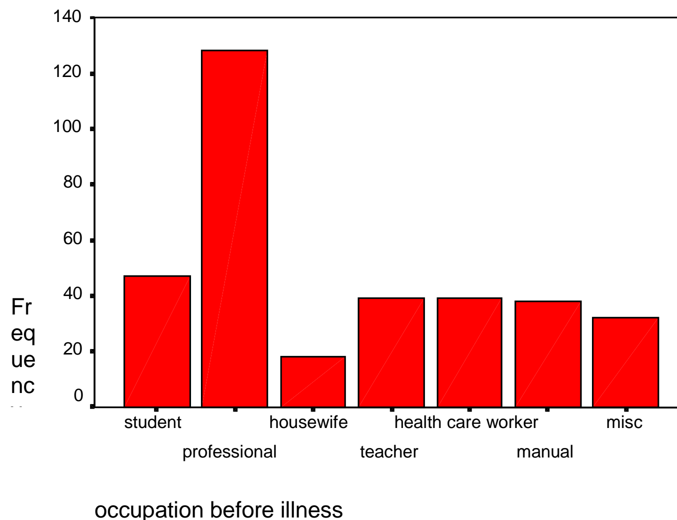
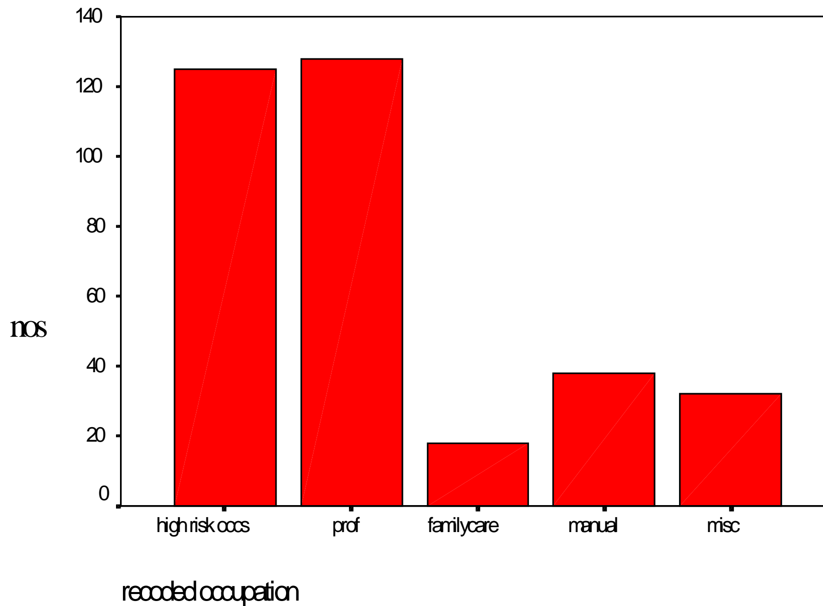



**Table 3: recoded occupation**

| | | Frequency | Valid Percent |
|---|---|---|---|
| Valid | high risk occs | 125 | 36.7 |
| | prof | 128 | 37.5 |
| | familycare | 18 | 5.3 |

|  |  |  |  |
|---|---|---|---|
|  | manual | 38 | 11.1 |
|  | misc | 32 | 9.4 |
|  | Total | 341 | 100.0 |
| Missing |  | 6 |  |
| Total |  | 347 |  |



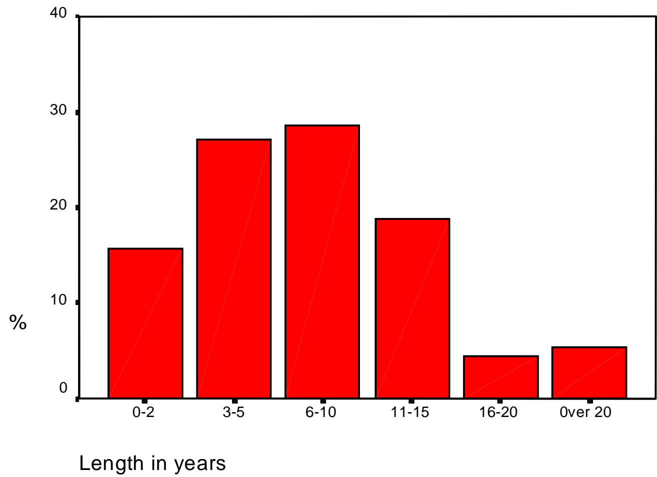

As with other questions it was not always possible for respondents to answer this question simply as some felt that they had symptoms for a long period before they definitely knew they had ME or were diagnosed with the illness. In order to establish some kind of criteria the moment when they definitely knew they had ME or were diagnosed was used. The high number of long term sufferers was significant. Most respondents (75%) had had the illness between three and fifteen years. Eighteen had been ill for over 20 years. These results contrast with those of the 25% group's survey. There the largest number of sufferers had been ill for over 15 years (68 out of 206 had been ill for 15 years or more).

**Table 4 Length of illness**

|  | Years | Frequency | Valid Percent |
|---|---|---|---|
| Valid | 0-2 | 53 | 15.6 |
|  | 3-5 | 92 | 27.1 |
|  | 6-10 | 97 | 28.6 |
|  | 11-15 | 64 | 18.9 |
|  | 16-20 | 15 | 4.4 |
|  | 0ver 20 | 18 | 5.3 |
|  | Total | 339 | 100.0 |

| Missing | -9.00 | 8 | |
|---|---|---|---|
| Total | | 347 | |

**Figure 4: Length of illness**




Length of illness was cross tabulated with sex to see if there was any difference in the length of time men and women tended to suffer from ME/CFS. In order to simplify matters the length of illness was recoded into two simple categories: up to five years and five years and over. 81% of men and 68% of the women had been ill for less than five years. 19% of the men and 31% of the women had been ill for over five years. Thus women appear to have the illness for longer. Chi Square tests on the results showed that these results were statically significant at the 5% level (P< 0.05). However the validity of this association could be tempered by other intervening variables such as the age of respondents.

### 3.7 Severity of Illness

Respondents were asked to tick the level of activity and mobility. This included four levels.

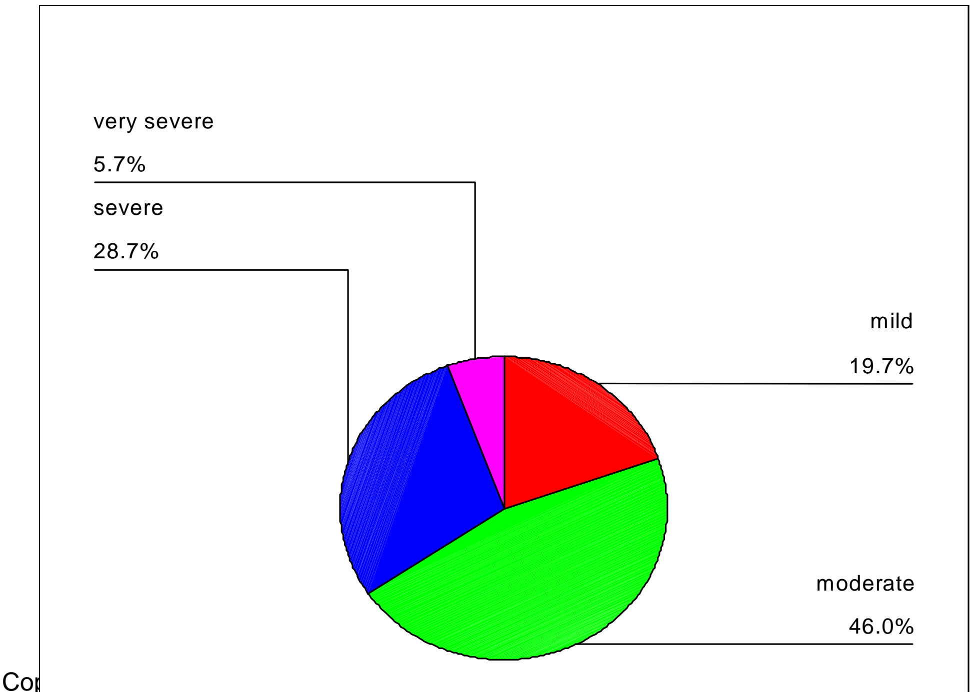
1. Mild: mobile and can care for self and do light domestic tasks with difficulty. If working have to stop all other activities.
2. Moderate: reduced mobility and restricted in all activities usually stopped work and required rest periods
3. Severe: able to carry out minimal tasks housebound.
4. Very severe: unable to carry out any daily tasks for oneself, bedridden for most of the time

Again, the answers to this question were not always clear-cut even though the question did not allow for any ambivalence. This is almost entirely due to the nature of ME. ME/CFS fluctuates in severity to the point where a sufferer can be feeling quite well one day and the next suffer from a relapse. This fluctuating nature was not taken into consideration when devising this questionnaire and future questionnaires should consider this. However, despite these fluctuations, which were noted by several respondents, who wrote that they moved between categories, the answers to this question still give a general idea of the range of severity. 19% said that they had a mild form of the illness, 45% had moderate symptoms and 28% had severe symptoms. A further 5% had very severe symptoms. It has been generally stated that 25% of people with ME are severely affected (hence the '25% Group'), although this has not been well evidenced.

**Table 5: severity of illness**

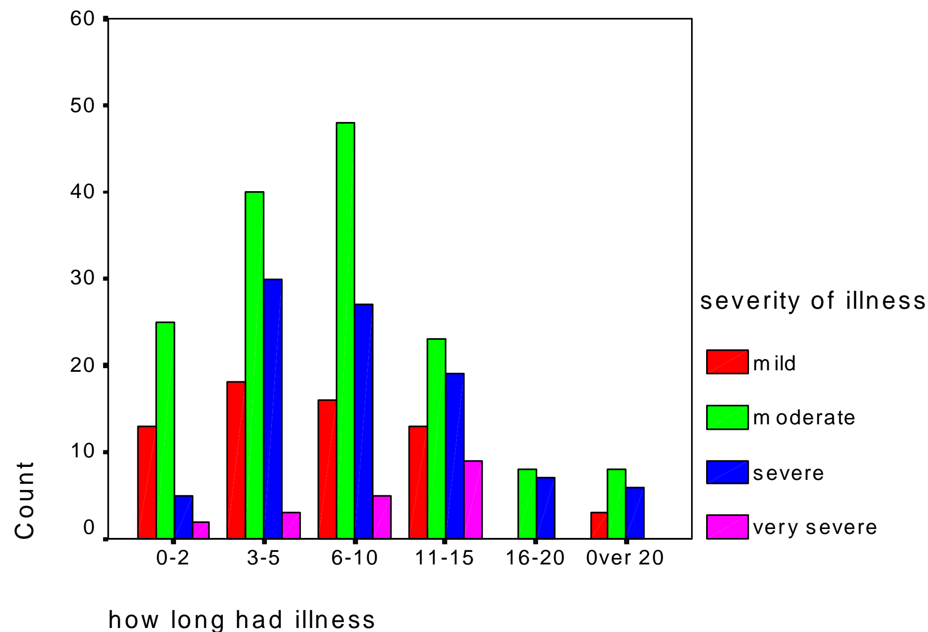
| | | Frequency | Valid Percent |
|---|---|---|---|
| Valid | mild | 66 | 19.7 |
| | moderate | 154 | 46.0 |
| | severe | 96 | 28.7 |
| | very severe | 19 | 5.7 |
| | Total | 335 | 100.0 |
| Missing | missing | 12 | |
| Total | | 347 | |

**Figure 6: severity of illness**



When severity is cross-tabulated with length of illness we can see that, with these respondents, those who had the illness for less than two years were more likely to be only moderately or mildly ill. This changes for those who have had the illness for slightly longer; this group are more likely to be severely ill. There are still more sufferers in all groups who are moderately or mildly rather than severely disabled. No one who had been ill for longer than fifteen years was severely ill to the point where they were bedridden for most of the time.

**Figure 7: length of illness cross tabulated with severity of illness**




When severity of illness was cross-tabulated with sex there were no significant differences.

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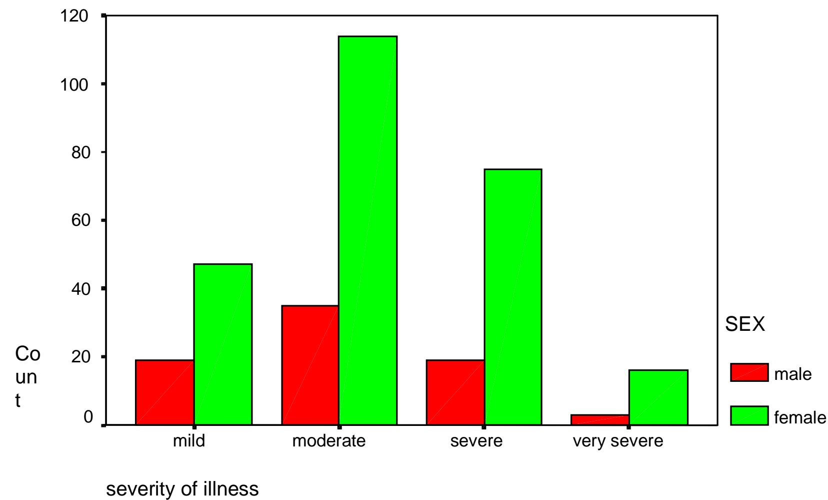
**Figure 8: severity of illness cross tabulated with sex**




### 3.8 Membership of National and local groups

In answer to the question ' Are you a member of any national patient groups?' respondents could tick Action for ME, ME Association or other (they could tick 1-3 as some belong to more than one group). 58% were members of AfME 57% were members of the ME Association whilst 20% were members of other groups. The latter were most likely to be members of local groups and some stipulated this. 21% were members of both AfME and the ME Association.

### 3.9 Concerns

The next set of questions endeavoured to establish what issues ME sufferers were worried about in order of priority. Were they for instance, more concerned about research than debates about the name of the illness? Were they concerned about areas that had not been previously mentioned in the debates about the illness? Fifteen concerns in total were listed and respondents were asked how concerned they were about each ( see appendix). The issues that respondents were most concerned about were research into treatment, and the aetiology of the illness. Thus research of any kind was seen as one of the most important issues surrounding ME/CFS. 88% of all the respondents were very concerned about research into treatment, and only one out of the 345 who answered this question was not at all concerned about this issue. Only 5% were not at all concerned about research into diagnosis and only 2% were not concerned about research into the causes of the illness. The issue of diagnosis and the psychological versus physical debate were also seen as primary concerns (76% were very concerned about this latter issue). However, whereas the debate over the name of

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the illness and the differences between CFS and ME have received a degree of publicity in ME circles, these respondents saw these as not as important as other issues. Only 35% were very concerned about the name of the illness and 36% very concerned about the differences between CFS and ME. At the same time, only a small percentage of respondents were not concerned at all about any of these issues and for instance, a total of 75% were still concerned in some degree about the name of the illness. When respondents were asked to tick 'other concerns' the kind of concern was not solicited, but they were asked to specify what these were. The majority of respondents that did, referred to the negative attitudes towards the illness and particularly the disbelief and hostility encountered from the medical profession. A typical comment was ' the ignorance of the medical profession and the attitude of the media and the public'. Another stated 'finding doctors sympathetic to ME'. Another concern specified was the need for the availability of alternative therapies on the NHS.

**Diagnosis**

| | How concerned | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 16 | 4.8 |
| | moderately | 85 | 25.6 |
| | very | 231 | 69.6 |
| | Total | 332 | 100.0 |
| Missing | | 15 | |
| Total | | 347 | |

**Research into treatment**

| | How concerned | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 1 | .3 |
| | moderately | 42 | 12.2 |
| | very | 302 | 87.5 |
| | Total | 345 | 100.0 |
| Missing | | 2 | |
| Total | | 347 | |

**Research into causes**

| | How concerned | Frequency | Valid Percent |
|---|---|---|---|
| Valid | Not at all | 6 | 1.7 |
| | moderately | 63 | 18.3 |
| | very | 276 | 80.0 |
| | Total | 345 | 100.0 |
| Missing | | 2 | |
| Total | | 347 | |

**Research into epidemiology ( how many have ME)**

| | How concerned | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 21 | 6.2 |
| | moderately | 192 | 56.3 |
| | very | 128 | 37.5 |
| | Total | 341 | 100.0 |
| Missing | Total | 6 | |
| Total | | 347 | |

**Name**

| | How concerned | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 80 | 23.4 |
| | moderately | 144 | 42.1 |
| | very | 118 | 34.5 |
| | Total | 342 | 100.0 |
| Missing | | 5 | |
| Total | | 347 | |

**Psychological or physical**

| | How concerned | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 12 | 3.5 |
| | moderately | 71 | 20.7 |
| | very | 260 | 75.8 |
| | Total | 343 | 100.0 |
| Missing | | 4 | |
| Total | | 347 | |

**Differences between ME and CFS**

| | How concerned | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 57 | 16.8 |
| | moderately | 166 | 49.0 |
| | very | 116 | 34.2 |
| | Total | 339 | 100.0 |
| Missing | | 8 | |
| Total | | 347 | |

**Sub-groups severely affected**

| | How concerned | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 20 | 6.2 |
| | moderately | 134 | 41.6 |
| | very | 168 | 52.2 |
| | Total | 322 | 100.0 |
| Missing | | 25 | |
| Total | | 347 | |

**Sub groups children**

| | How concerned | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 26 | 8.1 |
| | moderately | 143 | 44.5 |
| | very | 152 | 47.4 |
| | Total | 321 | 100.0 |
| Missing | | 26 | |
| Total | | 347 | |

**Sub groups with allergies etc**

| | How concerned | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 38 | 11.8 |
| | moderately | 165 | 51.2 |
| | very | 119 | 37.0 |
| | Total | 322 | 100.0 |
| Missing | | 25 | |
| Total | | 347 | |

**Help from social services**

| | How concerned | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 46 | 13.8 |
| | moderately | 117 | 35.1 |
| | very | 170 | 51.1 |
| | Total | 333 | 100.0 |
| Missing | | 14 | |
| Total | | 347 | |

**Respite care home visits**

| | How concerned | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 79 | 24.2 |
| | moderately | 123 | 37.7 |
| | very | 124 | 38.0 |
| | Total | 326 | 100.0 |
| Missing | | 21 | |
| Total | | 347 | |

**Benefits**

| | How concerned | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 27 | 8.1 |
| | moderately | 87 | 26.0 |
| | very | 221 | 66.0 |
| | Total | 335 | 100.0 |
| Missing | | 12 | |
| Total | | 347 | |

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**Money**

| | How concerned | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 30 | 9.0 |
| | moderately | 104 | 31.0 |
| | very | 201 | 60.0 |
| | Total | 335 | 100.0 |
| Missing | | 12 | |
| Total | | 347 | |

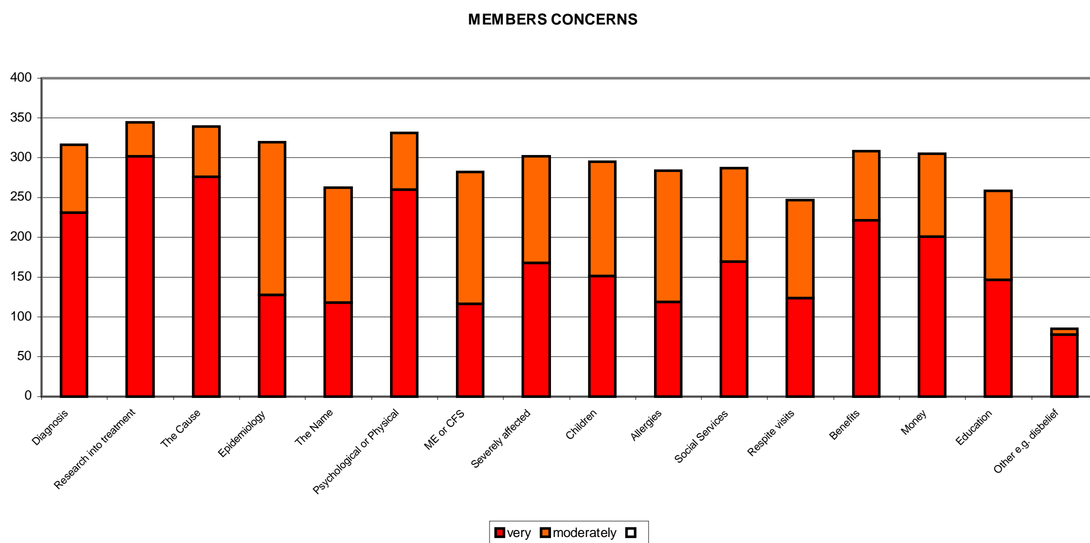
**Education**

| | How concerned | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 58 | 18.4 |
| | moderately | 111 | 35.1 |
| | very | 147 | 46.5 |
| | Total | 316 | 100.0 |
| Missing | | 31 | |
| Total | | 347 | |

**Other concerns- disbelief, hostility**

| | How concerned | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 8 | 8.6 |
| | moderately | 7 | 7.5 |
| | very | 78 | 83.9 |
| | Total | 93 | 100.0 |
| Missing | | 254 | |
| Total | | 347 | |

**Figure 9: Concerns about issues**



### 3.10 Formal Diagnosis

93% had been formally diagnosed with ME/CFS[viii]

### 3.11 Response to 'Who diagnosed your ME?'

Respondents were given a multiple choice question and asked to tick one or more of the following in answer to this question; hospital consultant, GP, ME specialist and/or alternative practitioner. At the same time they were also asked what name that practitioner gave them on diagnosis. Figure 10 shows that GPs and hospital consultants were most likely to diagnose the illness. Consultants were equally likely to call it CFS or ME whereas the GP and the ME specialist was twice as likely to call it ME than CFS and the GP was more likely to term the illness PVFS than CFS. This result contrasts with earlier findings (Cooper 1998) where it was found that 32% of GPs were likely to term the illness PVFS, 32% CFS and only 19% ME. However, in this study respondents were given the option to note where their GP or other practitioner had given more than one term. Thus a substantial percentage could have termed the illness both CFS and ME. The other difference is that this study asked patients whilst the earlier study asked practitioners. It may be that practitioners do not like to acknowledge that they term the illness ME and in some cases may use the label in order to keep the patient happy! Alternative practitioners, where they diagnosed, were most likely to call it ME.

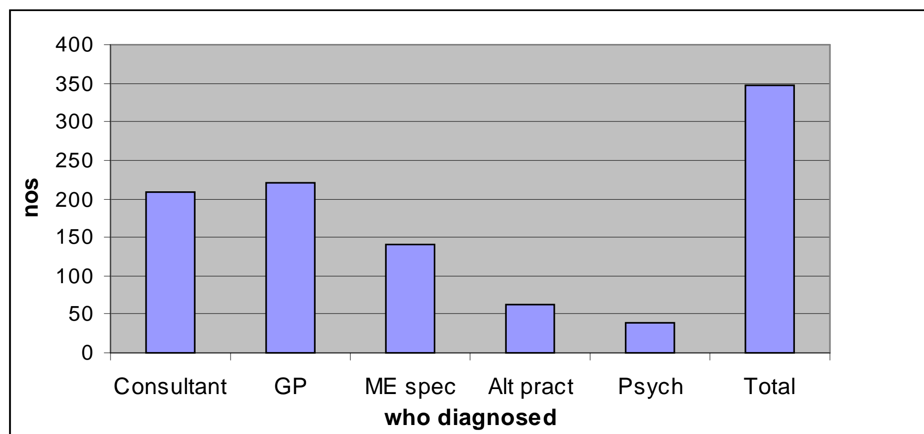



**Figure 10: who diagnosed ME**

**Hospital Consultant**

| | Name used | Frequency | Valid Percent |
|---|---|---|---|
| Valid | ME | 67 | 32.2 |
| | CFS | 69 | 33.2 |
| | PVFS | 33 | 15.9 |
| | Other | 5 | 2.4 |
| | More than one | 34 | 16.3 |
| | Total | 208 | 100.0 |
| Missing | | 139 | |
| Total | | 347 | |

**GP**

| | Name used | Frequency | Valid Percent |
|---|---|---|---|
| Valid | ME<br>CFS | 76<br>39 | 34.4<br>17.6 |
| | PVFS | 52 | 23.5 |
| | Other | 4 | 1.8 |
| | more than one | 50 | 22.6 |
| | Total | 221 | 100.0 |
| Missing | not ticked | 126 | |
| Total | | 347 | |

**ME specialist**

| | Name used | Frequency | Valid Percent |
|---|---|---|---|
| Valid | ME | 77 | 55.0 |
| | CFS | 32 | 22.9 |
| | PVFS | 4 | 2.9 |
| | more than one | 27 | 19.3 |
| | Total | 140 | 100.0 |
| Missing | not ticked | 207 | |
| Total | | 347 | |

**Alternative practitioner**

| | Name used | Frequency | Valid Percent |
|---|---|---|---|
| Valid | ME | 46 | 74.2 |
| | CFS | 5 | 8.1 |
| | PVFS | 5 | 8.1 |
| | other | 2 | 3.2 |
| | more than one | 4 | 6.5 |
| | Total | 62 | 100.0 |
| Missing | | 285 | |
| Total | | 347 | |

**Psychiatrist**

| | Name used | Frequency | Valid Percent |
|---|---|---|---|
| Valid | ME | 20 | 50.0 |
| | CFS | 6 | 15.0 |
| | PVFS | 7 | 17.5 |
| | other | 5 | 12.5 |
| | more than | 2 | 5.0 |

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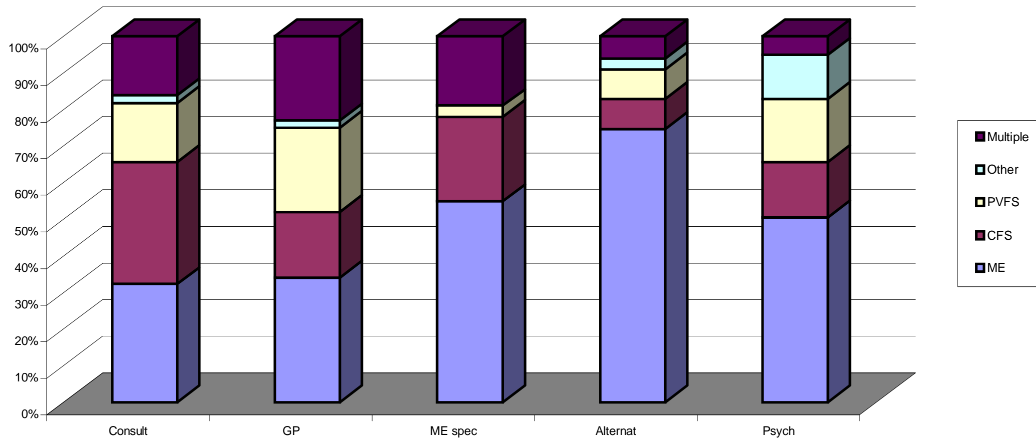
| | one | | |
|---|---|---|---|
| | Total | 40 | 100.0 |
| Missing | | 307 | |
| Total | | 347 | |

**Figure 11: Diagnosis and Nomenclature**




### 3.12 Problems

This question was an attempt to discover what problems affected people with ME the most. Respondents were asked to what extent were they affected by each problem. The problem that affected every respondent was fatigue with 93% considerably[1] affected , closely followed by pain and physical disability (94% were affected either moderately or considerably by both). Mental or cognitive problems such as difficulties with memory affected 95% whilst 84% were affected by emotional or psychological problems. 86% were affected by social problems such as loneliness, 90% of those who answered this question experienced problems with employment[2]. 31% were considerably affected by problems with professionals and 66% had problems with their family. All respondents were affected by most of the problems listed to some extent and in addition other problems were noted such as lack of sleep, sensitivity to noise, allergies, headaches, problems with education provision, and problems with people outside the family.

**Pain**

| | How affected | Frequency | Valid Percent |
|---|---|---|---|

[1] I am equating 'considerably' with 'a lot'- the wording in the questionnaire.
[2] It has to be remembered that 33 did not tick this one at all so they were probably not in employment to begin with. We can therefore take the 90% to be the percentage of those who were in employment.

| | | | |
|---|---|---|---|
| Valid | not at all | 20 | 5.8 |
| | moderately | 110 | 32.2 |
| | a lot | 212 | 62.0 |
| | Total | 342 | 100.0 |
| Missing | not ticked | 5 | |
| Total | | 347 | |

**Fatigue**

| | How affected | Frequency | Valid Percent |
|---|---|---|---|
| Valid | moderately | 26 | 7.6 |
| | a lot | 318 | 92.4 |
| | Total | 344 | 100.0 |
| Missing | not ticked | 3 | |
| Total | | 347 | |

**Physical disability**

| | How affected | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 20 | 5.9 |
| | moderately | 133 | 39.3 |
| | a lot | 185 | 54.7 |
| | Total | 338 | 100.0 |
| Missing | not ticked | 9 | |
| Total | | 347 | |

**Psychological/emotional**

| | How affected | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 48 | 14.4 |
| | moderately | 171 | 51.2 |
| | a lot | 115 | 34.4 |
| | Total | 334 | 100.0 |
| Missing | not ticked | 13 | |
| Total | | 347 | |

**Mental/cognitive**

| | How affected | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 17 | 5.0 |
| | moderately | 132 | 38.7 |
| | a lot | 192 | 56.3 |
| | Total | 341 | 100.0 |
| Missing | not ticked | 6 | |
| Total | | 347 | |

**Social**

| | How affected | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 48 | 14.2 |
| | moderately | 158 | 46.6 |
| | a lot | 133 | 39.2 |
| | Total | 339 | 100.0 |

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| | | | |
|---|---|---|---|
| Missing | not ticked | 8 | |
| Total | | 347 | |

**Financial**

| | How affected | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 59 | 17.7 |
| | moderately | 128 | 38.4 |
| | a lot | 146 | 43.8 |
| | Total | 333 | 100.0 |
| Missing | not ticked | 14 | |
| Total | | 347 | |

**Problems with professionals**

| | How affected | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 96 | 28.4 |
| | moderately | 134 | 39.6 |
| | a lot | 108 | 32.0 |
| | Total | 338 | 100.0 |
| Missing | Total | 9 | |
| Total | | 347 | |

**Problems with family**

| | How affected | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 112 | 33.9 |
| | moderately | 148 | 44.8 |
| | a lot | 70 | 21.2 |
| | Total | 330 | 100.0 |
| Missing | | | |
| | Total | 17 | |
| Total | | 347 | |

**employment**

| | How affected | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not at all | 34 | 10.8 |
| | moderately | 40 | 12.7 |
| | a lot | 240 | 76.4 |
| | Total | 314 | 100.0 |
| Missing | | | |
| | Total | 33 | |
| Total | | 347 | |

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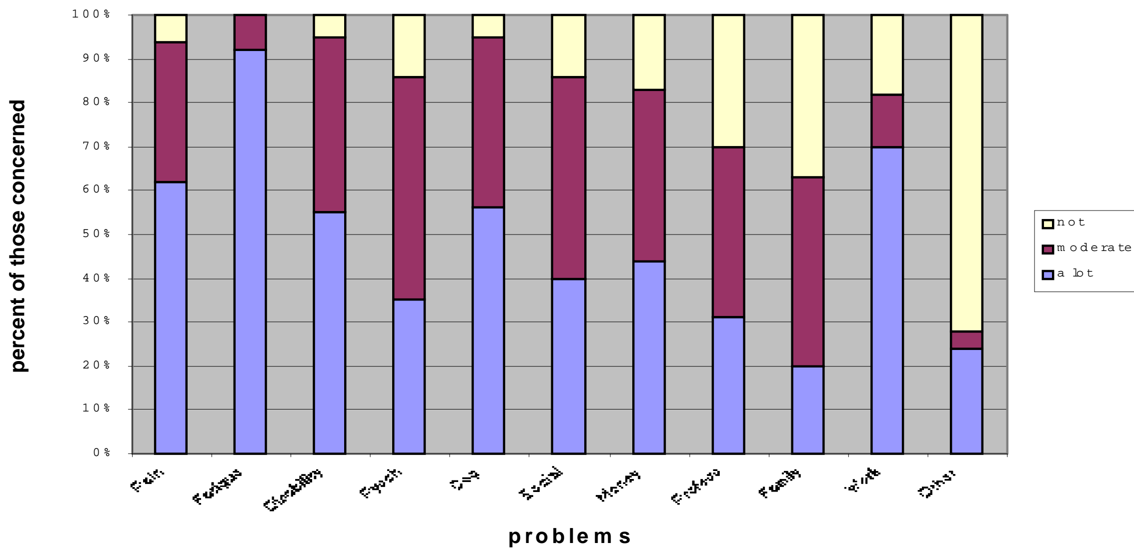
**Figure 12: problems**




### 3.13 Treatment

Respondents were asked to tick seven stated treatment or management strategies and to state whether they made them worse, did not help at all, helped a little or helped a lot. In addition they could state and evaluate any other treatment or regime that was not mentioned. The results are based on percentages of those who ticked the different regimes, assuming that those who had not ticked had probably not tried those particular treatments. Some regimes were obviously tried more frequently than others. For instance a pacing programme was ticked by 258 respondents whilst only 114 ticked Cognitive Behavioural Therapy (CBT) and 215 tried one form or another of alternative medicine, 274 medication, 245 diet and 208 tried graded exercise.

Due to the lack of space on the questionnaire the question on treatments was simplified, thus omitting important clarifications of various terms. For instance there are many different forms of alternative complementary medicines, CBT and graded exercise programs. Some of these may be the ones that help and some may hinder. Further studies might want to clarify these issues.

**Graded exercise**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | made worse | 81 | 38.8 |
| | helped not at all | 47 | 22.5 |
| | helped a little | 54 | 25.8 |
| | helped a lot | 27 | 12.9 |
| | Total | 209 | 100.0 |
| Missing | Total | 138 | |
| Total | | 347 | |

**Alternative therapy**[ix]

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | made me worse | 18 | 8.4 |
| | not at all | 38 | 17.7 |
| | a little | 81 | 37.7 |
| | a lot | 78 | 36.3 |
| | Total | 215 | 100.0 |
| Missing | .00 | 132 | |
| Total | | 347 | |

**Pacing activity programme and rest**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | made me worse | 8 | 3.1 |
| | not at all | 22 | 8.6 |
| | a little | 109 | 42.4 |
| | a lot | 118 | 45.9 |
| | Total | 257 | 100.0 |
| Missing | .00 | 90 | |
| Total | | 347 | |

**Cognitive behavioural therapy**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | made me worse | 15 | 13.3 |
| | not at all | 36 | 31.9 |
| | a little | 42 | 37.2 |
| | a lot | 20 | 17.7 |
| | Total | 113 | 100.0 |
| Missing | .00 | 234 | |
| Total | | 347 | |

**Complete bed rest**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | made me worse | 19 | 9.6 |
| | not at all | 32 | 16.2 |
| | a little | 74 | 37.4 |
| | a lot | 73 | 36.9 |
| | Total | 198 | 100.0 |
| Missing | .00 | 149 | |
| Total | | 347 | |

**Diet**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | made me worse | 4 | 1.6 |
| | not at all | 62 | 24.9 |
| | a little | 103 | 41.4 |
| | a lot | 80 | 32.1 |
| | Total | 249 | 100.0 |
| Missing | .00 | 98 | |
| Total | | 347 | |

**Other treatments**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | made me worse | 9 | 10.0 |
| | not at all | 6 | 6.7 |
| | a little | 23 | 25.6 |
| | a lot | 52 | 57.8 |
| | Total | 90 | 100.0 |
| Missing | .00 | 257 | |
| Total | | 347 | |

**Medication**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | made worse | 74 | 27.0 |
| | helped not at all | 41 | 15.0 |
| | helped a little | 111 | 40.5 |
| | helped a lot | 48 | 17.6 |
| | Total | 274 | 100.0 |
| Missing | | 73 | |
| Total | | 347 | |

Graded exercise was felt to be the treatment that made more people worse than any other. 39% were made worse by this whereas, in contrast, only 2% were made worse by diet. Graded exercise was also considered to be the least helpful treatment or management schedule. Only 13% said that it helped a lot and 26% said that it helped a little.

This stands in contrast to alternative therapy. 36% of respondents said that it helped them a lot and 38% said that it helped a little. Thus a total of 74% of all respondents that had tried alternative therapy said that it had helped them in some way[x]. Of course there are many different kinds of therapies on offer and respondents indicated some of these. A future survey might want to investigate which of these therapies helped the most.

Diet regimes also appear to work for many. A total of 73% of those who had indicated that they had tried some form of dietary therapy said that it had helped them and only 2% said that it had made them worse. Again changes in diet could cover a multitude of different regimes. Examples of diets tried by people with ME might include cutting out allergens or alternatively an anti-candida diet. Again future surveys might want to investigate what kinds of diet really help.

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Medications of various kinds were reported to have made over a quarter of respondents worse; 27% said that they had been made worse by medication. Again medication covers a vast array of treatments and some people actually indicated that by medication they meant vitamins or other nutritional substances. Where this was indicated, none of these made them worse. Other medications that were indicated were anti- depressants. Equally however 40% did say they have been helped a little by medication and 18% said they had been helped a lot.

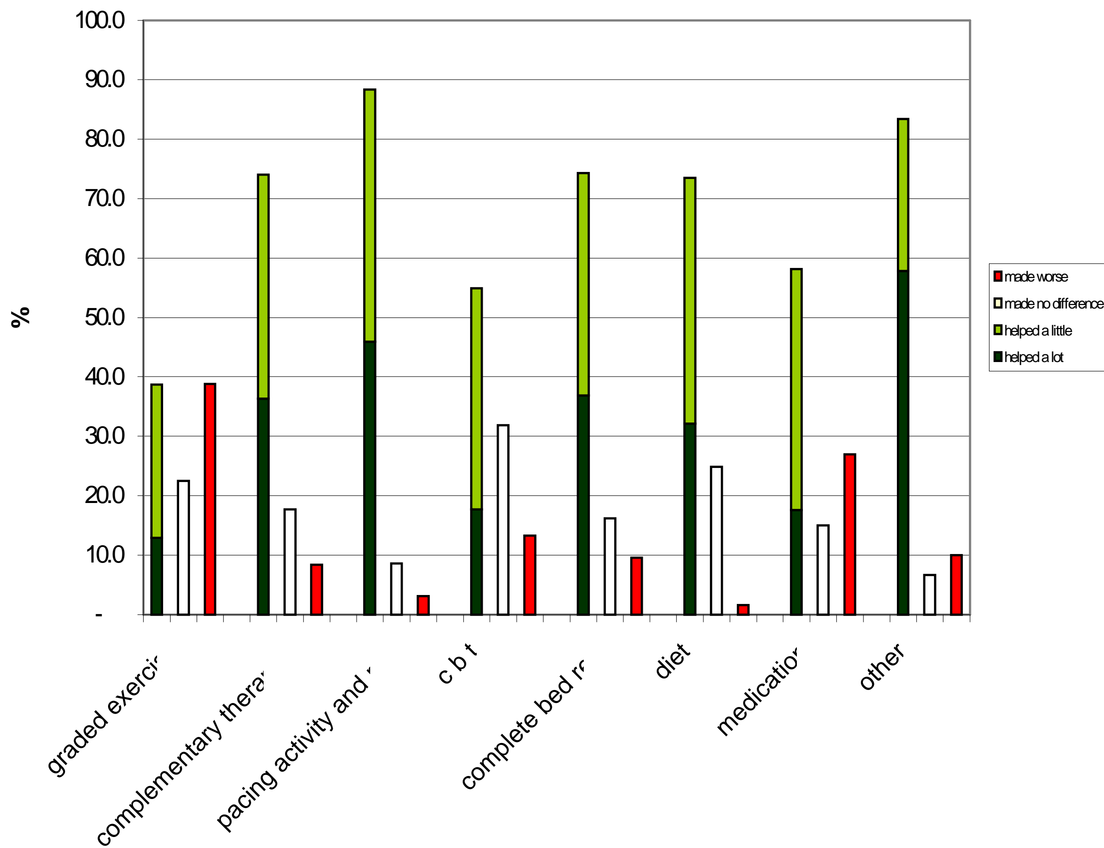
As can be seen from figure 13, a programme of pacing activity and rest was considered to be the regime that helped people the most. A total of 87%  (226) said that it had helped them and only 3% said it made them worse. This is an encouraging result for those who have encouraged ME patients to introduce gently pacing in their lives.

**Figure 13: members' experiences of treatments/management strategies; whether they were helpful.**

Complete bed rest did make 10 % of respondents worse. Yet 37% said they were helped a lot by doing this. Total bed rest helped a total of 74% of respondents who had done this.

13% were made worse by CBT (cognitive behavioural therapy), 32% were not helped at all 37% were helped a little and 18% were helped a lot. This shows that although CBT did not help these respondents as much as other regimes, its effects were quite different to graded exercise, a regime that it is often used alongside it.

These results show that many different kinds of treatments and regimes do help ME patients. Diet, alternative therapy and pacing seem to be the most successful, and yet there appears to be some room for medication, bed rest and CBT. Even the least successful regime, graded exercise did help 39% of the respondents to some extent. However, 38% (80) respondents said it made them worse. Conclusions are hard to reach given the individualistic, fluctuating nature of ME/CFS. These results do show some trends towards both the positive and negative effects of treatments and are perhaps the most interesting in this survey.




### 3.14 Benefits

Respondents were asked whether they had ever been refused or had difficulties in getting state benefits with the label ME/CFS. 55% (162) answered that they had and 42% (124) said that they had not. The remaining 2% or 6 said that this was not applicable and another 50 did not tick this at all so it is reasonable to assume that 56 had not needed to apply.

25% said that they had difficulties with or been refused private benefits. 65% said that they had not. The remaining had not tried.

### 3.15 NHS Services

Respondents were asked which NHS services they found most helpful. Again this was a multiple-choice question and they were asked to tick one or more of the following: Specialist out patient clinic, GP, nurse, consultant, specialist in patient clinic, other.

**Specialist out patient clinic**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not helpful | 52 | 28.1 |
| | Moderately helpful | 61 | 33.0 |
| | very helpful | 72 | 38.9 |
| | Total | 185 | 100.0 |
| Missing | .00 | 162 | |
| Total | | 347 | |

**GP**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not helpful | 76 | 23.7 |
| | Moderately helpful | 140 | 43.6 |
| | very helpful | 105 | 32.7 |
| | Total | 321 | 100.0 |
| Missing | .00 | 26 | |
| Total | | 347 | |

**nurse**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not helpful | 36 | 38.7 |
| | Moderately helpful | 27 | 29.0 |
| | very helpful | 30 | 32.3 |
| | Total | 93 | 100.0 |
| Missing | .00 | 254 | |
| Total | | 347 | |

**consultant**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not helpful | 78 | 36.6 |
| | Moderately helpful | 80 | 37.6 |
| | very helpful | 55 | 25.8 |
| | Total | 213 | 100.0 |
| Missing | .00 | 134 | |
| Total | | 347 | |

**specialist in patient clinic**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not helpful | 31 | 51.7 |
| | Moderately helpful | 5 | 8.3 |
| | very helpful | 24 | 40.0 |
| | Total | 60 | 100.0 |
| Missing | | | |
| | Total | 287 | |
| Total | | 347 | |

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**other NHS services**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not helpful | 7 | 11.5 |
| | Moderately helpful | 13 | 21.3 |
| | very helpful | 41 | 67.2 |
| | Total | 61 | 100.0 |
| Missing | .00 | 286 | |
| Total | | 347 | |

52% found that specialist in-patient clinics were not helpful and yet at the same time 40% found them very helpful. This result perhaps reveals the wide disparity between inpatient clinics; some are found to be very good and some inadequate. This latter response can be compared to that found by the 25% group's survey which found that in patient care was generally unhelpful rather than helpful (60 out of 81 who had had in-patient care found it unhelpful). In that survey the type of clinic was specified and both general medical wards and psychiatric units were found to be particularly unhelpful. Out of all the services specified, GPs were found to be more helpful than other services, with out patient clinics a close second. This compares well with the 25% group's findings where the GP was seen as offering the most helpful service. However, in this study, some respondents commented on the disparity between different GPs. Where they were unhelpful, many wrote that they had changed GPs till they found one. These comments were unsolicited but frequent. They also reflect the findings of the CMO's Working Group's sounding board event [xi] where several respondents reported changing GPs several times in order to find a sympathetic doctor. Thus the statistics do not tell the full story as they were computed on respondents' most recent experiences. A further study might want to differentiate between these different experiences.

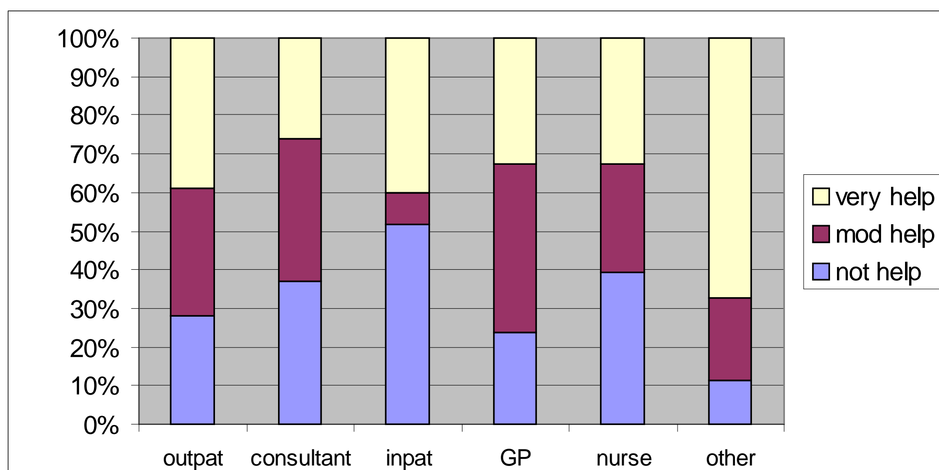


**Figure 14: NHS services**

### 3.16 Patient Organisations

Respondents were asked which services provided by the patient organisations they found most helpful. Around 50% found that the most helpful was the advice line with written information and the magazine also very helpful. Those that answered the question about other services found these to be the most helpful. Where stated, this was often talking to other members and being in contact with their local group. Press articles and web sites were found to be the least helpful.

There was no significant difference in the opinions of members of the two main patient groups with regards to these services.

**Advice line**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not helpful | 13 | 6.8 |
| | Moderately helpful | 69 | 36.3 |
| | very helpful | 108 | 56.8 |
| | Total | 190 | 100.0 |
| Missing | .00 | 157 | |
| Total | | 347 | |

**Campaigning**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not helpful | 17 | 12.2 |
| | Moderately helpful | 72 | 51.8 |
| | very helpful | 50 | 36.0 |
| | Total | 139 | 100.0 |
| Missing | .00 | 208 | |
| Total | | 347 | |

**Research**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not helpful | 19 | 9.9 |
| | Moderately helpful | 98 | 51.0 |
| | very helpful | 75 | 39.1 |
| | Total | 192 | 100.0 |
| Missing | .00 | 155 | |
| Total | | 347 | |

**Magazine**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not helpful | 15 | 5.5 |
| | Moderately helpful | 113 | 41.2 |
| | very helpful | 146 | 53.3 |
| | Total | 274 | 100.0 |
| Missing | .00 | 73 | |
| Total | | 347 | |

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**Press articles**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not helpful | 50 | 21.4 |
| | Moderately helpful | 128 | 54.7 |
| | very helpful | 56 | 23.9 |
| | Total | 234 | 100.0 |
| Missing | .00 | 113 | |
| Total | | 347 | |

**Web site**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not helpful | 14 | 13.5 |
| | Moderately helpful | 53 | 51.0 |
| | very helpful | 37 | 35.6 |
| | Total | 104 | 100.0 |
| Missing | .00 | 243 | |
| Total | | 347 | |

**Written information**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not helpful | 7 | 2.7 |
| | Moderately helpful | 115 | 44.7 |
| | very helpful | 135 | 52.5 |
| | Total | 257 | 100.0 |
| Missing | .00 | 90 | |
| Total | | 347 | |

**Other**

| | Whether helped | Frequency | Valid Percent |
|---|---|---|---|
| Valid | not helpful | 2 | 2.4 |
| | Moderately helpful | 15 | 18.3 |
| | very helpful | 65 | 79.3 |
| | Total | 82 | 100.0 |
| Missing | .00 | 265 | |
| Total | | 347 | |

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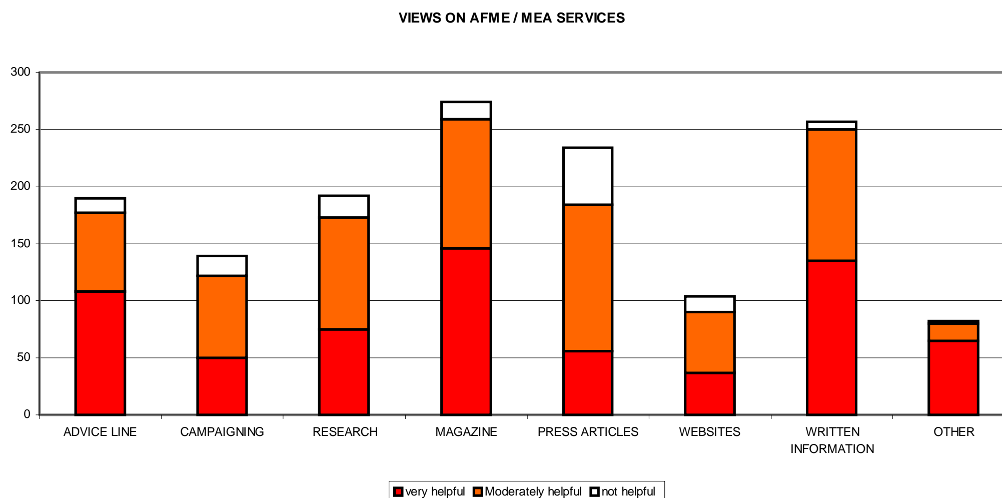


**Figure 15: patient group services**

## 4. Summary

Below is a summary of the main findings. As has already been mentioned, these results may be influenced by several biases. There may be a bias towards professionals as only those from middle class backgrounds may have responded. There may also be a bias towards those who have not recovered quickly. The high percentage of women as opposed to male respondents may not be representative of the actual ratio of male/female sufferers. It may be the case that more women than men are free to fill in these kinds of questionnaire or feel more responsible and conscientious about answering them. Those responding are also likely to include those with most experience of using health practitioners and who have become more familiar with the issues. Also, there may be patients who have been so helped by certain approaches to treatments that they have recovered to such an extent that they no longer are members of any patient group. These results could therefore be an underestimate of the benefits of some forms of treatment.

When it came to ascertain the severity and length of the illness, the reliability and validity of these findings were partially limited due to the fluctuating nature of the illness. The questionnaire used in this survey did not take these fluctuations into consideration. The severity of the illness does fluctuate and the length of the illness should not be measured necessarily from the time of diagnosis. Sufferers are often not diagnosed for several years after they have had the illness[xii] and future questionnaires need to consider this. After taking into consideration these likely biases, it is still

possible to hypothesise certain conclusions from these results and to acknowledge that a larger and more comprehensive survey would clarify and build on them.

**Male/female ratio**

- 76% of the respondents were women.
- 24 % were men.

**Age**

- The numbers of those responding to the survey peak between the ages 30- 60 with the age group 40-50 having the highest number of sufferers.

**Occupation**

- There was a much higher percentage of people who had previously been in professional or white collar occupations than those who had been manually employed ( this may be a sample bias).
- A high percentage of respondents were in professions which were likely to come into contact with infectious illnesses such as health care workers and teachers.

**Length of illness**

- The high number of long term sufferers was significant. Most respondents (75%) had had the illness between three and fifteen years. Eighteen had been ill for over 20 years.

**Severity of illness**

- 19% said that they had a mild form of the illness.
- 45% were moderately disabled.
- 28% were severely disabled.
- 5% were very severely disabled (bedridden).
- Those who had the illness for less than two years were more likely to be only moderately or mildly ill.
- There were more sufferers in all groups who were moderately or mildly rather than severely disabled.
- No one who had been ill for longer than fifteen years was severely ill to the point where they were bedridden for most of the time.

**Formal Diagnosis**

- 93% had been formally diagnosed with ME/CFS.

**Who diagnosed your ME?'**

- GPs and hospital consultants were most likely to diagnose the illness.
- Consultants were equally likely to call it CFS or ME.
- The GP and the ME specialist was twice as likely to call it ME as CFS.
- Alternative practitioners, where they diagnosed, were most likely to call it ME.

**Concerns**

- Respondents were most concerned about research into treatment, the aetiology of the illness, diagnosis and the psychological versus physical issue.
- They were less concerned about the debate over the name of the illness and the differences between CFS and ME.
- Only a small percentage of respondents were not concerned at all about any of these issues and, for instance, a total of 75% were still concerned to some extent about the name of the illness.

**Problems**

- Fatigue affected every respondent and a staggering 92% were considerably affected by fatigue.
- Pain and disability affected 94%.
- Mental or cognitive problems affected 95%.
- Most were also affected by emotional or psychological problems, social problems, problems in obtaining or keeping employment.
- A third were affected by problems with professionals.
- Two thirds had problems with their family.
- All respondents were affected by most of the problems listed to some extent.
- Other problems noted were lack of sleep, sensitivity to noise, allergies, headaches, education provision, and dealing with people outside the family.

**Treatment**

- Graded exercise was reported to have made more people worse than any other treatment or management regime.
- Diet, alternative therapy and pacing were the most successful.
- All treatments or management regimes made some people worse and some people better.

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**Benefits**

- 55% of those who had applied had been refused or had difficulties in obtaining state benefits.
- 25% said that they had difficulties with or been refused private benefits.

**NHS Services**

- There was a wide disparity in people's experience of inpatient care; some were found to be very good and some inadequate.
- GPs were found to be more helpful than other services, with outpatient clinics a close second. Nonetheless, 24% found that their GPs were unhelpful.

**Patient group services**

- Around half found that the most helpful service was the advice line with written information and the magazine also very helpful.
- Other services were also found to be the most helpful.
- Press articles and web sites were found to be the least helpful. Not everyone has access to the Web so this may account for this particular finding.

**Conclusion**

The initial hypotheses made at the start of this survey have to *some* extent been proven. Firstly, CBT and graded exercise does not benefit all ME sufferers and in some cases actually harmed them. At the same time alternative medicine was of benefit to ME patients. Secondly, many respondents experienced problems with medical services and private and public benefits. Thirdly, ME sufferers were concerned not only about issues of research, diagnosis and treatment, but about the more contentious issues such as the name of the illness and the difference between 'CFS' and 'ME'. However they were not nearly as concerned about these latter two issues as they were about other issues. Fourthly, ME patients did sometimes find GPs and other medical professionals unhelpful and yet at the same time many found them helpful, and indeed found GPs more helpful than other professionals, perhaps where they had changed GPs until they found one that was. In my own earlier study of GPs' attitudes towards ME patients I found that about a quarter of GPs surveyed saw ME patients as 'heart sink' patients, and that the attitude of the GP towards the ME patient was dependent upon several factors such as their illness model, their professional education and the presence or absence of preconceived notions about their patients[xiii]. Those who believed that the relationship between doctor and patient should be equal and who displayed a more humanistic or holistic attitude were more likely to accept their ME patients. Of course, it does not automatically follow that these GPs would be helpful to

their patients, as many of them might feel that even with a good relationship there is not a lot that they can do.

The many issues surrounding the illness we now call CFS or ME have been with us for several years. At the same time sufferers have often stated that they have not been listened to, that when they have voiced their concerns in the past, those that count have not heard their voices. This report was intended only as a preliminary step towards rectifying this situation; to discover what were the concerns of sufferers, what were their most pressing problems and experiences. These results show that sufferers are extremely concerned about many of the most basic issues and problems that would surround any illness, but that are made more difficult and serious by the lack of knowledge and understanding of this particular illness. In the light of the findings produced here, possible issues that policy makers might want to consider are: research into the aetiology and treatment of ME/CFS, the length and severity of the illness; the problems and concerns that sufferers face, which include the difficulty in obtaining benefits; the detrimental effects of certain treatments and the positive effects of others; and finally the disparity in some of the services provided for ME/CFS sufferers.

Future work in this area might want to cover some of the areas that were not covered in his study. It should be acknowledged for instance, on the basis of both anecdotal evidence to be found in patient group journals and the results of this study, that some forms of alternative or complementary medicine do help sufferers of this illness. Future work would need to ascertain which forms of alternative or complementary therapy helped and which hindered. Further work might also want to investigate why it is that graded exercise, more than any other form of treatment or management schedule, appears to make some people worse. Studies might want to differentiate between the different forms of graded exercise or other forms of treatment on offer. Again there are many different forms of cognitive behavioural therapy on offer just as there are many different kinds of medications. It may be that some forms help whilst others hinder.

This study shows that there is a sub group of sufferers for whom ME becomes long term and at times severe. Further surveys might want to consider what factors may influence these trends. It has been acknowledged that various groups of viruses may play an aetiological role in ME/CFS [xiv] .It may be that previous occupations, where there is contact with possible infections, have some influence on the length and severity of the illness.

There are always problems with quantitative surveys of this kind. The richness of an individual's experience can never be reduced to a few yes or no answers on two sides of A4. This point is particularly pertinent with regards to the experiences of sufferers and their GPs. Here, unsolicited comments suggest that many respondents changed GPs several times in order to find a sympathetic doctor. One or two commented in the margins that their GPs changed their attitudes over the course of several years and were ultimately helpful, even if at first they were not. Comments of this nature are reiterated and expanded on elsewhere in more qualitative studies (Ware, 1992; Cooper, 1997). Thus the statistics do not tell the full story as, given the limitations of the questionnaire design, they were computed on respondents' most recent experiences. More qualitative studies would therefore be helpful with regards to the experiences of ME sufferers. They would help to answer many of the questions that this survey has uncovered but has been unable to answer, the why questions, and the complexity of the experiences of the ME sufferers as he or she struggles to survive physically, financially and emotionally. However, quantitative studies have their place and more large-scale surveys could also demonstrate the validity and reliability of some of these very specific and telling results.

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Woodward, R. Broom, D. Legge, D. 1994, 'Diagnosis in chronic illness: disabling or enabling- the case of chronic fatigue syndrome'. *Journal for the Royal Society of Medicine,*. 88: 325-29.

[i]A copy of this study entitled ‘25% ME Group, ME Questionnaire results’ can be obtained from the 25% ME Group, 4 Douglas Court, Beach Road, Barassie, TROON, Ayrshire, KA10 6SQ. (a donation of £2.50 black and white or £5 colour is required to cover costs.)
[ii] Evidence of patients’ negative experiences of GPs can be found in Ware (1992), Ax et al (1997), in my unpublished PhD thesis (1998) and in my paper based on the narratives of eleven ME sufferers (Cooper,1997).
[iii] SPSS is a statistical computer software program written for the social sciences.
[iv] Location may affect respondents’ willingness to take part in the survey – again another possible bias.
[v] Further possible biases will be discussed in the summary.
[vi] As will be seen later most of these had actually been diagnosed.
[vii] Health care workers included doctors, nurses and pharmacists.
[viii] I do of course realise that the diagnosis of ME/CFS itself is not a cut and dried diagnosis. There are many overlapping conditions that could be mistaken for ME/CFS but we have to assume, despite the state of uncertainty of over the illness that, for the purposes of this survey these diagnoses are reasonably accurate.
[ix] The term ‘alternative therapies’ here includes both complementary and alternative therapies and would cover a wide range of therapies such as acupuncture, healing.
[x] When patient group membership was cross tabulated with the benefits of alternative therapies there was only a slight difference between members of the ME Association and members of AfME with regards to the results- the percentage of members of AfME was slightly higher than those of the ME Association for the variable ‘helped a lot’. This is despite the fact that AfME has focused more on the benefits of alternative therapies than the ME Association. This result implies that membership of patient groups does not have a significant effect on the benefits of alternative therapies.
[xi] This was held in June 2000.
[xii] Two reports show this to be the case; the 25% group’s report and a paper by Woodward et al (1994). The 25% group’s survey, actually asked the specific question ‘how long after onset did you receive a diagnosis?’ and found that sufferers are often diagnosed several years after onset. Here, a total of 39 did not receive a diagnosis until 2-5 years after onset and a further 23 did not receive a diagnosis until more than 6 years after onset. It is obvious from these findings that more work needs to be done on diagnosis.
[xiii] Cooper, L, 1998, Unpublished PhD thesis: chapter 7: a report on practitioners' beliefs about ME patients based on a quantitative survey of 124 GPs in North and Mid Essex, followed up with a number of interviews.
[xiv] The National Task Force Report, (1994) pg. 36. (obtainable from Westcare, 155 Whiteladies Road, Clifton, Bristol)

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**Questionnaire**

Could you please tick or complete the relevant boxes?

1. Do you have ME/CFS? ≥ 1

2. Or do you care for someone with ME/CFS and are filling out this questionnaire for them ≥ 2

3. Male ≥ 1 Female ≥ 2 4. Age in years

5. Occupation before you became ill ________________________________

6. What year did you get ME/CFS? _______________

7. Severity of illness[1].
Please tick the appropriate box according to your level of activity and mobility.

i. Mild: mobile and can care for self and do light domestic tasks with difficulty. If working have to stop all other activities. ≥ 1
ii. Moderate: reduced mobility and restricted in all activities. Usually stopped work and require rest periods. ≥ 2
iii. Severe: able to carry out minimal daily tasks, housebound. ≥ 3
iv. Very severe: unable to carry out any daily tasks for oneself. Bedridden for most of time. ≥ 4

8. Are you a member of any national patient groups?

Action for ME ≥ 1 ME Association ≥ 2 other ≥ 3

9. How concerned are you about the following (tick as appropriate)

| Issues | Not at all concerned | moderately concerned | very concerned |
|---|---|---|---|
| Diagnosis | | | |
| Research into treatment | | | |
| Research into causes | | | |
| Research into how many have the illness | | | |
| The name of the illness | | | |
| Perception of the illness as psychological or physical | | | |
| Whether there are differences between ME and CFS | | | |
| Sub groups: severely affected | | | |
| Sub groups: children | | | |
| Sub groups: with allergies etc | | | |
| Getting help from social services | | | |
| Respite care/home visits | | | |
| Benefits | | | |
| Money | | | |
| Education | | | |
| Any others (please specify) | | | |

10. Have you been formally diagnosed as suffering from ME/CFS Yes No

11. Who diagnosed your ME (tick all that are applicable) and what did they call it

| | ME | CFS | post viral fatigue syndrome | other |
|---|---|---|---|---|
| Hospital Consultant | | | | |
| GP | | | | |
| ME Specialist | | | | |
| Alternative practitioner | | | | |
| Other | | | | |

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