**CHROME**

**Case History Research on ME**

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**Responsibility for the Report lies entirely with the trustees. We are grateful to our advisors for the valuable contributions they have made to our thinking as we have built up the project, but they are in no way responsible for the content, format or underlying philosophy of this report.**

**Participants**

**The production of this report would not have been possible without the willing co-operation of all those who, often while in great pain, and at great cost to themselves, have provided, and continue to provide, the database with so much information in their completed questionnaires. The trustees wish to express their thanks to them and to remind them that, without their continued supply of information in the annual update questionnaires, the all-important monitoring process will not be able to proceed.**

 **May 1996**

**1. The ME Debate**

1.1 Introduction

To date, the debate about the nature of ME has taken place almost entirely within the medical establishment, with attitudes toward the illness being determined by the different medical disciplines to which interested physicians and researchers belong. These are predominantly endocrinology, immunology, infectious diseases, neurology, psychiatry, rheumatology, and virology. This fragmentation of approach and the nosology of the debate indicated by David Bell’s title *The Disease of a Thousand Names* (1991), symbolise the lack of consensus concerning the disease’s aetiology, pathophysiology and natural history. This has resulted, for many years, in patients being given for their condition either a range of different names, or no name at all. Indeed, the issue as to whether there is a homogeneous condition as opposed to a heterogeneity of conditions is still unresolved and remains a controversial topic among patients and physicians alike.

Before the founding of the patient organisations, especially the ME Association in the late 1970s and Action for ME in the mid 1980s, both of which have taken campaigning stances on the physical roots of the disease, diagnosis was almost impossible to obtain. The growth of these patient organisations and the role of the media in publicising the condition(s) overtook medical understanding and research, leading to a situation where patients presented to their physicians with the view that they were suffering from a particular type of physical disorder. Traditionally it had been the doctor who knew more than the patient, but with ME the reverse tended to occur, leading to a certain hostility over the years between the medical establishment and members of patient organisations. The distance that existed between researchers and clinicians on the one hand, and the most severely affected patients, who are confined to bed - or, at the least, to the house - on the other, was exacerbated by a breakdown of existing traditional relationships of trust between doctor and patient. The difficulties encountered by this subset of patients in attending the relevant clinics or hospitals, and the fact that domiciliary visits are a rarity, has meant that this group has not only remained almost entirely hidden but has suffered a neglect both in medical care and in support provided by the patient organisations, since the latter operate predominantly on the basis of local group activities in which this subset is too disabled to participate. The Task Force Report (1994) tends to perpetuate the view that ME is not a chronic condition from which a percentage of patients do not recover. This 133 page document contains details of only one case history. This is offered as a case of “severe” ME, presenting a fourteen year old girl who at one stage was unable to speak or swallow, but who recovered and returned to school in just over a year. The time is now ripe for a new epidemiological perspective on this section of the ME community. The story from ‘below’, as social historians would put it, should now be told.

1.2 History of the Debate

The survey by Donald Acheson (1959) presented a world-wide picture of epidemics of the ‘clinical syndrome variously called benign myalgic encephalomyelitis, Iceland disease, and epidemic neuromyasthenia’. Since that time speculation concerning the aetiology of the condition has been rife. Theories of its origins as post-viral (Behan 1989), persistently viral (Dowsett & Ramsay 1990), immunologically dysfunctional (Radda et al 1984, Behan, Behan & Bell 1985) and psychiatric (Kendell 1967, McEvedy and Beard 1970) being the most prevalent. Long-term monitoring of patients has been neglected. Consequently, apart from the work of Melvin Ramsay (1988), who has emphasised the chronicity of the disease, no model of its dominant symptomatology and natural history has been formulated.

Historically, polarisation of views of the illness, as a physical entity (Acheson, Behan, Dowsett & Ramsay) or as mass hysteria (McEvedy & Beard), compounded an already difficult position for patients seeking recognition for a severely disabling disorder. The research methodology of McEvedy and Beard, nearly 20 years after the outbreak at the Royal Free Hospital, London, in 1955, consisted of an analysis of the records of the women (chiefly nurses) involved in the epidemic which affected nearly 300 people. The conclusions of this study were probably influenced by earlier work on apparent outbreaks of mass hysteria in women’s institutions and the general view that women are more subject to hysteria than men. The influence of this piece of entirely text-based research, together with the work of Kendell, has been far-reaching. Its methodological perspective has survived two and a half decades, dominating the recent work of psychiatrists such as Simon Wessely and colleagues (1988), who stress the similarities between the postviral fatigue syndrome and common psychiatric disorders in the community, and more recently Michael Sharpe (1996), whose definition of the disease is based entirely on the concept of fatigue. In brief, this tradition in psychiatric thinking has been chiefly responsible for the prevalent view that recovery from ME is possible with the help of rehabilitation programmes chiefly in the form of cognitive behaviour therapy. These are designed to persuade the patient that, as no evidence of organic physical disease has been found, a programme of carefully graduated increasing activity should bring about a recovery. However, psychiatrists have over the last few years moved more towards the view that the physical aspects of the condition should be given more attention.

1.3 The Place of Patients’ Views

To date, the viewpoint of patients has been marginalised. On the whole, patients’ views of their own experiences have been energetically opposed, with systematic monitoring of those chronically affected not being considered relevant. Indeed, the view has been put that chronicity is a result of bad management and the patients’ belief that they are suffering from an illness which prevents them from returning to normal activity. Many diagnosed with ME have been left to their own devices over many years to cope with the consequences as best they can; they have often been blamed for not getting better. In fact the dominant medical discourse of recovery within *x* years (where *x* is usually between 2 and 10) has led those whose illness has extended beyond that period to believe that it has been caused by psychological inadequacy or inappropriate life-style. CHROME’s objective is to begin to bridge the gap, first, by collecting from patients in the UK diagnosed with ME case histories of those most severely affected, and second by monitoring them over the next ten years. What follows is the first instalment of the story from below, which may provide a model for the group most severely affected by the disease.

**2 Setting Up the Project**

2.1 The Problem of the Chronically Ill

Having had a diagnosis of ME in 1986, but with no indication of potential deterioration, Dr Chris Richards, a former university lecturer and researcher, speculated on how many other people were following a similar pattern of deterioration. She therefore decided that an attempt to characterise and quantify the problem at a national level should be made. One cannot make a prognosis without a model, and one cannot make a model without data. Further one cannot make a model of chronicity without a long run of data. CHROME’s function therefore is to collect and analyse data which may go towards the provision of a better model for the disease than at present exists.

At the end of 1993, therefore, Dr Richards started to investigate the plight and the progress of this ‘invisible group’ of patients. Her first objective was to identify the population which had been rendered housebound or bedbound as a result of an illness diagnosed either as ME or as one of its later synonyms. In the first nine months of 1994 contacts were made with the patient associations, Action for ME, the ME Association, Westcare and other smaller local self-help groups, requesting the names and addresses of members who were bedbound or housebound. Physicians and researchers known to be interested in the condition were also contacted.

2.2 Charitable Status

By April 1994 it had become clearer that the task to be undertaken was considerably larger than had been anticipated . An institutional context was needed; other concerned and interested individuals were drawn into the project, helping to uncover more cases, setting up a firmer financial backing, and making detailed plans for the future. Negotiations for charitable status were initiated with the Charity Commissioners which were completed by the autumn of 1994, and CHROME came into being with an initial group of seven trustees and an initial donation of £5,000.

 2.3 Objectives

The first objective of the research is to characterise and quantify the group of patients in the UK who have been rendered so chronically disabled by ME/CFS that they cannot leave home unassisted; the second is to assess and monitor the progress of aspects of the physical and cognitive levels of disability in this population over a period of ten years. The analysis in this report is the start of this process. Already the wealth of information supplied by the participants exceeds what was expected. This first report can therefore only be an introduction to the attempt to cover in detail all features and aspects of the disease(s), its social effects, and the consequent need for further investigation and for medical, social and political action.

**3 Setting up the Survey**

3.1 The Participants

Participants were sought through the patient organisations and through individual physicians, and data, in the form of detailed case histories, was collected by means of self-report questionnaires. All patients fulfilled the CDC criteria, and had received a diagnosis of ME/PVS/CFS from a general practitioner or a hospital consultant. The following further criteria were also applied: (i) chronicity (duration of illness of not less than two years); (ii) a specified level of disability (inability to leave home without assistance).

Well over 200 possible candidates had been put forward and, during the period January - October 1994, the majority of these were contacted by telephone, in order to explain to them the objectives of the project, to ascertain the level of their disability, and to ask - in all cases which met the criteria - if they would be willing to complete a detailed questionnaire. The sense of neglect among the group was such that there were no refusals. Volunteers continued to come forward throughout 1994 and 1995 as news of the project spread among the patient population.

3.2 The Questionnaires (see Appendix I)

While the list of volunteers was being compiled, a draft of the initial questionnaire was sent to experts in various fields (a statistician, a scientist and several medical practitioners with a particular interest in ME, a patient experienced in media work) for comments, many of which were incorporated into the final form of the initial questionnaire. In addition, criteria from the OPCS report, *The Prevalence of Disability among Adults* (1988), were used as a basis for the section on disability. This initial questionnaire will be followed up annually by further, shorter questionnaires, consisting mainly of sections on disability and symptoms, almost identical with the initial sections 7 and 8, in order to monitor the progress of the illness in the population responding.

Because controversies persist, not only about the symptoms of the disease, but also about its name, - note, for example, the title of Acheson’s paper (1959) and David Bell’s *The Disease of a Thousand Names -* the notes accompanying the questionnaires gave participants the following list of the most common terms used (although not all of them are used exclusively for diseases of physical origin):

*myalgic encephalomyelitis, myalgic encephalomyopathy, post viral fatigue syndrome, persistent virus disease, chronic fatigue syndrome, chronic fatigue immune dysfunction syndrome.*

Participants’ attention was also drawn to the variety of specialisms involved in the diagnosis of ME:

*Most consultants who diagnose ME are consultant physicians, or specialists in neurology, but other specialisms involved are endocrinology, immunology, infectious diseases, orthopaedics, paediatrics, psychiatry, rheumatology, homeopathy*.

Information concerning the content of subsequent questionnaires was also mentioned:

*Sections 7 and 8 are the most closely directed sections, which we hope to up-date annually, attempting to build up a picture of the progress of the disease over time. This follow-up will give the survey its greatest credibility because annual reports will contain data suggesting directions in which further research needs to be done.*

(For example, one of the patients in our survey who died had considerable dermatological symptoms at a clinical level. A second patient, 10 years ill and bedridden for 3 years, has also developed a pattern of skin changes. Many others report that their skin is dry but have not had the opinion of a dermatologist, nor has it been thought appropriate by their consultants that they should do so.)

General design points made were:

* *Most questions are inevitably prescriptive, asking for quantifiable data amenable to simple statistical analysis from which general patterns can emerge of the severe effects of ME.*
* *The design of Section 12, however, is deliberately open to give participants an opportunity to enter what they regard as significant information about their cases not covered in earlier sections.*
* *It is possible that from this section previously unrecognised patterns of information will emerge.*
* *In addition, information about benefits, attitudes of health workers, availability of social services, etc., may be of importance to pass on to relevant government departments and other bodies.*

3.3 The Database

A database was set up and, by the end of July 1995, 140 completed questionnaires had been returned and most of the data from these had been entered into the database. At the time of writing, over 170 questionnaires have been returned (the results of the first 169 form the basis of this report). Requests to participate continue to be received, potential participants continue to be contacted by letter and by telephone.
Consequently questionnaires continue to be sent out. The annually-updated information from each participant will be entered over the next ten years, forming the basis of annual reports.

3.4 The Current State of the Survey

Number of applicants:....> 300

Patients identified: 232 to date (& steadily accumulating)

Number of returns to date: 178

Number analysed: ............ 169

Duration of illness: ........... >5 years 69%;

 >10 years 32%

Deaths:...2 (the first, aged 51, after 7 years of ME; recorded cause of death: pulmonary embolism;

 the second, aged 49, after 15 years of ME; recorded cause of death: viral cardiomyopathy)

Many participants experienced difficulty in completing their questionnaires because the physical and mental effort involved increased their pain and disability levels. As shown below, only half the participants completed unaided.

Questionnaires

completed by:

* self alone........84
* self & carer.....16
* carer alone..... 69

Difficulties and inconsistencies of response were cleared up through telephone conversations where necessary.

**4 Population characteristics**

4.1 Duration of illness

The duration of the illness for the participants ranges from 2 years to 43 years, 53 having been ill for

ten years or more. Figure 1 shows the year of onset of their illness recorded by CHROME participants.



Figure 1 **Year of Onset of Illness**

It is interesting to note the marked increase in numbers from 1981 onwards - and the fact that the number of new cases per year appears to be falling away again since 1991. Questions suggested to account for the increase in numbers of new cases per year among this population from 1981 are:

* What proportion of the whole population does this sample of chronic cases represent ?
* Were there epidemics in the 80s?
* Was the illness contracted in the 80s a more virulent version than that experienced earlier ?
* Did it throw up a larger proportion of chronic cases, and, if so, why ?
* Have those who fell ill before the 1980s dropped out of the networks because they have lost hope ? or because they have recovered ? or
* Have a significant number died ?

Table 1 **Type of Onset**

|  |  |
| --- | --- |
| acute onset | 62 % |
| gradual onset | 38 % |

Similarly, with the falling off of annual numbers in the 90s, the question arises as to whether the total number falling ill per year decreased after 1991, or whether those who have only comparatively recently fallen ill will not be anxious to join in this type of survey. Although the population of 169 patients studied here is not put forward as a representative sample, the figures collected suggest that much more detailed research could profitably be done in this area to discover more about the causes, incidence, development and chronicity of ME through the collection of more detailed data from a much larger sample. Moreover, we would suggest that this statistic is the most unreliable in the whole survey because many patients, having given a date for the onset of their illness, then suggested an earlier date - in some cases many years earlier - when symptoms presented which could have marked the beginning of a disease process. In this context the type of onset - acute or gradual - may be significant. Participants were asked whether their illness had a gradual or acute onset and the results are shown in table 1, but, as will be seen in Section 6 below, the answers do not correspond in any meaningful way to the recording of the intensity of the symptoms experienced at onset.

4.2 Gender

Estimates of the ratio of women to men affected by ME vary, but it is commonly accepted that the proportion of women in the ME population is high. At the latest count 82 % of the participants in the survey were women, giving a ratio f:m as approximately 4:1. Questions this ratio might suggest are:

* Are women affected more seriously than men by this condition ? or
* Do women come forward more readily for a survey such as this one ? or
* Is a diagnosis of ME/PVFS/CFS given more readily to women than to men ?

4.3 Age and Life Style

Figure 2 **Age of participants at the onset of their illness**

Figure 2 shows the full age range of the participants at onset.

It is interesting to note that among the 169 participants at the onset of the disease

* 54 were 20 years old or less and
* 33 were 15 years old or less.

The present age range of the participants is 9 to 73 years.

**5 Work and Leisure and the Effects of Illness**

5.1 Range of occupations before illness and the changes on becoming ill

A more detailed analysis of occupations will be given in a later report. In this preliminary breakdown some of the most frequently mentioned categories, which indicate the types of social contacts experienced by participants prior to their illness are noted. A selection of other types of employment are mentioned to give an idea of the wide range of occupations represented in the survey population..

|  |  |
| --- | --- |
| **Occupation** | **No.**  |
| in full time education - at school or college/university: primary 13 |  |
|  secondary 36 |  |
|  tertiary 11 | 60 |
| employed in educational establishment: teacher, lecturer, assistant, technician | 24 |
| employed in health service: nurse, GP, researcher | 19 |
| clerical work | 14 |
| managing the home | 11 |
| varied work including council roadman, barmaid, carpet and upholstery cleaning  |  5 |
| social work/home help/care assistant |  4 |
| driving |  3 |

One of the criteria for participating in the project is being unable to leave the house unaided, so paid employment and study - even part-time - are not now possible for any of them. Typically the response to the question about the effect the illness had had on work, showing regret, and in some cases bitterness at having to abandon their working lives, were:

* from students - had to abandon course
* from others- early retirement

Examples of expansions of these statements are:

* gave up own home
* unable to complete A levels
* attempted school for 6 months then home tuition
* pre 1976 a good life; 1987 bedbound

5.2 Leisure activities abandoned

## The impression given by the variety of activities in which participants had been engaged in their leisure time was one of a lively, interested and physically active group of people who were grieving for the interests which their illness had forced them to abandon. “Had to give up everything “ or “had to give up all activities” were the most frequent comments, one person adding, “even thinking is painful”. The list of former interests actively followed was rich and varied.

86% took part in a variety of sport and other physical activities *(these included badminton, combat sport, cycling, dancing, hill climbing, swimming, walking)*

19% made music *(singing, playing the oboe, flute, guitar, piano, or keyboard, etc.)*

13% were gardeners in some of their spare time

Other activities mentioned which involve physical effort were painting, photography, Brownies, birdwatching, mineral collection, conservation volunteer. All except one of the participants listed a variety of interests followed. Some were more intellectual pursuits such as reading, writing, OU study, etc.

**6. Disability Levels**

6.1 Grading Disability

Respondents were asked to grade the level of difficulty they experienced at the onset of their illness, one year before completion of the questionnaire (“one year ago”), and at the time of completing (“now”) in carrying out a variety of activities. These activities included:

standing to cook, iron, etc., raising arms above head to comb hair, etc., using cup, spoon, knife, book, phone, etc., using a word processor, relating the contents of a half-hour radio or TV programme to someone else, washing, dressing, and walking to the toilet, inability to do the latter being taken as the criterion for “bedbound”

(see Appendix 1, section 7 of the questionnaire, for a full list).

It is intended that these disability levels will be monitored annually over the next ten years. Discrete response levels, useful for the purposes of analysis, do not accommodate easily all the subtleties of short-term variation experienced by a considerable number of respondents. Such fluctuation is one of the characteristics causing difficulties for patients with ME more generally (for example, when applying for benefits), and is possibly a reason why such doubt has been cast by the medical profession and the Department of Social Security on the “reality” of this illness in physical terms. Dr A M Ramsay (1988) put variability and fluctuation of both symptoms and physical findings in the course of a day as a characteristic feature of the clinical picture of ME

The following tables show the responses to date to the questions on disability in Section 7 of the questionnaire (see Appendix 1), from which these figures are derived. This section of the questionnaire, together with sections 8 and 9, caused particular problems for a number of respondents. Some of them were helped to complete their questionnaire responses by telephone. In addition, some of those who had been ill for a long period found it difficult to remember all the details of their condition at onset. For these reasons the total number of responses varies by one or two from question to question. The charts below show the proportions of the survey population reporting, on a scale of 0 - 3, levels of difficulty in a variety of everyday physical activities involving the use of muscles in various parts of the body and in tasks involving cognitive function. The levels indicate whether the activities under consideration were:

possible

possible but restricted and difficult

extremely difficult

impossible

As only a slight deterioration was indicated over the last year in all the activities measured, information concerning level of disability one year ago is omitted from this introductory report. (It will be of greater value when the monitoring process is further forward.)

6.2 Partitioning according to Acute/Gradual Onset

The population was partitioned in two ways for the purposes of the following initial analysis. First, a distinction was made between those who record an acute onset to their illness and those who experienced a gradual onset. Figures 1 and 2 show levels of disability reported among these two groups of participants. The records made clear that far more difficulty has been experienced with standing than with any other activity. Approximately one third of the population had found activities involving standing impossible from onset and this proportion had increased to around two thirds at the time of reporting.

Figure 1**. At Onset: Standing (to cook,** **iron, etc.)**

A surprising similarity was found between the levels of difficulty recorded by the two groups at onset and this similarity was found in the difficulty experienced in other activities questioned. This suggests that a further necessary line of research might concern itself with a clearer definition of the types of onset and how they affect the progress of the illness. Nor can a great difference be seen in the present standing capability of these two subsets, but in both groups the proportion reporting difficulty with activities involving

 Figure 2  **Now: Standing (to cook, iron etc.)**

standing increased considerably over time. A similar deterioration over time was shown in all the activities measured (except in activities involving finer motor skills, such as handling cutlery, using remote control knobs or picking up a cup among the acute onset group). Because of the overall comparability between the responses of the two groups, they are not differentiated in the results that follow. In this first report space does not permit the figures for all these activities to be given, but they will be given, at least as an appendix, in the next.

6.3 Partitioning according to date of onset

One of the questions underlying the analysis is whether length of illness relates to severity of disability. As it is usually assumed that, if a patient has not improved considerably in five years, their illness is chronic, the cut-off point for partitioning the population into two sets according to date of onset of illness was the end of 1989/beginning of 1990. All those whose illness began before 1990 had been ill for five years or longer at the time of completing the questionnaire.

* Around 50 participants had been ill for five years or less (since the start of 1990), and
* around 120 participants had been ill for five years or more (one for over 40 years).

 Figure 3 **Standing to cook, iron, etc. (pre-1990 onset)**

Figure 3 shows levels of difficulty not dissimilar, although a few points higher, to those in the overall population. Such a similarity was found in levels of disability recorded for all activities measured. It is expected that a clearer picture of how levels of disability relate to length of illness will emerge later in the monitoring process.

Figure 4 **Standing to cook, iron etc. (post-1989 onset)**

The proportion finding standing impossible at onset among this group is 10% lower than that in the earlier onset group, but the proportion experiencing no difficulty is not remarkably different for the two groups, and at the time of reporting there is little difference between the two. Corresponding similarities between the two groups were found overall , so what follows is a consideration of the proportions of the levels of difficulty experienced by the population as a whole.

6.4 Overall results

Difficulties with standing, walking around the house, getting to the toilet, crouching etc., involving the use of leg muscles, were recorded in general earlier in the illness than with those using arms and hands - such as brushing hair, picking up or holding objects, using cutlery, etc. Furthermore, standing or crouching, both involving the use of muscles to sustain a static position, caused more difficulty than walking. (More detailed figures for all these activities will be given in later reports as the monitoring progresses.)

Figure 4 **Walking** **around the house**

 Here again a clear indication of deterioration is given, with the proportion recording no difficulty walking around the house, falling from just under half at onset to only one tenth now. But the levels of difficulty reported are less extreme, both at onset and at present, than those experienced in standing.

Crouching to get a book from a low shelf was reported as causing a comparable level of difficulty. The only other activity causing such difficulty was having a bath, and close to this came washing, dressing and getting to the toilet as shown below:

 33% cannot dress themselves,

32 % find washing themselves impossible and

34% have to use a commode because they cannot get to the toilet (see Figure 4).

This compares with 19%, 16% and 17% respectively at onset.

Levels of difficulty for all other activities were less extreme both at onset and at present, but the deterioration rates indicated were comparable, except for the finer motor skills needed for such activities as using cutlery, picking up and holding a cup or the telephone handpiece, or using remote controls for appliances . For these activities the levels of difficulty reported changed little from onset to the time of reporting.

 Figure5 **Walking to the toilet**

Inability to walk to the toilet has been taken to be the chief criterion for the definition of bedbound. Fig. 4 shows that although more than half the population could walk to the toilet with no difficulty at the onset of their illness, this has now been reduced to one third and one third now find it impossible

6.5 Cognitive Ability

Although there are many anecdotal reports of loss of short term memory and confusion in logical thinking, the questions in this first questionnaire on cognitive dysfunction did not show unusually high levels of difficulty in absorbing and passing on information.

*(The percentages in brackets refer to the subset of participants whose illness started before 1985.)*

* 18% (20%) of the survey population are unable to pass on a message correctly;
* 37% (43%) are unable to relate the contents of a half-hour radio programme to which they have just listened ;
* 32% (35%) cannot do the same with a half-hour television programme immediately after watching it;
* at onset the percentages were 14%, 28% and 28% (20%, 31% and 29%) respectively.

6.6 The Mouth and Throat

Cleaning teeth proved difficult not only because of lack of mobility in arm and hand but because of the condition of the mouth. In a small proportion of cases, the most disabled group in the survey, chewing and swallowing were reported as extremely difficult; in fact there are at present 5 participants who have been tube-fed for some considerable time

**7 Sensory/Motor Disturbances**

7.1 What are the Questions ?

Following the exploration of changes in the severity of disability over time in section 7 of the questionnaire, section 8 (see Appendix 1) started by asking patients to describe the level of some of the sensory/motor disturbances they experienced in certain parts of the body. Some of the questions underlying the first part of this section are:

* Which are the most common sensory/motor disturbances experienced by this population?
* Does their severity increase over time ?
* How widespread over the body is a particular disturbance and is it uniformly distributed ?

The table below lists the disturbances measured and the parts of the body for which they were estimated..

|  |  |
| --- | --- |
| **Type of sensory/motor disturbance experienced** | **Part of the body affected** |
| Muscle pain | legs/feet |
| Tremor/judder/twitching | arms/hands |
| Tingling/burning/pins & needles | shoulders/neck |
| Anaesthesia (numbness) | chest/back |
| Stiffness | face |

An answer to the second question posed will emerge more fully as the monitoring of the survey population continues. At this stage an initial answer has been sought through partitioning the population according to year of onset of illness -

* Group 1: the 1990-onwards onset group of around 50 participants with a duration of illness of five years or less; and
* Group 2: the pre-1990 onset group of around 120 participants who have been ill for five years of more (one for over 40 years).

The levels of severity of disturbance are defined as follows:

not present

aware of at rest or following activity

severe, made worse by activity

severe and continuous

7.2 Muscle pain

For the vast majority, muscle pain is one of the most significant features of the condition. With the aid of the graphs on page 14 a comparison of muscle pain distribution in the two populations can be made. At onset a similar pattern is seen (Figures 1 & 2) in the proportions experiencing different levels of muscle pain in the five specified parts of the body in both these populations, but the level reported appears higher amongst those who conracted the illness before 1990 than amongst the 1990-onwards onset group. It is not surprising that a number of the former group has not entered an onset level for their muscle pain (see Figure 2 because of the time scale of their illness; for some it began 40 years ago.

Figure 1 **1990-on Onset** **Group: muscle pain at onset**

Figure 2 **Pre-1990 Onset** **Group: muscle pain at onset**



 Figure 3 **1990-On Onset Group: muscle pain now**





 Figure 4 **Pre-1990 Onset Group: muscle pain now**

In this group, all of whom have been ill for more than five years, the increase over time in the proportion experiencing severe and continuous muscle pain in chest/back , shoulders/neck and face is marked (see Figures 2 & 4). A comparison of Figures 1 & 3 indicates a significant decrease in the numbers in the 1990-onwards onset group reporting no muscle in all five parts of the body specified. For both populations it will be noted that more extreme muscle pain is experienced in the legs and feet than elsewhere in the body both at onset and at the time of reporting, and, overall, a deterioration over time is indicated. Patterns of change will become more clearly apparent as monitoring progresses.

7.3 Distribution of other sensory/motor disturbances

In the previous section the pattern of occurrence of muscle pain has been explored in some detail. What follows is a summary of the overall picture, formed by comparing the distribution of the changes in level of severity of the other four disturbances mentioned above with the pattern of muscle pain which is established in Figures 1-4. Space does not permit in this introductory report analysis of the information recorded in the questionnaires concerning other sensory/motor disturbances. As a picture of the progress of the illness builds up through the monitoring process further reports will analyse different motor/sensory features on which information will continue to is be collected.

The patterns of occurrence and change over time of tremor/judder, tingling/burning, anaesthesia and stiffness over the body were similar to those of muscle pain to the extent that they indicated an overall increase in severity over time, and the decrease in the proportions reporting no disturbance over the period from onset to the time of reporting was around 10% throughout. The more marked changes in the pre-1990 onset group could indicate a direct relationship between length of illness and level of motor/sensory disturbance. In all the other disturbances, it is in the legs that the greatest deterioration is recorded for both groups. For the face the figures were similar for all five measurements.

There were, however, the following differences in the patterns of occurrence and change in the other four motor/sensory disturbances recorded in these five areas of the body:

* around twice as many reported freedom from judder and tingling as from muscle pain;
* similar levels of tingling/burning were reported over all 5 areas;
* at onset in the 1990-onwards onset group proportions reporting muscle pain in legs and arms was well above all other disturbances over all;
* at onset less than 50% reported judder or numbness in any area, the proportions had increased by roughly 10 % in all areas by the time of reporting;
* in the pre-1990 onset group (except in the face) almost twice as many at onset and around three times as many at the time of reporting were free of judder as of muscle pain, level 3 judder was reported by around 10% fewer;
* tingling/burning showed the greatest increase in legs, other areas showing only slight increases;
* over all five, in both populations, little increase in the numbers reporting a disturbance level of 3 of any type for the face, but around 10%. fewer were free of disturbance there at the time of reporting than at onset.

7.4 Other questions asked

The scope of this first report does not allow an analysis of the other motor/sensory disturbances recorded in the questionnaire (see Appendix I for the complete list - section 8 of the questionnaire) There is still a dense resource to tap in the questionnaires on such features as co-ordination difficulties, digestive problems, hypersensitivity to sound and light and changes in the texture and quality of the skin. The particular problems women reported with their periods might suggest, for example, that useful research could be done in the area of hormonal imbalance. These disturbances, and the others noted, will be analysed in detail in subsequent reports as a clearer picture emerges with the ongoing monitoring process.

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**8 Treatment Offered and Its Effects**

8.1 Exercise

It would seem logical to assume that taking exercise to prevent deconditioning of muscles would guard against the worst damage that ME might do. However, many participants’ answers indicated quite the contrary, namely, that exercise can cause a decrease in muscle strength and a considerable increase in pain. Of the 144 who record having been given advice on exercise - including those advised by doctors of the “keep your chin up” persuasion to push themselves by going for long walks, swims, or bicycle rides - 59 (41%) report functional deterioration, in some cases very serious, following sustained, incrementally increased, physical exertion, while two suggested that forcing themselves beyond appropriate physical limits might well have been the cause of their illness becoming chronic. Even the most careful exercise regime, performed under the guidance of health professionals, appears in a number of cases to have been harmful.

Our impression from replies of respondents is that those who listened to their bodies in a regime of reasonable self-management fared better than those who undertook regimes which embraced, either implicitly or explicitly, the general principles of cognitive behaviour therapy. It is in “listening to the body” that some respondents seem to have found a way to make gentle exercise alternating with periods of rest work for them. Unfortunately, few of the respondents were given this advice. Furthermore, many people were given contradictory or no advice, or advice such as “push through the pain barrier”, which they consider did damage. What is clear, however, is that little information is available about the problem of management in relation to exercise.

8.1.1 Categories of advice

Tables 1 and 2 categorise the types of exercise participants were advised to take and the effect of these exercise programmes on their illness.

Table 1 **The categories of exercise advice recorded in the returned questionnaires**

|  |  |
| --- | --- |
|  **Advice**  | **No. Advised** |
| 1. | Push as hard as possible without listening to body (swim/jog etc.)  | 23 |
| 2. | Light push (e.g. get out of bed each day or do physio even if don’t feel up to it ) - this includes programmes of graded exercise, increasing each session, with aim to improve fitness, (again including programmes of even the gentlest physio) | 56 |
| 3. | Find your own balance/stay within body’s limits/use own judgement | 21 |
| 4. | More than 1 Advice: Contradictory - Push Hard/ Don’t Exercise at All | 10 |
|  |  Moderate - Graded Exercise/Own Judgement/Rest | 12 |
|  |  Various | 11 |
| 5. | Rest and/or relaxation exercises | 5 |

Thirty three respondents either recorded that no advice was given, or did not give details. Twelve more considered the advice they were given to be inappropriate and therefore refused the programmes they were offered .

Table 2 **Summary of the effects of exercise recorded by participants**

|  |  |
| --- | --- |
| **Effects** | **No. Affected** |
| Condition worsened  |  91 |
| Condition improved | 16 |
| No change  | 10 |
| Variable results  | 11 |

8.1.2 Comments from the questionnaires

Below is a fairly representative selection of quotations from answers to question 10.9 of the questionnaire:

 *a) What advice have you been given about exercise ?*

 *b) What effect did it have on your condition ?*

 *(The questionnaire number is given in each case.)*

 **Advice Effects**

59 Gentle physio Severe deterioration

63 Physiotherapy Caused relapse

72 Hospital exercise & hydrotherapy Made her much worse

82 Physio & own gentle exercise Made her so ill she had panic attacks at the thought of going to do it

114 Extensive physio Legs and hands seized up, unable to walk since

147 Graded physio Extreme deterioration

155 Asked GP for physio referral Went into hospital with relapse.

 In hospital did hydrotherapy Caused further relapse, longer stay

157 When unable to walk advised to Made me very much worse; I was falling over

 push myself, go through the in great pain while trying to do that. “pain barrier” like an athlete

161 Programme of graduated activity Slow progress for 6 months and then bad and cognitive therapy under relapse until sicker than before psychiatrist who was researching CFS

167 Physio made her [adolescent girl] Screamed with pain. The physio made her

 take 4 steps: much worse. A consultant told her that “she

 would die if she didn’t start to walk”

 and told us [parents] to make her walk,

 “to increase her endorphins”.

8.2 Diet

Table 3 **Diet prescribed by a health professional**

|  |  |
| --- | --- |
| **Type of Diet**  | **No. of People** |
| Type Unclear | 21 |
| Exclusion: of Yeast/Sugar Sugar or Sugar/Wheat/Dairy Wheat or Wheat/Dairy Dairy |  8 8 7 3 = 26 |
| Anti-candida/Anti-fungal | 20 |
| Exclusion - not specified | 7 |
| Elimination | 5 |
| Tube Fed | 5 |
| Rotation | 4 |
| High Carbohydrate | 2 |
| Stone Age | 2 |
| Organic  | 1 |
| **Total following a diet**: | **\_\_****93** |
|  |  |

Respondents were asked to describe any diet they had followed, whether prescribed by a health professional (Table 3), or followed outside medical advice (Diet B) and a summary of the responses is shown in Tables 3 and 4.

Results of following a prescribed diet were seldom recorded. One person reported “very good” results, one that no benefit had been noted, and two that their diets made them worse. Three mentioned diets they no longer followed. This, together with the fact that such a large proportion of respondents had tried diets at one time or another, indicates an area where more detailed research could profitably be done in the future.

Eighty one respondents had not followed any prescribed diet.

Table 4 **Diet followed outside professional advice)**

|  |  |
| --- | --- |
| **Type of Diet**  | **No. of People** |
| Type Unclear | 31 |
| Exclusion: No Sugar & no Yeast/Gluten/Milk/Caffeine No Wheat & No Wheat/Dairy/Gluten No Caffeine & No Caffeine/Alcohol/Fat |  11 9  3 = 23 |
| Anti-candida/Anti-fungal | 20 |
| Hay Diet | 8 |
| Low Fat | 7 |
| Vegetarian | 4 |
| Organic  | 4 |
| Elimination | 3 |
| Stone Age | 2 |
| Rotation | 1 |
| **Total following a diet:** | **\_\_\_****102** |
|  |  |

Eleven people reported that the self-imposed diet they had followed did not help, 2 reported a diet they had tried in the past, implying that they received no benefit from it. However, it is significant that 102 people were following diets of their own volition.

8.3 Alternative Therapies

The determination to find some route back to health is indicated again by the numbers who reported trials of a wide variety of alternative therapies, as table 5 demonstrates. Records of exercise programmes attempted (noted in section 7.1), not to mention the courses of prescribed drugs, mineral supplements and vitamins recorded in the questionnaires (details of which will be given in a future report), suggest that the label of therapeutic nihilism, which has been applied to people suffering form ME, is entirely inappropriate for this group of patients. Moreover, the costs of some of these therapies demonstrate even more clearly how keen patients are to find a way out of their present constricted life styles and back to health. Indeed, serious concern has been expressed by many involved in the welfare of patients with ME concerning the large amounts of money some have spent in their desperate search for a cure. Many of these patients are living on benefits, the partners of some have had to give up full time employment to care for them, and some have crippling debts they have been trying to pay off over many years to therapists, healers, dieticians, etc. Details of these problems also will be given in future reports.

Table 5 **Alternative therapies tried**

|  |  |
| --- | --- |
| **Type of Alternative Therapy**  | **No. of People who tried treatment:****(& commented on result:)** **Total Good Bad Nil** **No. Result Result Result** |
| Homeopathy | 71 | 13 | - | 18 |
| Acupuncture | 42 | 4 | 4 | 9 |
| Reflexology | 30 | 3 | - | 10 |
| Osteopathy | 26 | 5 | - | 4 |
| Healer (Faith/Colour or Counselling)  | 20 | 8 |  | 4 |
| Herbals | 19 | 3 | - | 6 |
| Hypnotherapy | 11 | 1 | - | 3 |
| Allergist | 8 |  |  | 1 |
| Chinese Herbs | 7 | - | 1 | - |
| Aromatherapy | 7 | 1 | - | 2 |
| Shiatsu  | 6 | - | 1 | - |
| Naturopath | 6 | 2 | - | - |
| Chiropractor | 5 | - | - | - |
| Massage | 4 | - | - | 1 |
| EPD | 4 | 1 | - | - |
| Transcendental & other Meditation  | 3 | 2 |  | - |
| Unspecified or 1-off mention**Number of separate treatments** | 25**292** | 2 | - | - |
|  |  |  |  |  |

Only just over 20% of respondents recorded no attempt at alternative therapies.

Table 6  **Costs of programmes of alternative therapy**

|  |  |
| --- | --- |
| **Amount spent on alternative therapies** | **No. of people** |
| £10 - £999 (\*NB under-estimate because weekly costs have been included, where the overall amount spent could have been considerably more .)  | 94 |
| Over £1,000 | 9 |
| No costs because: no treatment  treatment obtained through NHS money refunded because treatment had no effect  | 3531 |
| Costs not stated | 24 |

**9 Conclusion**

In one short report it has proved impossible to analyse and provide a commentary on the mass of information which continues to build up in the database. Clearly, future annual updates will, first and foremost, present a developing picture of both the aetiological features and the neuro-sensory progress of the illness, especially as it is shown in the numerical sections of the questionnaire, but other sections which will also feature prominently in the future are:

* attitudes of medical practitioners, other health workers, social services, etc.;
* accessibility of medical advice and monitoring when patients are no longer capable of attending a clinic;
* management strategies which have proved helpful;
* the prescription of drugs, vitamins, minerals, etc. and their effect on the progress of the illness;
* the burden of care shouldered by relatives and friends;
* problems encountered in getting benefits and allowances, etc.;
* other financial matters, e.g. cost of obtaining a diagnosis, management advice and treatment;
* development of symptoms at later stages of the illness.

The initial analysis suggests that, in a percentage of cases of ME/CFS, chronicity, of a scale not previously documented, is a significant feature of the disease. This analysis also suggests that certain physical and cognitive disabilities increase with increasing chronicity, but both these trends will be analysed in greater detail as monitoring continues and as the size of the sample grows (a steady flow of enquiries continues and, from among these, people fulfilling CHROME’s criteria for the issue of questionnaires are found). Because of the controversial nature of attitudes to patients, it seems certain that many more people who would fulfil the criteria have not gained diagnoses and have not yet heard of CHROME. One of the most difficult questions posed for the project is how further hidden cases may be unearthed.

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**Appendix I**

CHROME QUESTIONNAIRE

**1 GENERAL**

1.1 Name \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ 1. 2 Gender \_\_\_\_\_

1.3 Date of Birth \_\_\_\_\_\_\_\_\_\_\_\_\_

1.4 Address \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Post Code \_\_\_\_\_\_\_\_\_

1.5 Questionnaire completed by \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 (give name if different from 1 and state relationship)

1.6 Date of completion \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**2 BEFORE ONSET OF ME**

2.1 Occupation (job/education - give details)

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2.2 Hobbies & other activities

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2.3 Please list - with dates if possible - any significant illnesses, operations, infections, allergies, etc. before the onset of ME

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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**3 ONSET**

3.1 a) If your illness began acutely, give

 year and month (or season) it began \_\_\_\_\_\_\_\_\_\_\_\_\_

**or** b) if the onset was gradual, state when

 you were first aware of it \_\_\_\_\_\_\_\_\_\_\_\_\_

 3.2 Age at onset \_\_\_\_\_\_\_ years

3.3 Where were you during the month before you became ill?

 a) Home address, if different from above (including post code if possible)

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Post code \_\_\_\_\_\_\_\_\_\_\_

 b) Place of work/education \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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3.4 Did anyone else (friend/member of family/neighbour/work mate) have similar symptoms at the same time? If so, give their relationship or link with you.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

3.5 Is there any specific event or visit to a place or institution that you associate with the onset of your illness? If so, give details.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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**4 EFFECTS**

4.1 What effects has ME had on work or education (early retirement, unable to attend school/college/university etc.)

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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4.2 Give details of any other activities which were curtailed by ME

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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**5 DIAGNOSIS**

5.1 What was the diagnosis? (myalgic encephalomyelitis/myopathy, CFS, PVFS,.....) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

5.2 Who made the diagnosis - GP or consultant?

(name and, for consultant, specialism if known) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

5.3 Where was the diagnosis given?

 a) Town \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 b) Hospital or general practice if known \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

5.4 When was the diagnosis given?

 (year and month or season) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

5.5 Was the diagnosis given on the NHS or privately? NHS/Private

6 **PROGNOSIS**

6.1 Following diagnosis, what advice were you given about recovery?

 0 = no advice

 1 = limited advice - would get well eventually

 2 = outcome uncertain

 3 = outcome uncertain, recovery unlikely

 4 = deterioration

6.2 If this advice changed later, state when \_\_\_\_\_\_\_\_\_\_\_\_\_\_

6.3 and to what (answer 0 - 4 as above)

**7 DISABILITY LEVEL**

Please indicate your level of disability now and in the past by putting a number 0 - 3 in each box where:

 0 = possible

 1 = possible but restricted and difficult

 2 = extreme difficulty

 3 = impossible

|  |  |  |  |
| --- | --- | --- | --- |
|  | At onset | 1 year ago | Now |
| 7.1 Able to raise arms above head (to comb hair etc.) ................. |  |  |  |
| 7.2 Able to crouch (to select book from low shelf etc.) ................. |  |  |  |
| 7.3 Able to stand (to iron, cook etc.) ............................................. |  |  |  |
| 7.4 Able to get out of bed without assistance ............................... |  |  |  |
| 7.5 Able to walk to toilet ............................................................... |  |  |  |
| 7.6 Able to use commode by the bed ........................................... |  |  |  |
| 7.7 Able to walk around the house ............................................... |  |  |  |
| 7.8 Able to use control knobs on radio etc. .................................. |  |  |  |
| 7.9 Able to use remote control on TV etc. .................................... |  |  |  |
| 7.10 Able to hold phone handset .................................................. |  |  |  |
| 7.11 Able to pick up phone handset .............................................. |  |  |  |
| 7.12 Able to hold a mug/cup of liquid ............................................ |  |  |  |
| 7.13 Able to pick up a mug/cup of liquid ........................................ |  |  |  |
| 7.14 Able to use a knife and fork ................................................... |  |  |  |
| 7.15 Able to use a spoon ............................................................... |  |  |  |
| 7.16 Able to wash without help ...................................................... |  |  |  |
| 7.17 Able to dress without help ..................................................... |  |  |  |
| 7.18 Able to clean teeth ................................................................. |  |  |  |
| 7.19 Able to chew .......................................................................... |  |  |  |
| 7.20 Able to swallow ...................................................................... |  |  |  |
| 7.21 Able to wipe your own bottom ............................................... |  |  |  |
| 7.22 Able to have a bath ............................................................... |  |  |  |

|  |  |  |  |
| --- | --- | --- | --- |
|  | At onset | 1 year ago | Now |
| 7.23 Able to sign your name ............................................................ |  |  |  |
| 7.24 Able to pass on a message correctly ....................................... |  |  |  |
| 7.25 Able to watch a half-hour TV programme all the way through and tell someone what it was about ................................................ |   |  |  |
| 7.26 Able to listen to a half-hour radio programme and tell someone what it was about ............................................................. |  |  |  |
| 7.27 Able to listen to music ............................................................. |  |  |  |

For the next questions please give in each box numbers of minutes, pages or days

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | At onset | 1 year ago | Now |  |
| 7.28 Able to hold a book for ........................................... |  |  |  | minutes |
| 7.29 Able to read for ..................................................... |  |  |  | minutes |
| 7.30 Able to read ........................................................... |  |  |  | pages |
| 7.31 Able to use a word processor for ........................... |  |  |  | minutes |
| 7.32 Able to use a pen or pencil for ................................ |  |  |  | minutes |
| 7.33 Able to have hair washed every .............................. |  |  |  | days |

7.34 If you have suffered from relapsing ME (i.e. bedbound spells defined as unable to get to the toilet) followed by partial recovery, please try to list the times

- e.g. Spring ‘92 - and duration of these spells.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**8 PAIN, DISCOMFORT AND OTHER SENSATIONS**

Please indicate level of pain or sensation, now and in the past, by putting a number 0-3 in each box where: 0 = not present

 1 = aware of at rest or following activity

 2 = severe, made worse by activity

 3 = severe and continuous

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | At onset | 1 year ago | Now |
| 8.1 Muscle pain in | a) leg/foot ....................... |  |  |  |
|  | b) arm/hand ................... |  |  |  |
|  | c) shoulder/neck ............ |  |  |  |
|  | d) chest/back ................. |  |  |  |
|  | e) face ............................ |  |  |  |
| 8.2 Tremor/judder/twitching in | a) leg/foot ....................... |  |  |  |
|  | b) arm/hand ................... |  |  |  |
|  | c) shoulder/neck ............ |  |  |  |
|  | d) chest/back ................. |  |  |  |
|  | e) face ............................ |  |  |  |
| 8.3 Tingling/burning/pins & needles in | a) leg/foot ....................... |  |  |  |
|  | b) arm/hand ................... |  |  |  |
|  | c) shoulder/neck ............ |  |  |  |
|  | d) chest/back ................. |  |  |  |
|  | e) face ........................... |  |  |  |
| 8.4 Anaesthesia (numbness) in | a) leg/foot ...................... |  |  |  |
|  | b) arm/hand ................... |  |  |  |
|  | c) shoulder/neck ............ |  |  |  |
|  | d) chest/back ................. |  |  |  |
|  | e) face ........................... |  |  |  |
| 8.5 Stiffness in | a) leg/foot ....................... |  |  |  |
|  | b) arm/hand ................... |  |  |  |
|  | c) shoulder/neck ............ |  |  |  |
|  | d) chest/back ................. |  |  |  |
|  | e) face ........................... |  |  |  |

|  |  |  |  |
| --- | --- | --- | --- |
|  | At onset | 1 year ago | Now |
| 8.6 Joint pain |  |  |  |
| 8.7 Bone pain |  |  |  |
| 8.8 “All over shaking”/juddering |  |  |  |
| 8.9 Head a) pain |  |  |  |

 b) explain the quality of the pain and where it occurs

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Please indicate in the following your level of pain or sensation now and in the past by putting a number 0-2 in each box where:

 0 = not present

 1 = moderate

 2 = severe

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | At onset | 1 year ago | Now |
| 8.10 Swelling in | a) leg/foot ..................... |  |  |  |
|  | b) arm/hand .................. |  |  |  |
|  | c) shoulder/neck ........... |  |  |  |
|  | d) chest/back ................ |  |  |  |
|  | e) face .......................... |  |  |  |
| 8.11 Co-ordination difficulties | a) balance problems ..... |  |  |  |
|  | b) stumbling .................. |  |  |  |
|  | c) tripping ...................... |  |  |  |
|  | d) giddiness .................. |  |  |  |
|  | e) fainting ...................... |  |  |  |
| 8.12 Experience pain when pressure is applied to a muscle |  .......................................  |  |  |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | At onset | 1 year ago | Now |
| 8.13 Sleep | a) insomnia - not enough sleep .................. |  |  |  |
|  | b) hypersomnia - too much sleep ............... |  |  |  |
|  | c) disturbed sleep with wakening periods ... |  |  |  |
|  | d) reversal pattern - sleep during day ......... |  |  |  |
|  | e) poor quality - i.e. non-restorative ............ |  |  |  |
| 8.14 Sensitivity to | a) foods ....................................................... |  |  |  |
|  | b) chemicals ................................................ |  |  |  |
|  | c) smells ...................................................... |  |  |  |
| 8.15 Digestion | a) nausea .................................................... |  |  |  |
|  | b) wind (up) ................................................. |  |  |  |
|  | c) wind (down) ............................................ |  |  |  |
|  | d) diarrhoea ................................................ |  |  |  |
|  | e) constipation ............................................ |  |  |  |
|  | f) pain/cramp: chest ................................... |  |  |  |
|  |  upper abdomen ................... |  |  |  |
|  |  lower abdomen ................... |  |  |  |
|  | g) bloating ................................................... |  |  |  |
| 8.16 Bowels | incontinence ............................................... |  |  |  |
| 8.17 Urine | a) retention ................................................. |  |  |  |
|  | b) frequency ................................................ |  |  |  |
|  | c) incontinence ........................................... |  |  |  |
| 8.18 Eyes | a) light sensitivity ........................................ |  |  |  |
|  | b) pain ......................................................... |  |  |  |
|  | c) blurred vision .......................................... |  |  |  |
|  | d) discharge ................................................ |  |  |  |
| 8.19 Ears | a) noise sensitivity ...................................... |  |  |  |
|  | b) pain ......................................................... |  |  |  |
| 8.20 Mouth | a) general dryness ...................................... |  |  |  |
|  | b) bad taste ................................................. |  |  |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | At onset | 1 year ago | Now |
| 8.21 Teeth/gums | a) bleeding .................................................. |  |  |  |
|  | b) often too painful to clean ........................ |  |  |  |
|  | c) ulcers ...................................................... |  |  |  |
| 8.22 Skin | a) texture changes ...................................... |  |  |  |
|  | b) dryness ................................................... |  |  |  |
|  | c) hair loss .................................................. |  |  |  |
|  | d) hair gain ................................................. |  |  |  |
|  | e) lost fingerprints ...................................... |  |  |  |
|  | f) nail changes ............................................ |  |  |  |
|  | g) burning ................................................... |  |  |  |
|  | h) itching ..................................................... |  |  |  |
| 8.23 Weight  | in stones ..................................................... |  |  |  |

 If there is a gain in weight, is it’s distribution unusual? (Describe)

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**\* FOR WOMEN**

8.24 a) How has ME affected your periods?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 b) How do your periods affect ME?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**9 MORE RECENT DIAGNOSES, TREATMENTS ETC.**

9.1 Since deterioration or development of other symptoms, has there been a change in diagnosis (e.g. to MS or myasthenia gravis)? If yes, give details.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

9.2 Give name and specialism of practitioner who gave the new diagnosis.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**10 CARING/MONITORING/MANAGEMENT**

10.1 Principal carer’s relationship to patient \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

10.2 Principal carer’s age \_\_\_\_\_\_\_\_\_\_ years Gender \_\_\_\_\_\_\_\_\_\_

10.3 Carer’s duties \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

10.4 What support is available from friends? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

10.5 a) Do you get support from:

|  |  |  |
| --- | --- | --- |
|  |  Yes or No | Number of visits per year |
| GP |  |  |
| Hospital consultant |  |  |
| Hospital services physio, OT etc. |  |  |
| Social services |  |  |
| Voluntary services |  |  |

c) What management advice or other help do you receive from any of the above? Please list. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

10.6 Drugs

 a) Are you on any prescribed drugs at present? (Please list)

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 b) What drugs have you been on previously? (Please list)

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 c) What were the reasons for changing or stopping certain drugs?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

10.7 Diet

 a) Have you been prescribed a diet by a health professional? If so which diet and by whom was it prescribed?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 b) Have you followed a diet outside medical advice?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

10.8 Have you had a consultation and advice from an alternative health practitioner? If so please state type, value and cost.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

10.9 a) What advice have you been given about exercise and by whom?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 b) What effect did it have on your condition?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**11 Aids**

Please tick any of the following that you use:

|  |  |  |
| --- | --- | --- |
| 11.1 Home help | cleaning |  |
| 11.2 | shopping |  |
| 11.3 OT equipment | wheel-chair |  |
| 11.4 | commode |  |
| 11.5 | hands-free phone |  |
| 11.6 | bed pan |  |
| 11.7 | hair washing trough |  |

11.8 Other (please specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**12 Any other comments** you wish to make to expand information given above or on any significant aspects of your illness which have not been covered, for example:

* The number of physicians you saw before getting a diagnosis of ME/PVFS/CFS:
* Whether you had to travel a considerable distance to get a diagnosis of ME/PVFS/CFS:
* Any periods of hospitalisation since onset of ME:
* Treatments that have proved helpful - or the opposite:
* Any inappropriate psychiatric/psychological explanations of or therapies for your illness:
* Stress suggested as cause of illness:
* Disbelief:
* Difficulties with benefits:
* Etc.

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**Appendix II**

**Medical Discourse: a suitable case for treatment ?**

(this review first appeared in *Perspectives*, the magazine of the ME Association, Autumn 1991)

 **Chris Richards**

There was no vice too small in the 19th century - even the vigorous polka - to be regarded as the cause of consumption for those infected by the tubercle bacillus. In 1881 Austin Flint published, with his co-author Welch*,* his standard “textbook”’ *The Principles and Practice of Medicine*[[1]](#footnote-1)*,* a book which ran to six editions and dealt at length with the subject of tuberculosis and its causes: hereditary, disposition, unfavourable climate, sedentary indoor life, defective ventilation and “depressing emotions”. Never has a medical discourse become so rapidly outmoded. The following year (1882) Robert Koch[[2]](#footnote-2) published his epoch-making paper announcing his discovery of the tubercle bacillus, the primary cause of tuberculosis. From that moment, TB, as the new acronym went, became, unarguably, an infectious disease.

*Post-viral Fatigue Syndrome*, the recent collection of essays edited by Rachel Jenkins and James F Mowbray[[3]](#footnote-3) with a foreword by Anthony Clare - two psychiatrists and an immunopathologist - is a book which for its apparent advantages is rooted firmly in the Flint and Welch tradition. Post-viral fatigue syndrome is a catch-all phrase which implies a field so open that even the concept of ‘field’ as a distinct research entity disappears. In his foreword Anthony Clare extols the virtues of the “multidisciplinary” approach to this disease, but at no point does he confront the real issues of mulitdisciplinarity, such as the rationale on which certain disciplines have been included, excluded , or why. With a foreword which does not even rationalise its text, it is not surprising to find a subtext which tells an alternative story. Multidisciplinary? Yes ... well ... hardly.

**Disciplines**

Seven contributors are psychiatrists, a contribution rate nearly 50% higher than that of any other discipline, including virology, neurology and neurovirology - in spite of the upfront “post-viral” of the title. Astoundingly, there is no contribution from epidemiology, although three contributors from psychiatry describe themselves as workers in this field. There is only one contributor from infectious diseases in spite of the long history of epidemics in the literature of ME, to which, to give her credit, Rachel Jenkins does give an account. But what has happened to the distinction between the sick and the able in Jenkins’s account of hill walking and other physical exercise of this type? Lost in intellectual webs of “multiaxial diagnostics”, these editors and most of the contributors dodge the whole issue of disability.

**Direction**

Moreover, almost one third of the contributors are from what might broadly call the behavioural disciplines, namely behavioural therapy, psychology and psychiatry, a direction in keeping with Rachel Jenkins’s research record in “abnormal illness behaviour”[[4]](#footnote-4). What victims of ME should perhaps be questioning in these very serious circumstances is whether they are happy or unhappy with the overall description of their condition as “post-viral fatigue”. Consideration of this issue could not be more vital since, as it forms the substance of the title of the book, the term post-viral fatigue will become the dominant message to be passed on the new generations of researchers in the future, as well as one which plays a part in the controlling imagery of official medical discourse on the subject at present.

**Bona fide**

I am not knocking this area as a bona fide discipline or research field. What I am saying is that emphasis on it will result in a failure to stimulate research in the key areas needed. Looking in Jenkins and Mowbray for a guide to a new project the potential researcher has to plough through to page 433, to the section entitled “Directions of Future Research”, to learn that, to date, almost no systematic observation of ME patients in the form of regular monitoring and data collection has ever taken place. James Mowbray, Chair of the ME Association’s Scientific and Medical Advisory panel, reveals the real truth about the state of research in ME when he cites the field of natural history as one of the areas requiring prospective study. This is a point to be born in mind by those who continue to be refused mobility and/or other attendance allowances .

The historical shift in the usage of the term ME to post-viral fatigue syndrome in the titles of medical papers and books is also worth a moment’s speculation. The main shift took place in 1984 in the Lancet[[5]](#footnote-5) followed by another in the Journal of Infection the following year[[6]](#footnote-6). The first paper is an account of the findings in one patient with “a” postviral fatigue syndrome while the second is a study of 50 patients with “the” postviral fatigue syndrome. Both papers are always included in bibliographies on ME. Why? What is the pathological justification for “a ”postviral fatigue syndrome being considered in the same body of work as “the” postviral fatigue syndrome? Melvin Ramsay pointed to the importance of making distinctions between these terms. Quite right. The only cultural reference point for “fatigue” with any meaning is buried in the 1985 paper. These researchers define the nature of “fatigue” by introducing an equivalent. “The nearest clinical equivalent,” they say, “is the exhaustion reported by middle aged males with multiple sclerosis affecting the spinal cord.” Now this approach is in the language which most people, both lay and professional, will understand, so it is a mystery to me why its authors should have chosen to use the phrase “postviral fatigue” for the title of their paper. Perhaps they felt that, as the preferred term of the patient, ME was declasse. Academy tactics. Keeping the perimeter fence around fields of knowledge. In the context of “fields of knowledge”, therefore, I have a short suggested reading list for all researchers in the field of the much abused “disease of a thousand names”[[7]](#footnote-7). It consists of the legislation which took place last century in public health which both campaigners and works by Dickens and Elizabeth Gaskell especially helped to provoke by increasing public awareness of infectious disease and epidemics. These writers were not waylaid by the vagaries of psychiatry, because, as social historians, they knew about, and documented, the relationship between poverty, education and public health. They were also believers in social justice. But as Dr Betty Dowsett commented in the last issue of *Perspectives* “those who do not study history will indeed be forced to repeat it”[[8]](#footnote-8).

**Appendix III**

**Letter to the *British Medical Journal* 312: 1096 27 April 1996**

**Cognitive behaviour therapy for the chronic fatigue syndrome**

 **Patients were not representative of all patients with the syndrome**

 Editor, - Michael Sharpe and colleagues conclude that cognitive behaviour therapy leads to a sustained reduction in functional impairment for patients with the chronic fatigue syndrome[[9]](#footnote-9). The levels of disability of the 60 patients who took part in the study suggest, however, that these patients do not represent a comprehensive cross-section of patients with the syndrome. The 60 patients scored 60-78 on the Karnofsky scale assessing disability and so represent a different population from the 143 patients reported on by Case History Research on ME (myalgic encephalomyelitis), who would have scored 30-60 (R Gibbons et al, first world congress on chronic fatigue syndrome and related disorders, Brussels, Nov 1995). Fifty nine of these 143 reported functional deterioration following sustained, incrementally increased physical exertion.

The authors did not assess other symptoms common in chronic fatigue syndrome, such as pain, nausea, muscle weakness or balance problems - a measure of the reduction of which was taken as a standard for “success” in an earlier trial[[10]](#footnote-10). The lack of evidence of significant changes in other measures, besides "the principal complaint of severe fatigue" in the authors’ study tends to diminish the validity of his conclusions.

If functional capacity alone is to be assessed in a trial a validated instrument of measurement should be used. The Karnofsky scale is not sensitive enough to measure function since a value of 80 implies "normal activity with effort; some signs or symptoms of disease". But what does the phrase “normal activity” mean ? Does it mean being able to get up, dress and walk at a level sufficient to maintain (unemployed) independence, or does it mean an ability to perform all these activities together with a return to full-time employment and participation in sport ?

Given the heterogeneous nature of the chronic fatigue syndrome, we are concerned at the apparent enthusiasm for cognitive behaviour therapy, which may be helpful for patients who have factors such as depression or maladaptive behaviour (too much bed-rest) but may in the long term be detrimental to a specific sub-group of patients. We note that in Sharpe and colleagues' trial the condition of four of the 30 patients given cognitive behaviour therapy had deteriorated after 12 months. Could these patients have a distinct type of the chronic fatigue syndrome, meeting the original clinical criteria for myalgic encephalomyelitis[[11]](#footnote-11), and be at risk from cognitive behaviour therapy?

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2. See Victor Robinson (1932) *Robert Koch*, New York, Medical Life Press. [↑](#footnote-ref-2)
3. (eds) Jenkins, R & Mowbray, J F (1991) *Post-viral Fatigue Syndrome*, Chichester, John Wiley & Sons. [↑](#footnote-ref-3)
4. Jenkins, R, Aggett, P and Newall B (1988) “Teaching medical students and registrars: a multidisciplinary team approach to the management of chronic pain and abnormal illness behaviour”. Association of University Teachers of Psychiatry Newsletter, London. [↑](#footnote-ref-4)
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6. Behan, P O, Behan W M H & Bell, E J (1985) “The postviral fatigue syndorme - an analysis of the findings in 50 cases”. *Journal of Infection*, **10**:211-222. [↑](#footnote-ref-6)
7. See Bell, David (1991) CFIDS*: The Disease of a Thousand Names,* New York, Pollard Publications [↑](#footnote-ref-7)
8. See *Perspectives: The Magazine of the ME Association* (Summer 1991), p. 24. [↑](#footnote-ref-8)
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11. Ramsay AM. *Myalgic Encephalomyelitis and Postviral Fatigue States: the saga of Royal Free disease*. Gower Medical Publishing, London, Second Edition 1989; 29-31 [↑](#footnote-ref-11)