

the three strategies was determined to be “potentially beneficial” is not as clear as it might appear. As regards the published evidence, the thorough review by Whiting *et al* (2001) state that it is very difficult to draw overall conclusions (from the forty-four randomised clinical trials) since very little information is available on baseline functioning. Most of the interventions were evaluated in only one or two studies, so the validity of generalising the findings is limited. Since there are few patient reports favouring cognitive behavioural therapy, and a sizeable proportion of patients feel that graded exercise therapy worsens their condition, the inference must be that the major recommendation for the use of cognitive behavioural therapy and graded exercise therapy was *clinical opinion*, the only other source of evidence left to the Working Group. If this is the case, then the professional composition of the Key Group was the crucial factor in determining the strength of recommendation for particular “potentially beneficial” management strategies.

It is also important to realise that research funding is critical to whether or not evidence is available. There are indications that psychiatric and psychological research groups conducting trials of cognitive behavioural therapy and graded exercise therapy have been particularly well funded (Abbot & Spence, 2002); hence, the forty-four trials available for analysis by Whiting *et al* (2001). This funding bias is itself worthy of examination as it informs us that the research agenda in CFS/ME has been driven, in the main, by a relatively small number of clinicians with a professional interest in exploring biopsychosocial models of illness. These clinicians were proportionately well-represented within the Working Group.

3.4.1 Cognitive behavioural therapy

The issues surrounding the true usefulness of cognitive behavioural therapy for CFS/ME patients have been widely discussed (e.g. Lancet 2001; 358: 239-41) but can be summarised as follows:

- Of the forty-four randomised clinical trials identified, only five involved some variant of cognitive behavioural therapy, and of these, three had a ‘positive’ result and two a ‘negative’ result.
- Two of these trials used the Oxford criteria which greatly limits the applicability of the findings as far as ME and CDC-defined ‘CFS’ is concerned.
- Dropout rates were high - 40% in the active arm (vs. 20% in the control) of the flagship trial on cognitive behavioural therapy by Prins *et al* (2000). As Whiting *et al* (2001) state in their review: “Dropout rates may be an indication of the acceptability of an intervention” and “cognitive behavioural therapy may be acceptable to only a small number of patients, limiting generalisability.”
- As is the case with most clinical trials, the results cannot be extrapolated to apply to the most severely ill (up to 25% in CFS/ME), nor to children or young people. Both categories having been excluded from these trials.

- While cognitive behavioural therapy most likely has some role in helping some patients to better cope with their symptoms until a cure is found, this role is limited (as it would be with cancer patients) and non-curative.
- Cognitive behavioural therapy is expensive and, with such a variable outcome, the cost-benefit ratio is problematic.
- As well as the limitations of the clinical trials in CFS/ME patients, there are doubts even among professionals about the specific efficacy of cognitive behavioural therapy. As a recent review commented: “...the foundations on which it rests are not as secure as some of its proponents would have us believe.” (Holmes, 2002).

“The foundations of cognitive behavioural therapy are not as secure as its proponents suggest.”

Though the CMO report states that “application of a cognitive behavioural model to CFS/ME has been found successful in most patients in the trials” (4.4.2.2), this bald statement is almost certainly untrue: of five randomised controlled trials, two were negative, dropouts were high, and some ‘improvements’ were seen in the control groups, indicating that not all improvement can be ascribed to CBT. The same section of the report contains a remarkable statement:

“The Working Group accepts that appropriately administered cognitive behavioural therapy can improve functioning in most patients with CFS/ME who attend adult outpatient clinics.” (4.4.2.2)

This is a masterful piece of drafting which skilfully suggests great benefits of cognitive behavioural therapy while leaving several exits in case of attack. What is “appropriately administered” cognitive behavioural therapy? What aspect of ‘functioning’ is meant? How can the Working Group accept that ‘most’ patients improve on the basis of the extrapolation of the results of three positive and two negative trials to the whole population of CFS/ME patients in the UK?

There are several quotations in the report which - probably unwittingly - go to the heart of the matter:

“Cognitive behavioural therapy for people with CFS/ME is currently unavailable or very difficult to obtain in much of the UK.” (4.4.2.2)

“There was disagreement among clinicians as to the precise value and place of cognitive behavioural therapy, which partially reflected the varying models of the therapy and disease.” (4.4.2.2)

“We also noted that misunderstanding, misplaced concern, and poor practice in this area could potentially undermine the beneficial application of this therapy or its principles in patients with CFS/ME.” (4.4.2.2)

“In one patient-group survey, only 7% of respondents found the therapy [CBT] ‘helpful’, compared with 26% who believed it made them ‘worse’. The remaining 67% reported ‘no change’.” (4.4.2.2)

As these quotes help to illustrate, cognitive behavioural therapy is non-curative (Wessley, 2001); is expensive and time-consuming, and beyond the resources of Health Authorities to fund; has an irrecoverably poor reputation among ME patients, especially the severely ill whom it incenses; has been found helpful by only a small minority of patients surveyed; and requires skilled therapists who need the consent of malleable patients rather than irate unwilling ones. As a recent commentary in the British Medical Journal stated: “Until the limitations of the evidence base for cognitive behavioural therapy are recognised, there is a risk that psychological treatments in the NHS will be guided by research that is not relevant to actual clinical practice and is less robust than is claimed.” (Bolsover, 2002). Or, as one patient has said, cognitive behavioural therapy is “not curative, not cheap, not accepted, and not the answer for everyone.”

3.4.2 Graded exercise therapy

Graded exercise therapy was the other “potentially useful” therapy identified by the Working Group on the basis of the three positive clinical trials out of the forty-four identified. The limitations of these trials have been discussed in depth elsewhere (BMJ 1997; 315: 947 and electronic responses to BMJ 2001; 322: 387), but the main points can be summarised as follows:

- The success of randomised controlled trials depends on strict comparability of control to treatment groups. In these trials there was not the same contact with the controls and patients, raising the possibility that factors other than treatment were involved in the “positive” outcome.
- All three trials consisted of patients classified by the Oxford criterion which does not diagnose ME or the CDC-CFS criteria (Fukuda *et al*, 1994) exclusively. The weakly-positive trial results may reflect this bias, have little relevance to CFS/ME patients, and have no relevance to the large numbers of severely affected or young sufferers.
- Graded exercise therapy involves a patient-motivation component to encourage compliance with the exercise regimen. However, the true usefulness of such programs is by no means clear (Harland, 1999).

- Its use is predicated on the belief that deconditioning is a factor in the perpetuation of illness in CFS/ME patients. However, there is good evidence that deconditioning is not a significant factor (Brazelmanns, 2001; Van der Werf, 2000) and that it cannot account for delayed post-exertional symptoms or the documented changes in muscle metabolism (Lane *et al*, 1998; Lane, 2000).

None of these is successfully dealt with in the CMO report, though some limitations are alluded to:

“One key controversy that exists over graded exercise rests on whether the nature of the treatment is appropriate for the nature of the disease, at least in some individuals. Existing concerns from voluntary organisations and some clinicians include the belief that some patients may have a primary process that is not responsive to or could progress with graded exercise, and that some individuals are already functioning at or very near maximum levels of activity.” (4.4.2)

“Voluntary organisations, as well as the Sounding Board events, note that graded exercise therapy can be effective in some individuals, but substantial concerns exist regarding the potential for harm.” (4.4.2.1)

Fortunately, some hard evidence from patient surveys is shown in the Working Group’s report, albeit in Annexe 3. This showed that of 1,214 patients using graded exercise therapy, 34% found it helpful but 50% (610 patients) reported that it made them worse. Graded exercise therapy had the greatest number of ‘worse’ reports of any therapy.

Clearly, as a management strategy, graded exercise therapy has its limitations for CFS/ME patients: “Best practice in this area indicates that the initial stages of any graded exercise programme should only be carried out by therapists (i.e., occupational therapists, physiotherapists, exercise physiologists, sports therapists, etc.) who have the necessary expertise to manage CFS/ME patients.” (4.4.2.1) At present, very few therapists are available with such expertise.

3.4.3 Pacing

In contrast with the two professionally-dictated interventions, pacing has been included as a ‘management strategy’ in response to patient experience - an example (some might say) of patients voting with their feet. Pacing allows patients to choose their own acceptable level of activity in accord with their fluctuating symptoms. It accepts that in the rehabilitation of sufferers, rest and relaxation also have an important role to play (Shepherd, 2001). The report clearly states the rationale for pacing:

“Clinical wisdom suggests that management of limited energy and supervision of any increases in physical or mental activity are an essential part of ongoing care for individuals with CFS/ME.” (4.4.2)

“A survey of more than 2,000 members of a voluntary organisation (Annexe 3, section 3) who were or had been severely unwell showed that 89% of group members found pacing ‘helpful’.” (4.4.2.3)

While pacing is intuitively sensible, its status as a clinical management strategy chosen after three years of deliberation by a Working Group is debatable, and there is a lingering suspicion that it has been recommended by the Working Group only as a concession to patient-based opinion. Whether sufferers will be allowed by healthcare professionals to choose this “recommended” therapeutic strategy in preference to psychological strategies is an open question. Indeed, almost as soon as the Working Group’s report was published, an item in the British Medical Journal commented: “The clinicians argued that the psychosocial side of the condition should have had greater emphasis and were concerned that ‘pacing’... was included as a form of treatment,” and quoted one professional as saying that “...doctors would not accept pacing just because it was recommended in the report” (Eaton, 2002).

3.4.4 Conclusions about the choice of management strategies

The preamble to the CMO report was explicit in its aims:

“Throughout, we have aimed where possible to base our commentary and recommendations on the best quality evidence, and from a range that includes randomised controlled trials and clinical anecdote. In the absence of research evidence to inform many issues, the bulk of the report is derived from a synthesis of patients’ and clinical experience. Where some data exist, albeit incomplete and not fully agreed, we considered the trident approach together with the likely resource implications to inform our conclusions.” (1.3.3)

How far have these aims been achieved? By conventional standards of literature reviewing, formal evidence for the use of cognitive behavioural therapy, graded exercise therapy and pacing is rudimentary. The fact that a few more clinical trials exist for cognitive behavioural therapy and graded exercise therapy than for any other intervention merely reflects the funding support which the interventions attract in the UK (Abbot & Spence, 2002). Patient evidence suggests that a small subgroup of patients might find either cognitive behavioural therapy or graded exercise therapy helpful (7% and 34% respectively) - possibly reflecting the heterogeneity of the patient grouping inside the construct ‘CFS’ - but that a substantial proportion (93% or 66% of patient responders, respectively) either find them ineffective or harmful. Pacing is nothing more than a commonsense approach enforced on most patients by their circumstances, and can hardly be described as a therapeutic management strategy. To use an analogy, pacing could describe the ability

of an amputee to hobble around in difficult circumstances: a “therapeutic management strategy”, however, might include a new prosthesis individually designed. Strangely, in a recondite section (but not in the easily-accessible overall conclusions) the report itself admits the truth:

“Review of the evidence highlights the lack of good quality research to support effectiveness of various therapies. Patient responses suggest that no approach is universally beneficial and that all can cause harm if applied incorrectly.” (4.0)

3.5 Failure to highlight data on the most severely ill patients

At several points, the report mentions the problems of the most severely ill patients:

“Severely ill are severely overlooked; just ignored and invisible.” (2.3.1)

“In general, this group is excluded from research, so they may not fulfil criteria used to test evidence-based approaches. Some report that they want to believe doctors and feel ‘frightened to say no’ or that they do not have the energy to disagree. Fears were also expressed over: being branded as a ‘difficult patient’, losing benefits, letting people down, not trying, losing the love of the family, and being labelled as mentally ill.” (2.3.1.1)

“Not enough is known about severe forms of the condition CFS/ME that are reported to affect up to 25% of patients.” (4.4.1)

Yet, a database of information collected and analysed on behalf of severely-ill sufferers by the 25% ME Group, which was presented to the Working Group, has not been used to full effect, and remains unmentioned in Annexe 3 (Patient Evidence). MERGE takes the opportunity of highlighting it in Table 2 below.

The 25% group, in a questionnaire report (25% ME Group, 2000), revealed that of 215 questionnaires returned some interesting observations could be made: 55% of respondents had been ill for more than ten years, and 50% of them had taken more than two years to obtain a formal diagnosis of CFS/ME. Twenty-five percent of respondents described themselves as bedridden, and 57% had been either housebound or bedridden for more than six years. As regards appropriate medical advice or treatment, 29% reported that none had been offered during the course of their illness. Only 25% of respondents felt that their condition was improving, or had improved from an even more chronic level. Important additional findings were that 76% (162/212) of respondents felt that the lack of a diagnosis or appropriate advice in the early stages of their illness had impacted on the severity and longevity of their symptoms; that 38% (81/212) described themselves as totally dependent on others; and that 48% (104/215) reported no regular assessment or management of their

condition. The management strategies recommended by the report are inappropriate for this group of sufferers, whose continued ill health - its aetiology, perpetuation and cure - remains a neglected challenge.

Table 2. Survey of severely affected CFS patients, reproduced courtesy of the 25% group

Age (years)	Number (%)
<20	5 (3)
20-39	70 (36)
40-59	90 (47)
>60	28 (14)
Time housebound/bedridden (years)	
<2	10 (5) / 10 (5)
2-5	49 (24) / 19 (9)
6-10	59 (29) / 16 (8)
>10	35 (17) / 6 (3)
Present condition	
improved/improving	53 (25)
stable at low level of functioning	105 (49)
slowly deteriorating	56 (26)
Duration of illness (years)	
2-5	31 (14)
6-10	66 (31)
10-14	49 (23)
>15	68 (32)
Illness onset	
sudden	104 (49)
gradual	110 (51)
Time to formal diagnosis (months)	
<12	76 (36)
13-24	28 (13)
25-60	53 (25)
>60	53 (25)
Time to appropriate advice/treatment (months)	
<12	66 (32)
13-24	14 (7)
25-60	40 (20)
>60	24 (12)
none given	60 (29)

3.6 Undue prominence given to the 'biopsychosocial' model of the illness

From the report of the first recorded outbreak in 1934 until the late 1980s, the emphasis was on the elucidation and treatment of the biomedical aspects of the illness (e.g., Acheson, 1959). Since then, a "biopsychosocial model" has been proposed - primarily by psychiatric/psychological professionals - defined by the report as:

"The biopsychosocial model of pathophysiology, applicable to all disease, suggests that once an illness has started its expression is affected by beliefs, coping styles, and behaviours, while consequential physiological and psychological effects act in some ways to maintain and/or modify the disease process." (3.3.4)

"Illness beliefs - The way in which abnormal illness behaviour and illness attributions (especially about cause) may be perpetuating ill health and disability in some CFS/ME patients remains a contentious issue." (3.3.3)

Psychological factors do, of course, accompany chronic illness - every patient has a mind and feelings which are affected by the experience of disease. The problem concerns the ascription of causation. The view that "psychosocial factors" either precede (cause?) CFS/ME, or play a major role in maintaining the illness after it has developed, has taken root among some, but not all, members of the medical profession, and has influenced the perception of CFS/ME in the media and among the general public. Naturally, patients have come to feel stigmatised and alienated, and perceive the influence of the model, particularly among medical practitioners, to have a pernicious effect on their care. To complicate matters, patients' beliefs that their illness is "physical" are seen by proponents of the biopsychosocial model as a sign of psychological dysfunction. Such psychologising of patients illness experience is not unique to CFS/ME patients. A recent study on Gulf War Syndrome was entitled: "Prevalence of Gulf war veterans who believe they have Gulf war syndrome" (Chalder *et al*, 2001). The principal author of this study was one of the Key Group members of the report. Many CFS/ME patients await with interest the next study in the series: to continue the analogy of the amputee used above, it could perhaps be on amputees (with or without CFS/ME) who believe that they have lost a limb. The CMO report itself - in select sections possibly written to assuage its lay members - does state the central problem with this model succinctly:

"Although they may have speculated about causation, mostly what has been demonstrated is an association. For example, the various psychological factors claimed to be causal may be a consequence of severe, prolonged CFS/ME." (4.2.1.4)

"Certain strongly held attitudes to the illness and coping mechanisms do seem to be associated with a poorer prognosis, but studies done so far have not enabled the direction of causation to be determined. Some have inferred that a poorer prognosis may be caused by such attitudes, but it can equally be argued that severe, prolonged illness may have a negative impact on attitudes and coping mechanisms... the various psychological factors claimed to be causal may be a consequence of severe, prolonged CFS/ME, and for the most part the study designs adopted would not enable the question of causality to be resolved." (4.2.1.4)

“However, it seems likely that cognitive dysfunction in CFS/ME cannot be explained solely by the presence of a coexistent psychiatric disorder.” (3.3.4)

“The biopsychosocial model of CFS/ME has influenced its perception among the general public.”

Nevertheless, peppered throughout the remainder of the report are examples of classical biopsychosocial modelism, despite the resignation of its supporters from the Key Group on the grounds that “the condition’s psychological aspects were being underplayed” (Hospital Doctor, 17th Jan 2002). Thus,

“An individual’s symptom profile is modified by the impact of illness on the person affected and those around them.” (3.4.2)

“Re-enablement should encompass cognitive, emotional, and social aspects as well as physical aspects.” (4.1.2)

“Ideally, services would be patient-centred, and adopt a biopsychosocial model or a holistic view of care.” (3.3.4)

“It is thought that certain strongly held beliefs about the cause of the illness can impede progress. These include the view that the illness is entirely physical or is caused by a persistent virus. These beliefs could be partially correct - e.g., a virus could have provoked a persistent or prolonged change in physical functioning. However, they could also act as obstacles to recovery or to necessary treatment.” (3.3.3)

Given that the evidence of efficacy for these interventions in CFS/ME sufferers is weak (Whiting *et al*, 2001), the relevance of these statements in the Working Group report is questionable. Why should the “ideal” service (which patients and their carers are paying for through their taxes) be one which adopts a biopsychosocial model, given the available evidence? More generally, how would it be if the same statements were applied to either asthma or angina, both of which have psychosocial elements yet are recognised as predominantly physical illnesses? As Susan Sontag says in her book, *Illness as Metaphor* (1978), “Theories that diseases are caused by mental states and can be cured by will power are always an index of how much is not understood about the physical terrain of a disease.” Some consider this insight to be particularly apt in the case of CFS/ME at the beginning of the 21st century.

3.7 Downgrading of relevant research findings

At points the Working Group’s report mentions its role in assessing research evidence: “...we sought to bring together

knowledge on CFS/ME to support initiatives to improve care for patients. This has been an intricate process, drawing on research evidence, the experience of patients and diverse clinical opinion.” (Foreword) “... make recommendations for further research into the care and treatment of people with CFS/ME.” (Remit, 1.1)

Yet, despite this, the main body of the CMO report deals with the research findings in 639 words (section 3.3.4) out of a total of some 34,600 in the main report. However, there is a large body of research literature on CFS/ME. As the CFIDS Association of America makes clear, though the aetiology of the illness remains elusive, numerous biological abnormalities have been reported in:

- Immune function - in the form of cytokine overproduction or poor cellular function (Patarca-Montero *et al*, 2000; Patarca-Montero *et al*, 2001).
- Brain and CNS - with possible involvement of the basal ganglia (Chaudhuri & Behan, 2000) or the functioning of the blood-brain barrier (Bested *et al*, 2001).
- Muscle - in the form of oxidation defects (McCully & Natelson, 1999) or post-exertional deficits (e.g., Lane, 2000; Paul *et al*, 1999).
- Autonomic functioning - as neurally-mediated hypotension (e.g., Bou-Holaiigah *et al*, 1995).
- Hormonal function - most prominently at the hypothalamic-pituitary-adrenal axis (e.g., Scott & Dinan, 1999).
- Cardiovascular integrity - endothelial sensitivity to acetylcholine (e.g., Spence *et al*, 2000).
- Neuropsychological functioning - including impaired working memory and information processing unrelated to psychiatric illness (review: Michiels & Cluydts, 2001).

“The research literature contains several hypotheses and proposals to explain how CFS/ME may be caused or maintained. The quality of the evidence is variable, however, and many suggested mechanisms are as yet based on associations rather than cause or linkages.” (3.3.4)

Interestingly, these reasons for bypassing a full consideration of the research evidence, namely, the variable quality and lack of causal evidence, could also apply to the evidence for the choice of management strategies (cognitive behavioural therapy, graded exercise therapy, and pacing) and, it could be plausibly argued, to the biopsychosocial model itself.

The downplaying of the research evidence partly reflects the constrained remit, which was restricted to management strategies. With a different remit, the report might have been able to recommend a direction for future fundamental research after a thorough review of the literature. Instead, the message presented to the media, the public and opinion formers is that the best that can be done is to manage symptoms, most prominently with psychological strategies.

3.8 Inadequate coverage of social care and welfare issues

The foreword to the report states that: “In 1998, the Working Group on CFS/ME set out to consider how the NHS might best provide care for people of all ages who have this complex illness.”

While the NHS is the major player in care provision for patients, it is only one agency among many providing care for people. By focusing so closely on one agency, the CMO report has missed an opportunity to highlight more clearly the responsibilities to CFS/ME patients of other agencies and the professionals who work for them. The nature of the illness and its practical consequences, particularly for the severest sufferers, are such that social services should be closely involved in both care planning and direct service provision. Consideration should be given to those most severely affected, identifying them as a special interest group in terms of joint community care planning and in planning for children and young people’s services.

“The report’s message is that the best that can be done is to manage symptoms.”

The report recognises that, on the ground at present, the range of services are not ‘joined up’.

“Beyond primary care level, the issue that causes most concern is the lack of specialists and services... Some patients find themselves in geographical ‘black holes’ that lack specialist provision.” (2.2.4)

“Patients can encounter arbitrary and poorly informed decision-making on other issues such as home help and mobility badge schemes, as well as sheer resource limitation. Failure to access appropriate support from social services can be compounded if doctors fail to provide clear guidance about diagnosis and need.” (3.5.1)

While the recommendations on equipment and practical assistance (4.3.3) and the call for service networks (6.3) is welcome, statements about the services CFS/ME sufferers ‘should’ receive in the community are little more than howling for the moon: without the full support and practical backing of local social work departments, sufferers will struggle to see these needs either fully met or met appropriately. For example, a recommendation that clinicians should inform patients about local services is one thing, but providing clinicians with the ability to refer patients to the relevant agencies themselves would be truly useful. Indeed, with the advent of joint social work/health teams, this is no longer impractical. As regards recommendations to employers - even the NHS itself - the Working Group’s report is light on the provision of practical

advice about how the illness should be managed in the workplace. A fuller exploration of this issue would have been a welcome extension to the report, as would advice on good employment practice to all tax-funded employers.

It is re-assuring to see that Welfare Benefits have been accorded their own priority by the Working Group:

“A small subgroup of the Working Group was established to produce a paper on CFS/ME and the benefits system. This working paper was then submitted to the CMO in April 2000. Professor Donaldson formally copied the paper to the Chief Medical Advisor of the Department of Social Security to inform that Department’s Working Group, which was established to review the benefits system for people with chronic illness.” (1.3)

Yet, how useful it would have been, for patients and carers, to have had this information summarised in the main report, and attached in full as another Appendix.

The journey through public service provision is often a daunting one that can leave individuals feeling powerless and damaged by the very system that is supposed to support them. The experiences of patients in the health service, service users in local authorities, and claimants in the welfare benefits system, continually highlight the need for more independent advocacy services to ensure that people receive the services and support to which they are entitled, and to receive them with their dignity intact. Unfortunately, the Working Group report barely addresses these issues.

3.9 Words are not action - will anything actually change?

Though the CMO report makes some heroic suggestions for improving the quality of the patient-provider interaction, insisting that “Patients can be empowered to act as partners in care” (4.0), it carries with it no executive power, no funding to stimulate change, and no commitment to reconvene at a future date to report on the changes which may have been implemented. This severely limits its usefulness.

Given this, several aspects of the situation on the ground make significant beneficial change unlikely in the short to medium term. First, a significant number of patients have not been well served by healthcare professionals. For example, section 3.5 (above) has shown that 61% of the most severely ill patients report waiting more than 2 years for appropriate advice and symptomatic help (there is no ‘treatment’). Although the Working Group is, in places, upbeat about the prognosis for patients with the illness, e.g., “The likelihood is that most patients will show some degree of improvement over time, especially with treatment... Gradually progressive deterioration is unusual in CFS/ME.” (1.4.3), research studies on prognosis (e.g., Bombardier & Buchwald, 1995; Hines *et al*, 1993; Vercoulen *et al*, 1996) are less optimistic: around one third of sufferers regain up to 80% of their premorbid levels, but the remainder

experience remissions and relapses, albeit at a 'stable' level of functioning, often for years, or steadily deteriorate into severe incapacity and dependency. This often occurs without any support or significant help from healthcare professionals: without teeth, the recommendations of the Working Group are unlikely to alter this unfortunate picture. Again, research reports have shown that a substantial proportion of GPs do not believe they are dealing with a distinct clinical entity when they see CFS/ME patients (Stevens *et al*, 2000; Ho Yen & McNamara, 1991). A MERGE in-house analysis found that 20% of patients

“The report carries no executive power, funding, or commitment to follow up its recommendations.”

reported changing GP at some stage during their illness, and that roughly one third found their GP's attitude to be at best non-committal and sometimes openly sceptical. In a recent development, “Chronic fatigue syndrome/Myalgic encephalomyelitis” was voted by 12.6% (72/570) of respondents to the website of the British Medical Journal as one condition that best fitted the description of a “non-disease” (BMJ 2002; 324: 7334, data supplement). Published items of in-house literature for doctors perhaps clearly reveal how some feel about these patients:

“Never let patients know you think ME doesn't exist and is a disease of malingerers. Never advise an ME patient to make a review appointment. At the end of the consultation, I say goodbye, not *au revoir*.” **Dr Mary Church (a member of the BMA Medical Ethics Committee) quoted in the GP magazine, Pulse. 20th October 2001.**

“Question: What would be your initial response to a patient presenting with a self-diagnosis of ME?
Possible answers:

- a) Are you by any chance a teacher?
- b) Thank you for making the effort to come along. I am sure we will be able to help.
- c) For God's sake, pull yourself together, you piece of pond life.
- d) Well, lets just explore that, shall we?”

Dr Tony Copperfield (a pseudonym), described as being a GP in Essex, in Doctor magazine, 2000. (The 'correct' answer was (c).)

“I have every symptom of the disease. The pathogenesis of ME is increasing workload; being undervalued socially, politically, and financially; and being abused by those I try to help. You just have a get on with life.” **Name and address withheld. Doctor magazine. 18th March 1995.**

“If they really insist on a physical diagnosis tell them chronic fatigue syndrome is a complex disorder in which multiple biopsychosocial factors are mediated via the anterior hypothalamus - in other words, it's all in the mind.” **Dr Douglas Carnall, Bluffer's Guide: Chronic Fatigue. 12th January 1995.**

“ME is usually (in my surgery, always) a self-diagnosis: somebody comes in, sits down and says, 'I think I've got ME, doc'. This is what we in general practice call a '*heart-sink encounter*.'” **Dr Michael Fitzpatrick, “The making of a new disease”. The Guardian 7th February 2002.**

These quotes sit uneasily with the aspiration in the CMO report:

“The doctor's job should be to 'heal sometimes, relieve often, comfort always'.” (4.1.2)

“Positive attitudes and cooperation based on mutual respect seem likely to produce best outcomes.” (3.3.3)

Rather than promoting a culture in which CFS/ME patients and their carers can begin to be 'partners in care', a more likely outcome is the imposition of cognitive behavioural therapy and graded exercise therapy on some patients due to the media spin surrounding the report's conclusions. Patients should remember, however, that doctors have a duty to prescribe cognitive-behavioural interventions or exercise regimens with *as much care* as they prescribe drugs, and that CFS/ME patients who experience adverse effects or relapse - as indicated by patient reports of graded exercise therapy - may well be entitled to redress through the courts.

End piece - Patient voices



In the plethora of views about the research and management of this illness, the authentic voice of the sufferer is rarely heard. For this reason some individual poignant experiences are given below.

“I was eighteen years old when I was struck down with severe, virally-induced ME. I am now thirty-three. It has destroyed my quality of life. My feelings of loss and helplessness are often overwhelming. My parents have to care for me and the illness has deprived me of a career, a social life, and the possibility of marriage and children. I am 90% bed-bound and feel wretchedly ill every waking moment. At worst I am unable to hold a conversation, watch TV, or even read. My only hope is for a research breakthrough in this illness. More than anything else, I want to see ME recognised and a treatment found.” **Clare**

“The worst thing about having ME is, obviously, having ME. It is spending three years in your bedroom looking at the walls, in pain, isolated, unable to read, write, or talk, with a brain like spaghetti. The worst thing is having a brain which no longer works and which I can't do anything about. It's like being in solitary confinement, except that I haven't done anything wrong.” **Josh**

“The feelings of pain and sickness are with me all the time. The illness has changed my life. I can do none of my former hobbies, and am left hanging around on the fringes of a no man's land between the dying and the well. It's a double torture - having the illness and having it unrecognised. It has been said that patients like me should just move on, but after twenty years it seems to me that the only things moving on in this illness are professionals - medical and charitable - making careers out of my misery. A little humility and some humanity by those in the so-called 'caring professions' would go a long way towards helping me cope with what has been a truly awful experience.” **Alex**