The Chief Medical Officer's Working Group Report on CFS/M.E.

A guide

Terms of reference

"To review management and practice in the field of CFS/M.E. with the aim of providing best practice guidance for professionals, patients, and carers to improve the quality of care and treatment for people with CFS/M.E., in particular to:

- develop good clinical practice guidance on the healthcare management of CFS/M.E. for NHS professionals, using best available evidence
- make recommendations for further research into the care and treatment of people with CFS/M.E.
- identify areas which might require further work and make recommendations to CMO"

The report contains nearly 150 pages divided into six chapters and seven annexes. In this guide we repeat the Key Messages and Recommendations in full, and quote selectively a number of extracts. Where relevant we also record our response.

To view the report in full, please visit
www.doh.gov.uk/cmo/cfsmereport/index.htm

action for M·E

Chairman's introduction

Over the last few months, Action for M.E. (AfME) has been working hard to prepare the ground for the publication of the Chief Medical Officer's report, which we believe is a milestone in the field of M.E. It has the power to transform how people with M.E. are treated.

At long last, the major issues that have such a huge impact on people's lives have been addressed: the importance of early diagnosis and effective and prompt advice on managing the illness; the urgent need for better research and recognition of the severity of the illness; the problems experienced in the benefit system and the acknowledgment of the damage that is done by disbelieving or sceptical attitudes. All of these factors are vitally important if the patient is to stand a chance of recovery and the report has achieved a great deal in attempting to get to grips with these issues.

That the report has managed to achieve all this is partly a tribute to the manner in which it was created. A strong balance was struck from the outset between the patient voice and the opinions of the medical profession, with AfME at the centre of the process, giving evidence on a whole range of subjects along with other charities. The close involvement of the voluntary sector has been hugely validating, and is a relationship we will seek to maintain as the findings are rolled out to individual health authorities and primary care trusts.

However, while this is a breakthrough it is by no means the end of the road. In fact it is just the first step in a long journey. We will continue to campaign for real change, ensuring consistent services for people with M.E. are adopted throughout the UK.

However, one thing has changed for good. No-one can be in any doubt now that the Government recognises the seriousness of the illness.

Ondine Upton
Chair
Action for M.E.

Table of contents

Contents

Highlights from the report

1. Evidence on the extent of distress and disability that this condition has on patients, carers, and families.
2. Patients and carers often encounter a lack of understanding from healthcare professionals.
3. Inadequate awareness and understanding of the illness among many health professionals and in the wider public.
4. Under-provision of treatment and care, with patchy and inconsistent service delivery and planning.
5. A paucity of good research evidence and very little research investment.
6. Insufficient attention has been paid to children and young adults, the severely affected, cultural, ethnic and social class groupings.
7. Existing controversy cannot and should not be used as an excuse for inaction or unsuitable practice.
8. Those affected number over 100,000 possibly approaching 250,000.
9. No single cause is established. The report provides a balanced view of the known facts and theories.
10. The severity is recognised even for those most mildly affected. But the report highlights the special difficulties and invisibility of those most severely affected.
11. The report highlights difficulties experienced with benefits, employers and insurance
12. Diagnostic criteria are established, with diagnosis expected within six months at the latest.
13. No management approach to CFS/M.E. has been found universally beneficial, and none can be considered a cure. However, general principles can be outlined to guide management.
14. Most people with CFS/M.E. can expect some degree of improvement with time and treatment, so a positive attitude towards recovery needs always to be encouraged.
15. Each individual is best managed according to a unique flexible management plan, in which specific strategies and therapies are tailored to his or her particular circumstances.
16. All clinical interventions carry a potential risk of harm, especially if applied incorrectly; for CFS/M.E. in particular, imposed, rigid programmes can be actively harmful.
17. A number of approaches are identified that may help in the absence of a cure. As expected, these include CBT and graded exercise, but for the first time pacing is recognised as a useful approach.
18. The needs of children highlighted, with robust recommendations for multidisciplinary approach.
19. Major recommendations (reported here in full) for education, training, NHS services and research.

The report's recommendations

CFS/M.E. is a relatively common clinical condition, which can cause profound, often prolonged, illness and disability, and can have a very substantial impact on the individual and the family. It affects all age groups, including children. The Working Group has encountered extensive evidence on the extent of distress and disability that this condition causes to patients, carers, and families. It has examined the evidence on the effectiveness of interventions used in the management of this condition.

Patients and carers often encounter a lack of understanding from healthcare professionals. This lack seems to be associated with inadequate awareness and understanding of the illness among many health professionals and in the wider public. Many patients complain of the difficulty of obtaining a diagnosis in a timely manner. There is evidence of under-provision of treatment and care, with patchy and inconsistent service delivery and planning across the country. Finally, there is a paucity of good research evidence and very little research investment for a serious clinical problem that in all likelihood has a pervasive impact on the individual and the community. Insufficient attention has been paid to differential outcomes and treatment responses in children and young adults, the severely affected, cultural, ethnic and social class groupings.

The Working Group has identified measures that should be taken with some urgency to address the current situation.

Recognition and definition of the illness

- The NHS and healthcare professionals should recognise CFS/M.E. as a chronic illness that, despite uncertain aetiology, can affect people of all ages to varying degrees, and in many cases substantially.
- In view of current dissatisfaction among some groups over the nomenclature applied to this illness, we recommend that the terminology should be reviewed, in concert with other international work on this topic.

Treatment and care

- Patients of all ages with CFS/M.E. must receive care and treatment commensurate with their health needs and the disability resulting from the illness.
- Healthcare professionals should have sufficient awareness, understanding, and knowledge of the illness to enable them to recognise, assess, manage and support the patient with CFS/M.E. Healthcare workers who feel they need extra skills should seek and receive help from those experienced in this area.
- GPs should usually be able to manage most cases in the community setting, but must be able to refer patients for specialist opinion and advice where appropriate (e.g. because of complexity in diagnosis and treatment).
- CFS/M.E. of any severity in a child or young person – defined as of school age – is best co-ordinated by an appropriate specialist – usually a paediatrician or sometimes a child psychiatrist – in concert with the GP and a paediatric or Child and Adolescent Mental Health Services (CAMHS) multi-disciplinary team.
- Sufficient tertiary level specialists in CFS/M.E. should be available to advise and support colleagues in primary and secondary care.
- Management should be undertaken as a partnership with the patient, should be adapted to their needs and circumstances, and should be applied flexibly in the light of their clinical course.
- The support of the patient with CFS/M.E. and the management of the illness should usually extend to the patient's carers and family.
- Clinicians must give appropriate and clear advice, based on best national guidance, on the nature and impact of the illness to those involved in providing or assessing the patient's employment, education (primary, secondary, tertiary, and adult), social care, housing, benefits, insurance, and pensions.

Recommendations

Health service planning

- Service networks should be established to support patients in the primary care and community setting, to access when necessary the skills, experience, and resources of secondary and tertiary centres, incorporating the principles of stepped care. Services should be configured so that individual professionals and aspects of the service can meet individual needs, particularly in the transition from childhood to adult life.
- Health service commissioning through primary care organisations, supported by health authorities or wider consortia, must ensure that local provision for these patients is explicitly planned and properly resourced, and that health professionals are aware of the structure and locale of provision. Health commissioners should be requested to take immediate steps to identify the current level of service provision for CFS/M.E. patients within their locality.
- Each Strategic Health Authority should make provision for secondary and tertiary care for people with CFS/M.E., based on an estimated annual prevalence rate of approximately 4,000 cases per million population in the absence of more refined data.
- People who are so severely affected that their disability renders them house-bound or bed-bound have particular constraints in regard to their access to care. These specific needs must be met through appropriate domiciliary services.
- The NHS should make use of the wide range of support and resources available through partnership arrangements with voluntary agencies, enabling suitable self-management by the patient.

Education and awareness

- The education and training of doctors, nurses, and other healthcare professionals should include CFS/M.E., as an example of the wider impact of chronic illness on the patient, on carers and family, and on many aspects of society.
- Healthcare professionals, especially in primary care and medical specialities, should receive postgraduate education and training so that they can contribute appropriately and effectively to the management of patients with CFS/M.E. of all ages.
- GPs and medical specialists should consider CFS/M.E. as a differential diagnosis in appropriate patients, and should at least be able to offer initial basic guidance after diagnosing this condition.
- Awareness and understanding of the illness needs to be increased among the general public, and through schools, the media, employers, agencies, and government departments.

Research

A programme of research on all aspects of CFS/M.E. is required.

Government investment in research on CFS/M.E. should encompass health-services research, epidemiology, behavioural and social science, clinical research and trials, and basic science.

In particular, research is urgently needed to:

- elucidate the aetiology and pathogenesis of CFS/M.E.
- clarify its epidemiology and natural history
- characterise its spectrum and/or subgroups (including age-related subgroups)
- assess a wide range of potential therapeutic interventions including symptom control measures
- define appropriate outcome measures for clinical and research purposes
- investigate the effectiveness and cost-effectiveness of different models of care

The research programme should include a mix of commissioned or directed research alongside sufficient resource allocation for investigator-generated studies on the condition.

Section 1 Patient evidence

Key messages

- Patients' voices are not being listened to and understood.
- People affected by CFS/M.E. indicated improvements needed in three main areas:
  - recognition, diagnosis, acceptance, and acknowledgement
  - healthcare service provision
  - care of groups with special circumstances.
- Patients reported the need for more healthcare professionals who know about and understand CFS/M.E. Public awareness campaigns, professional education, and information for patients and carers are accorded high priority.
- Experiences of primary care are polarised. Positive experiences are characterised by: 'willingness' of clinicians to treat the patient as an equal; supportive attitudes; belief in the patient's experiences; and early recognition and diagnosis.
- Experiences of further care are predominantly negative. Needs identified include access to specialists and respite-care services.
- Those severely affected by CFS/M.E. (up to 25% of patients) feel 'severely overlooked' by services. They experience isolation, lack of understanding, and particular barriers to accessing all forms of care.
- Children and young people are profoundly affected by public and professional uncertainties over the illness. Young people also suffer from impact on their families and from lack of support and expertise within the education system.
- Individuals with CFS/M.E. from disadvantaged class/ethnic groups face special difficulties, yet they are under-represented in research.
- Carers, particularly of young people, need more recognition, support, and respite.

Disbelief and controversy

The Working Group has continued to be concerned at the widespread controversy surrounding the existence and nature of CFS/M.E. Patients, their carers, and healthcare professionals encounter different levels and varying manifestations of disbelief and prejudice against people affected by the condition. The disbelief and controversy over CFS/M.E. that exists within the professions has done nothing to dispel public disbelief in the existence of such a seemingly varied and inconstant illness.

The Working Group agreed that existing controversy cannot and should not be used as an excuse for inaction or unsuitable practice.

Every patient's experience is unique and their illness must be considered and treated flexibly in its own right.

The name

We recognise that no current terminology is satisfactory, so in line with our original terms of reference, we have used the composite CFS/M.E. for the purposes of this report, acknowledging that CFS is widely used among clinicians and M.E. among patients and the community.

The Working Group decided that the most important requirement in terminology is for patients and doctors to agree a satisfactory term as a means of communication.

A group in the USA, with international input, is currently discussing terminology for this condition, and this work will, we hope, lead to an internationally acceptable terminology for patients and professionals.

AfME's response

We remain unhappy with CFS because it does little justice to the wide ranging and severe symptoms. Nevertheless we accept that there is as yet no commonly agreed name and the necessity of the compromise within the report of CFS/M.E.

Epidemiology

CFS/M.E. affects many people and their families in the UK and elsewhere in the world. Information about actual numbers of people with the condition is very hard to come by. Estimates are likely to under-represent the true scale of the disease, particularly the number of people with severe CFS/M.E.

Many estimates of incidence and prevalence are based on extrapolations which could be unreliable. The likelihood is that natural variation does exist between populations and geographical locations, and that results obtained in one study cannot be extrapolated to another with any degree of accuracy. However, even this cannot be said with certainty.

Overall, evidence suggests:

- a population prevalence of at least 0.2% – 0.4%
- the commonest age of onset is early twenties to mid-forties
- in children, the commonest age of onset is 13-15, but cases can occur as young as five
- CFS/M.E. is about twice as common in women as in men. It affects all social classes to a similar extent
- it affects all ethnic groups

AfME's response

We welcome confirmation that CFS/M.E. affects adults and children, across all social classes and ethnic groups. The estimate of the number of those affected ranges between 100,000 and 250,000. This higher figure is greater than previously estimated and we support the call for a study that will clarify further the prevalence of the illness.

The report makes clear that CFS/M.E. affects all social groups and classes. Past caricatures of those affected have blighted the field.

There is an urgent need to address the impact of the illness on the socially disadvantaged and those from ethnic minorities.

Section 2
Nature and impact of CFS/M.E.

Key messages

- CFS/M.E. is a relatively common condition of adults and children that is clinically heterogeneous and lacks specific disease markers but is clinically recognisable.
- The broader impact of the disease even in its milder forms can be extensive; people who are severely affected and/or with long-standing disease are profoundly compromised, and improvement of their care is an urgent challenge.
- The aetiology (cause) of CFS/M.E. is unclear, although several predisposing factors, disease triggers, and maintaining factors have been identified.
- The pathogenesis (disease process) underlying CFS/M.E. is also unclear. Research has demonstrated immune, endocrine, musculoskeletal, and neurological abnormalities, which could be either part of the primary disease process or secondary consequences.
- One highly heterogeneous disease might exist that encompasses CFS/M.E. or several related pathophysiological entities may exist; these distinct hypotheses should be studied.
- Current evidence does not allow complete distinction between CFS and M.E., or useful delineation of subgroups. Every patient's experience is unique, and the illness should be managed individually and flexibly.

Aetiology, pathogenesis and disease associations

The aetiology (cause) and pathogenesis (disease process) of CFS/M.E. are not clearly elucidated, and uncertainty continues to surround these issues. Although CFS/M.E. has certain characteristic features, the condition is heterogeneous either in causative factors or in its clinical nature. The heterogeneity could represent the range of a single condition (as with other diseases, such as diabetes), or could mean that several distinct diseases are being bracketed together because of the similarity of their clinical appearance (as with severe combined immunodeficiency). These possibilities complicate the consideration of aetiology and pathogenesis, as they do other aspects of the condition.

Research has demonstrated immune, endocrine, musculoskeletal, and neurological abnormalities. To what extent these abnormalities are part of the primary disease process or secondary consequences remains the subject of debate. The possibility that one highly heterogeneous disease might exist that encompasses CFS/M.E. or that several similar pathophysiological entities occur should be kept in mind so that these opposing hypotheses can be tested in research studies (see also Annexe 4).

Several overarching possibilities, which are not mutually exclusive, have been proposed to explain the occurrence of CFS/M.E., including:

- CFS/M.E. is an umbrella term for several different illnesses
- one (or more) 'core' disorder(s) exist
- several different causative factors trigger a common disease process
- the aetiology and/or pathophysiology are multifactorial
- certain factors are necessary but not sufficient to cause CFS/M.E.
- certain factors can influence individual manifestations or duration
- some features are downstream (secondary) consequences of the primary disease process

There is good-quality evidence that some factors trigger CFS/M.E., while others maintain it, although evidence of predisposing factors is limited.

Predisposing factors

Gender – Incidence in females exceeds that in males of any age.

Familial – The familial incidence of CFS/M.E. is slightly higher than expected.

Personality – There is evidence both for and against the possibility that certain personality traits might predispose people to develop CFS/M.E.

Other disorders – Some patients have a past or current history of other disorders, particularly fibromyalgia and irritable bowel syndrome.

Previous mood disorder – Most, but not all, studies have found a history of mood disorders in individuals with CFS/M.E. This finding might simply reflect the fact that previous mood disorders predict future mood disorders, which often coexist with chronic illnesses, including CFS/M.E. Alternatively, this finding could reflect a common predisposition to both mood disorders and CFS/M.E.

Triggering factors

Infections – Good-quality evidence indicates that certain infections are more common triggers for CFS/M.E. than others. Glandular fever, viral meningitis, and viral hepatitis are followed by CFS/M.E. in about 10% of cases of the primary infection. CFS/M.E. can follow infections with, herpesviruses, enteroviruses, hepatitis viruses, and some other viruses, and also non-viral infections such as Q fever. CFS/M.E. has been reported after salmonellosis, toxoplasmosis, and brucellosis. Influenza and 'flu-like infections can trigger CFS/M.E., but common upper respiratory tract infections do not seem to. Available evidence suggests that abnormal persistence of infectious agents does not occur in CFS/M.E., although certain chronic infections can cause similar symptoms.

Immunisations – A few case reports have suggested that CFS/M.E. has occurred after immunisations, though intercurrent events, including infection, might have played a part in the disease process. It is biologically plausible that some processes seen after infections could also occur after immunisations but this has yet to be confirmed by a good quality cohort study. Current advice to avoid immunisations during infections is designed to avoid such triggering.

Life events – The evidence that life events can trigger CFS/M.E. is weak. Severe life events are much more likely to provoke a mood disorder, which can be misdiagnosed as CFS/M.E. However, clinical and patient experience suggests that increased 'stress' may be common around the onset of symptoms or a triggering event, such as infection. It is unclear whether this is as a triggering, a predisposing or a maintaining factor. Stress is also recognised as a trigger for setbacks.

Physical injuries – These may be more likely to trigger the seemingly related condition of fibromyalgia than CFS/M.E., though instances of CFS/M.E. after physical or operative trauma have been described.

Environmental toxins – Reports have suggested an association between exposure to environmental toxins, such as organophosphorus compounds, and development of disease in isolated cases. The balance of evidence indicates that this is not a common or widespread trigger.

Maintaining factors

Sleep disturbance – The majority experience sleep difficulties, which are generally independent of mood disorders, but can contribute to cognitive dysfunction. Poor sleep quality will also exacerbate fatigue and other symptoms.

Mood disorders – Disorders of mood, especially depressive and anxiety disorders, occur in a large minority of CFS/M.E. sufferers. They are important to identify or exclude because they can either mimic or co-exist with CFS/M.E. Mood disorders can exacerbate, modify, or contribute symptoms, and can affect adaptation and recovery. However, mood disorders can also be misdiagnosed in patients with CFS/M.E. because of the overlap of key symptoms.

Inactivity – A decrease in activity is an obvious consequence of CFS/M.E. If prolonged, inactivity may then become a problem in its own right, with consequent loss of physical fitness, problems with balance and temperature control, autonomic dysfunction, loss of confidence, and sleep disturbance. Research evidence suggests that patients with CFS/M.E. seem no more physically unfit than sedentary people and may be as fit as non-sedentary people, although one study suggested that pervasive inactivity occurs in a quarter of patients. The importance of deconditioning in the disease process is contested.

Overactivity – Activity beyond the level that an individual can usually tolerate will prompt a delayed worsening of symptoms. Observation suggests that patients who show cycles of overactivity followed by setbacks ('boom and bust') may have a more protracted course.

Intercurrent stressors – Clinical experience suggests that emotional and physical stressors, 'stress' including intercurrent infections, vaccinations, and surgical operations can cause setbacks in some CFS/M.E. patients.

Iatrogenic illness – As with all conditions, clinical management strategies can sometimes contribute to maintenance of the disease. These could include inappropriate advice (to exercise too much, or to rest too much), misdiagnosis (e.g. diagnosing a psychiatric disorder when one is not present, or missing such a disorder or other diseases because of misattribution of symptoms to CFS/M.E.), and inappropriate prescribing. Failure to acknowledge the patient's illness or to provide supportive care can cause additional distress and alienation, and might encourage the patient to seek unconventional/untested remedies, some of which may cause harm.

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/M.E. patients remains a contentious issue. 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. It seems important that patients and professionals keep open minds since knowledge continues to grow. Positive attitudes and cooperation based on mutual respect seem likely to produce best outcomes.

Possible disease mechanisms

The research literature contains several hypotheses and proposals to explain how CFS/M.E. 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. This overview outlines the scope of the ideas:

Biomedical model – In this overarching conceptual framework, CFS/M.E. is seen as a condition like many other medical conditions where illness results from a specific pathological defect in physiological functioning, mediated at organ, tissue, cellular and/or molecular level, by as yet undefined mechanisms.

It is not incompatible with the following, but implies that a primary disease entity exists and that the biopsychosocial aspects are consequential.

Biopsychosocial model – 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.

Immune – Immunological abnormalities are common in patients with CFS/M.E. The findings are mostly non-specific, and their relationship to the illness has not been established. The pattern suggests some immune dysregulation, with activation or suppression of different components, as indicated by changes in cytokine concentrations and cell surface markers. In atopic patients, case reports suggest that allergic manifestations can be exacerbated or triggered.

Hypothalamic-pituitary-adrenal axis – Several studies have found subtle neuroendocrine abnormalities, particularly hypoactivity of the hypothalamic-pituitary-adrenal axis. It is also possible that disturbances in hypothalamic function could contribute to some CFS/M.E. symptoms such as fatigue, sleep problems, and disturbed thermoregulation. The possibility remains that these changes are directly or indirectly involved in pathogenesis.

Central nervous system – Many of the symptoms of CFS/M.E. suggest dysfunction of the central nervous system. These could include cognitive disturbance, central

fatigue (e.g. when movement requires increased mental effort), and disrupted neural regulatory mechanisms (e.g. those involved in sleep and temperature regulation). These changes could be primary or secondary to some widespread process.

One suggested primary change in the central nervous system of patients with CFS/M.E. is abnormal brain blood flow, particularly involving the brain stem. However, many of these findings are inconsistent.

Magnetic resonance imaging studies have found subtle white matter abnormalities in some individuals, more common in those without coexistent psychiatric conditions, leading to the hypothesis that some CFS/M.E. patients have a subtle encephalopathy.

Peripheral lesions – The roles of dysfunction in the peripheral nervous system and muscles are uncertain, though some indirect evidence and specific symptoms in individuals have implicated them.

Autonomic nervous system – Autonomic dysfunction seems to play a part but its role is not established. There is inconsistent evidence as to whether autonomic abnormalities, in particular neurally mediated hypotension, are part of a primary disease process or due mainly to inactivity associated with CFS/M.E.

AfME's response

In an ideal world we would have established the cause or causes of the illness. However not only was this outside the remit of the Group, but there is no likelihood in the near future that an answer concerning a definitive cause will be forthcoming.

Given this, the report manages to summarise those factors considered to act as predisposing, triggering or maintaining factors. These may be of use in future research.

The report finally and totally dismisses the notion that CFS/M.E. is all in the mind. No longer should patients have to tolerate their illness being trivialised by those responsible for their welfare.

Severity

The term 'severely affected' has been widely applied to patients whose physical disability is most severe, leading to serious restrictions in mobility and functioning. In many, these restrictions are accompanied by other markers of severity, such as cognitive impairment or prolonged course. This degree of physical restriction, especially if prolonged, has profound effects on personal and social functioning, which in turn substantially affects the patient's ability to access health and social services, and has an impact on the patient's carers.

A recent description has suggested four categories of severity in CFS/M.E. Although care must be taken not to diminish inadvertently the experience of any patient by descriptors of severity.

- **Mild** – Are mobile and can care for themselves and can do light domestic tasks with difficulty. The majority will still be working. However, in order to remain in work, they will have stopped all leisure and social pursuits, often taking days off. Most will use the weekend to rest in order to cope with the week.
- **Moderate** – Have reduced mobility and are restricted in all activities of daily living, often having peaks and troughs of ability, dependent on the degree of symptoms. They have usually stopped work and require rest periods, often sleeping in the afternoon for one or two hours. Sleep quality at night is generally poor and disturbed.
- **Severe** – Will be able to carry out minimal daily tasks only, face washing, cleaning teeth, have severe cognitive difficulties and be wheelchair dependent for mobility. These people are often unable to leave the house except on rare occasions with severe prolonged after-effect from effort.
- **Very severe** – Will be unable to mobilise or carry out any daily tasks for themselves and are in bed for the majority of the time. These people are often unable to tolerate any noise, and are generally extremely sensitive to light.

Indeed, there may be severe impact on people's lives even of less overtly severe CFS/M.E. Such patients may suffer most impact through the discrepancy between what they were able to achieve previously and what they can now do. Even less prolonged illness, whatever the severity, can have very substantial personal and social impact, mainly intrusions on the individual, relationships, work, and finances. Self-confidence and self-esteem are severely eroded in many cases.

Attempts by individuals to maintain activity close to a previous level of functioning can be unrealistic and unsustainable. This realisation can cause additional distress, compounded by the responses of those around the patient to the confusing signals they receive, and the unpredictability of the patient's levels of functioning.

People with severe illness

The descriptions above give an indication of the functional impact of severe disease and an indication of consequent needs. Current provision of services falls well below what is needed for the vast majority of severely and very severely affected patients.

Special difficulties arise from being physically unable to access the many services that now require patients to be ambulant, or to travel to the point of service assessment or delivery. Immobility and isolation can easily lead to what some people describe as 'invisibility'. The lack of simple technical solutions and the great difficulty that some professionals and others have in facing the uncomfortable reality of the illness, especially in a severe form, can compound the problem.

The duration of illness and disability due to CFS/M.E. can itself become part of the severity of the disease's impact, for any duration of illness can be intrusive and cause substantial problems. Severe illness that continues over many years with no sense of improvement has a profound cumulative personal and social impact. A minority of those with CFS/M.E. remain permanently severely disabled and dependent on others. Yet, even if we lack easy solutions, professionals can still support, care, and provide for many patients' needs by reaching such patients in their homes, maintaining contact, and continually exploring potential options. Those who are most severely affected need acknowledgement, encouragement, and support to remain optimistic.

AfME's response

The report *Severely Neglected: M.E. in the UK* published by Action for M.E. highlighted the appalling lack of provision for this group, and this is now recognised in the report.

It is shocking that the report concludes 'provision of health care for these severely affected patients is often seriously inadequate. However, we found insufficient evidence available to guide specific management of those people who are severely affected'.

We call on government to implement the recommendations of the report in relation to the severely affected as a matter of urgency.

Benefits, employers and insurers

Evidence from patients and clinicians suggests that there can be a substantial impact on work, finance, and education. Many people's circumstances are linked to continuing income from full-time working, and if an individual is unable to work, the consequences can be considerable. If available, sick pay is often halved within six months and then may cease within a relatively short time. People with CFS/M.E. frequently experience problems with accessing state benefits. This is partly because of the variable nature of CFS/M.E. and uncertain prognosis, but sufferers may also have difficulty obtaining a diagnosis, and thus in obtaining benefits. Improved knowledge and understanding of the condition among clinicians will help to eliminate this.

Such factors, of both a financial and social nature, can often dominate patients' early approaches to their illness, sometimes encouraging premature return to unsustainable levels of work, which exacerbates their own and their employers' loss of confidence. Return to work, even after prolonged absence, can be hard to negotiate at levels realistic for these patients, and the potential for a 'benefits trap' is only partially ameliorated by current rules on therapeutic work and therapeutic earnings.

A small sub-group of the Working Group was established to produce a paper on CFS/M.E. and the benefits system. The working paper was 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.

Another problematic gap can occur for patients who are too ill to work for long periods, but are unable to access remuneration from insurance policies or ill-health retirement. This often occurs because the loss of functioning that prevents work is different from that deemed necessary to claim from health insurance or allow ill-health retirement. The most common obstacles are duration or the need to demonstrate permanence of the condition.

The period of absence from work that can lead to complete loss of earned income is typically 12 months, but ill-health retirement is usually only considered after illness of some three years' duration. The requirement of many pension or personal health insurance schemes to demonstrate permanence (usually through medical reports) requires a level of prognostic foresight that may not be realistic. Also, such a requirement could potentially encourage a negative and fatalistic view of long-term rehabilitation so that people can access sufficient financial support to cope through prolonged illness.

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.

Similar issues arise over education, not only school but also higher education. Access to educational institutions represents a serious barrier for children and young people with CFS/M.E. Once there, the individual's inability to sustain his or her expected normal rate and level of achievement can cause further difficulties. Peer pressure and disruption from usual peer-group activities have a particularly adverse impact. Premature pressure to return to education may be particularly damaging.

Good-quality communication will also be needed on behalf of the patient with employers, schools, universities, benefits agencies, private health insurers, pensions and health-insurance schemes, social services, and so on, as well as between other professionals involved in care.

Amelioration of (the impact of the illness on finance, work, and education) is an important aspect of clinical management, and it should be considered as early as practicable

Support from clinicians is needed for the provision of medical reports and assistance with negotiations with the Benefits Agency, employers, educational institutions and insurance companies. Medical advisers for the Benefits Agency need to be aware of the incapacity experienced by CFS/M.E. patients.

It is not appropriate that participation in a particular treatment regime is made an absolute condition for continuation of sickness/disability payments.

AfME's response

We strongly endorse the report's recognition of the importance of the wider impact of the illness on people's economic and social circumstances.

Our evidence consistently confirms that many patients encounter ignorance, prejudice and inflexibility of approach from benefits staff, insurers and employers.

We thank the CMO for formally copying the paper on the benefits system as it applies to CFS/M.E., to the Chief Medical Advisor of the Department of Social Security and now call on the CMO and the CMA to publish the report in full.

Section 3 Treatment and management

Key messages

- Initial professional responses to CFS/M.E. can have a major impact on the patient and carers. Clinicians should listen to, understand, and help those affected to cope with the uncertainty surrounding the illness.
- Early recognition with an authoritative, positive diagnosis is key to improving outcomes. Symptoms are diverse, but increased activity frequently worsens fatigue, malaise, and other symptoms with a characteristically delayed impact.
- All patients need appropriate clinical evaluation and follow-up, ideally by a multi-disciplinary team. Care is ideally delivered according to an agreed flexible management plan, tailored from a generically applicable range of options.
- Therapeutic strategies that can enable improvement include graded exercise/activity programmes, cognitive behavioural therapy and pacing; intrusive symptoms and co-morbid conditions may also require specific management.
- The overall aim of management must be to optimise all aspects of care that could contribute to any natural recovery process. Management strategies need regular review to guide their application and adaptation to the individual.
- Education and support, plus measures to tackle the broader impact of the disease, need to be initiated as early as practicable. Much support is provided by the voluntary sector. Patients can be empowered to act as partners in care.
- 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.
- The goal of rehabilitation or re-enablement will often be adjustment to the illness; improvement is possible with treatment in the majority of people.

Principles

CFS/M.E. is a genuine condition that imposes a substantial burden on patients, carers, and families. The lack of certainty surrounding CFS/M.E., as for other chronic illnesses with no certain cause or disease process, also poses very real problems for healthcare professionals. Although the Working Group acknowledges this uncertainty, our conclusion is that clinicians need to apply current knowledge despite the remaining uncertainty; inaction due to ignorance or denial of the condition is not excusable.

Much of the distress surrounding CFS/M.E. is caused by difficulties in recognition, acknowledgement, and acceptance of the condition and its impact, by both professionals and the public. In the NHS, as in society, increased awareness, knowledge, and supportive attitudes are needed.

The Working Group agreed that a positive therapeutic relationship, built from the time the patient first approaches clinical services and based on a recognition of the impact of the illness, will lead to a more successful outcome. Healthcare professionals should adopt an understanding attitude and should not get into disputes with patients about what to call the illness, or about the belief that 'it doesn't exist'. A name or 'label' for the illness should be agreed to facilitate communication.

What clinicians can do

- listen to the patient, recognise and believe his or her individual experience
- acknowledge uncertainty and the impact that this has on the patient, family, and carers
- provide information on and discuss: the nature of the condition, approaches to self management, helpful therapies,

and how to access other agencies for support and services

- agree a name for the condition
- give advice on symptomatic treatment

Information and support is needed as patients and carers continue to cope with an evolving illness. Treatment should always be a collaboration between the patient and the clinician, and not something imposed. Good communication and a good therapeutic relationship can make an appreciable difference to the response of the patient who feels the need to be understood and listened to empathically. For example, there are many techniques for self-help which clinicians can make easier with guidance and support. Each patient needs repeated assessment of his or her illness to guide individual adaptation of management strategies from a generically applicable range of options.

Diagnosis and evaluation

CFS/M.E. should be treated in the same way as any other chronic illness of unknown aetiology. The aim is to develop a supportive relationship, and provide information and education to assist the patient, families, and carers towards self-management with support. Management plans and therapeutic approaches require continual assessment, supervision, and re-evaluation. The frequency of the evaluation will be based on the severity of the illness, and on the plan agreed jointly between clinician and patient, and, in the case of children, the child and parents.

An appropriate evaluation is sometimes difficult to achieve. When faced with complex decisions on management, primary care physicians have sometimes found it difficult to identify an expert from whom to seek additional advice. Furthermore, people with severe and long-standing symptoms, who may be house-bound or bed-bound, may find accessing primary care difficult and help from more specialised care services almost impossible to access. A point made consistently by patients is that the exertion involved and impact of attending hospitals (and to a lesser extent primary care services) have a negative effect on their health and their ability to communicate effectively with practitioners. These obstacles must be overcome in practical ways if we are to ensure that the most affected do not continue to be the least supported.

Evaluation requires an acceptance on behalf of clinicians, patients, and their family/carers that management is dynamic, even though sometimes change occurs slowly. Within health service management and commissioning structures, there must be an acceptance of the need to provide the additional sources of advice and support that primary care teams need. Patients' needs are key to determine appropriate referral pathways, irrespective of the speciality. Openness on the referral and the reasoning behind it is vital.

Adults, young people, and children can obviously develop new illnesses while they are suffering from CFS/M.E. Evaluation of new symptoms needs always to be from first principles, to ensure appropriate recognition and therapy, if necessary through referral to specialist care.

Diagnostic process

An early, authoritative, positive diagnosis is crucial to minimise the impact of the uncertainty surrounding the illness and early responses to it, such as attempting to 'work through fatigue'. Furthermore, some patient evidence indicates that the lack of a name for the condition, sometimes until quite an advanced stage, prevents people from coming to terms with their illness and may also limit the ability to implement an effective management plan.

A positive diagnosis of CFS/M.E. is needed, rather than one of exclusion. Without a validated test for the illness, diagnosis is based on recognition of the typical symptom pattern together with exclusion of alternative conditions. Thus, a positive diagnosis can usually be made from clinical history, examination, and a few appropriate laboratory investigations, as in other chronic illnesses of uncertain nature.

When other diagnoses have been excluded and CFS/M.E. remains as one of the possible diagnoses, a limited set of investigations is usually appropriate. However, this should not dissuade clinicians from pursuing lines of clinical inquiry that will alter management or reduce uncertainty for patients and clinicians. In addition, clinicians may wish to conduct investigations that may improve our understanding of aetiology and pathogenesis, and better treatment; such clinical research, with appropriate consent,

is important, but it must be explicitly distinguished from normal clinical care.

Diagnostic criteria

Current diagnostic criteria are useful only for research purposes.

A diagnosis of CFS/M.E. relies on the presence of a set of characteristic symptoms together with the exclusion of alternative diagnoses. One of the most common and characteristic complaints of adults, particularly in the early stages of the illness, is of intolerance to both physical and mental exertion with delayed impact. So perhaps the key pointer to a diagnosis of CFS/M.E. is the way in which the symptoms behave after increased activity.

Persistent fatigue should be differentiated from acute fatigue, which may follow illnesses such as influenza. It should also be differentiated from other kinds of fatigue (for instance, tiredness due to over-exertion, weakness due to neuromuscular disease, and loss of motivation and pleasure due to major depression). These other fatigue states do not present with the characteristic delayed fatigue seen in CFS/M.E. Another distinguishing feature of the illness, in comparison with other 'fatigue states', is its prolonged relapsing and remitting course over months or years.

Characteristic features

The characterising features of CFS/M.E. are overwhelming fatigue, related effects on both physical and cognitive functioning, and malaise, typically exacerbated after physical or mental exertion, accompanied by a wide range of other symptoms. The fatigue is commonly described as like no other in type and severity, and is evidently very different from everyday tiredness.

Perhaps the prime indicator is the way in which symptoms behave after activity is increased beyond what the patient can tolerate. Such activity, whether physical or mental, has a characteristically delayed impact, which may be felt later the same day, the next day, or even later. This is followed by a recovery period, which again may last for days or even weeks. In some instances, the patient can sustain a level of activity for some time, but a cumulative impact is seen, with a setback after several weeks or more. The amount of activity that provokes increased symptoms is related to the severity of the disorder, and in some individuals is very modest. Delayed fatigue, post-exertional malaise, or increase in other symptoms after activity can be helpful to make a diagnosis. However, the consequent variability in functional disability can make adaptation to the illness very difficult for the patient, and can be confusing to those around the patient or who assess them.

Characteristic or common symptoms include:

- persistent/excessive tiredness or fatigue
- cognitive impairment
- post-exertional malaise
- pain
- sleep disturbance
- other symptoms related to neurological or endocrine function
- recurrent sore throat
- digestive disturbances
- intolerances

Onset and course

The onset of CFS/M.E. can be sudden or gradual. In cases of sudden onset, the condition commonly follows an acute infective episode. Patients with gradual onset disease often have an episodic course, or a stepwise decline. An insidious and gradually progressive course is uncommon. Antecedents or triggers are harder to identify in patients with less acute onset of disease.

Many patients report that they attempt at first to keep going with usual activities, or to return to work or education before being fully recovered, and then are repeatedly or progressively unable to sustain previous levels of activity. Others have had additional physical or psychological stressors around the time of the onset. Predisposing, triggering, and maintaining factors [are] conceptually helpful, but fraught with problems of interpretation and attribution at the level of the individual.

Timescale

In clinical practice, six months should be viewed as an endpoint for the diagnostic process, as patients will need help to manage the illness much before then. An approximate timing of the diagnostic pathway for adults might be:

Six weeks – A differential diagnosis is considered that includes acute fatigue syndrome.

Three months – A provisional diagnosis of CFS/M.E. might be made.

Six months – The provisional diagnosis should have been confirmed but the plan for managing its consequences will already have been put in place.

Clinical evaluation

The intended purpose of initial clinical assessment is: to increase the probability of a correct diagnosis of CFS/M.E.; to rule out other conditions; to confirm the diagnosis; to identify any clinical sub-grouping relevant to the patient; and to identify and characterise clinically significant consequences.

Full clinical history – At present, this is crucial diagnostic procedure for CFS/M.E.

Physical examination – Is essential and may be helpful in excluding other conditions.

Basic screening tests – These include full blood count, C-reactive protein (CRP) concentration, blood biochemistry, and urinalysis.

Mental health evaluation – Assessment for mental health problems at an early stage is important, so that any such problems can be either dealt with or excluded.

Sleep evaluation – Exclusion of primary sleep disorders, especially if drowsiness or day-time somnolence are prominent.

Specialised tests – These may be required to exclude differential diagnoses that are suggested by particular symptom patterns, or abnormal findings on physical examination or investigation (eg, blood markers of rheumatic diseases or antibodies to gliadin or endomysium to identify coeliac disease). Tests used in research, such as specialist neuroimaging, do not currently seem necessary as part of routine care.

Specialist referrals

A GP should be able to make a firm diagnosis of CFS/M.E. in most instances among adult patients. However, there is a proportion of cases in which referral to a specialist experienced in CFS/M.E. may be useful in confirming a diagnosis, or where complex issues or symptom patterns give rise to uncertainty.

AfME's response

Again and again patients have reported delay in diagnosis, often resulting in poor or no advice, leading to a worsening of their condition.

The report sets out a series of practical steps GPs can take to make a diagnosis, with a timeframe of six months within which time crucial management advice will have been given by the GP, and by when a provisional diagnosis will have been confirmed.

We see this as a major breakthrough and will, we hope, reduce the likelihood of many people becoming chronically and severely ill.

Symptoms

Patients with CFS/M.E. experience an individual array of symptoms from the overall range seen in the illness. Some, such as physical and/or cognitive fatigue are seen in almost all patients, though their extent can vary. Others are very common, such as pain, disturbed sleep, and gastrointestinal disturbance.

In addition to symptoms that occur in the majority, individual symptom complexes may vary according to the individual's medical history and activity pattern. In some individuals, recurrence of symptoms from the triggering event is part of the symptom profile (eg, recurrent sore throats and lymphadenopathy after glandular fever, or vertigo after labyrinthitis). In others, old symptoms or susceptibilities relapse or recur with development of CFS/M.E. (eg, pain from old injuries, headaches or migraines in predisposed individuals, mood disturbance in patients with previous anxiety or depression).

Symptoms can reflect the predominant activity, whether they are prompted by the activity or highlighted as a result of effects on the activity (eg, muscle pain in the physically active, concentration impairment in those who rely extensively on cognitive performance). Symptoms such as postural hypotension and dizziness can in part reflect the secondary effects of inactivity and/or isolation resulting from enforced inactivity.

Over and above these patterns, some patients seem to have a dominant locus of symptoms (eg, flu-like malaise,

neuromuscular symptoms, cognitive impairment, or gastrointestinal disturbance). In some patients, symptoms remain relatively constant in type, whereas others experience an evolution through different 'layers' of symptoms, in some cases with a recurrence of early symptoms during recovery. In some women, premenstrual or menstrual exacerbation of symptoms is reported by patients.

The profusion of symptoms in several body systems can be confusing and alarming for patients, who can find this hard to encompass in a single overarching explanation. Consequent fear over the possible significance of discrete symptoms can be very intrusive and distressing. This uncertainty is difficult for patients and those around them. As in other chronic conditions, a new symptom can raise new questions about the reliability of the diagnosis, or concern that a quite different pathology could be missed if the symptom is immediately attributed to CFS/M.E.

An individual's symptom profile is modified by the impact of illness on the person affected and those around them. Patients' experience can be one of frustration about the inability to function at previously normal levels, about continual setbacks and about the lack of understanding or disbelief from people around them. Anxiety or depression, anger and withdrawal from social interaction are relatively common consequences in response to the impact of any chronic illness on personal and social functioning. These understandable reactions add to distress, and in some cases become part of, or even dominate, the clinical picture in CFS/M.E. In vulnerable patients or at difficult times, suicidal ideation can occur and suicide becomes a serious risk.

Despite these difficulties, most patients establish a tolerable level of functioning, especially with appropriate support of family, friends, and professionals. The extent of constructive adaptation to their very changed circumstances and expectations is often remarkable.

Different models of treatment and management

A key difficulty is the divergence of views on general models of disease. The nature of such divergence can be illustrated by considering polar views: one view holds that a disease is caused by an external disorder that "strikes people down" and for which one can seek a cure or learn to live with the disease burden; an opposing view (the biopsychosocial model) holds that illness arises out of an interplay between a set of external and internal circumstances, which may include physical, psychological, and social factors that precipitate and/or modify the condition. Another classic divergence is the designation of disease as purely physical or psychological, although others adopt a more holistic view – ie, that physical, psychological, and other features are inter-related.

Divergence of views on the model of disease can influence clinical management of CFS/M.E., since the model of disease held can inform management sought and offered. In the example considered above on disease causation, the former view implies that management should be symptomatic only, while seeking a cure for the specific cause; moreover, any behavioural, psychological, or social aspects of the individual's disease may be viewed as maladaptive responses and necessarily treatable. The second view implies that management strategies should target any factors that seem modifiable in the individual and address triggers and modifiers as part of the disease process rather than as symptomatic therapy. The Working Group has attempted to synthesise aspects of these styles of management, since ideally all approaches are applicable irrespective of one's view of the disease.

The Working Group has not aimed to achieve consensus in all areas but rather to delineate explicitly agreement and difference of views where they exist. We agreed that we could:

- Identify approaches to management for which there is evidence of clinical effectiveness.
- Identify approaches that are considered 'common sense' clinically or are reportedly beneficial to patients, for which there is limited scientific evidence.
- Develop as annexes resource tools to guide diagnosis and clinical management.

AfME's response

In discussing illness models the report openly refers to the controversy within the field. Such models are hypotheses often based more on opinion than evidence and have fed rather than resolved the controversy.

Indeed the discussion of models involves crude caricatures. For example a patient who follows an exclusively physical model is caricatured as wanting only symptomatic treatment while waiting for a cure to come along.

However belief in a physical model does not prevent people actively seeking improvement by pacing or other more formal rehabilitation programmes. Nor should such beliefs preclude the acceptance that CBT might help someone manage better the impact of having a chronic and debilitating illness.

We object to the reference to models within the report's comments on services, believing that this is inconsistent with the report's balanced approach to such issues.

We prefer to remain agnostic about models until evidence is found that will explain the baffling and devastating condition that is CFS/M.E.

We will, however, challenge any practitioners who, in discussing models, appear to diminish the illness or provide the means for people to exercise their prejudices.

Overview of treatment and management

No management approach to CFS/M.E. has been found universally beneficial and none can be considered a 'cure'. However, general principles can be outlined to guide management. Most people with CFS/M.E. can expect some degree of improvement with time and treatment, so a positive attitude towards recovery needs always to be encouraged. Each individual is best managed according to a unique flexible management plan, in which specific strategies and therapies are tailored to his or her particular circumstances. All clinical interventions carry a potential risk of harm, especially if applied incorrectly; for CFS/M.E. in particular, imposed, rigid programmes can be actively harmful.

The aim for management will in most cases be rehabilitation or re-enablement, according to the patient's needs and circumstances. Re-enablement should encompass cognitive, emotional, and social aspects as well as physical aspects. Management strategies supervised by a therapist, including activity management, cognitive behavioural therapy (CBT) and so on, can be beneficial, provided that they are agreed and viewed as a partnership. Any rehabilitation or increase in activity should start from an agreed, and possibly very low, baseline and should be gradual. It seems important that all practitioners working with an individual are consistent in approach, and share professional perspectives, while utilising their distinct skills and experience.

Most patients can expect some improvement, especially with treatment. Although a return to previous levels of functioning in the short to medium term is often unrealistic, patients can be encouraged to set targets that involve steadily increasing both physical and mental activities once their condition has started to stabilise. Fluctuations in the condition are natural, potentially resulting in the need to recognise natural plateaux, setbacks or more substantial relapses. Such fluctuations should not be seen as reasons to abandon the management plan, but rather to reassess or perhaps slow down. The fact that not all patients will benefit means that any therapy needs to be carefully supervised.

A multi-disciplinary assessment is key to the provision of a supportive package of health care and social care provision. Although care packages need to be individually tailored, where appropriate they should include visits from primary care teams and assessment of the need for equipment and practical assistance.

Several charities and voluntary organisations offer information, training, education, and support as well as investment in research on CFS/M.E. Patients may need advice on how to access support from these and other agencies.

Responses to treatment and guiding principles

The Working Group agreed that there is no cure for CFS/M.E. but identified three specific strategies as potentially beneficial in modifying the illness: graded exercise, cognitive behavioural therapy, and pacing.

Members of the Working Group expressed widely differing opinions on the potential benefits and disadvantages of these approaches. However, we agreed that all could be considered as management options, in line with general principles outlined here, and adapted to the circumstances of each individual patient. 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/M.E. The Group also found it important for clinicians to use the pharmacological and non-pharmacological means available to relieve disabling symptoms. Patient experience suggests that some complementary therapies can also play a role in this respect.

Often, the most essential aspect of continuing care will be for clinicians to provide advice on appropriate ways of relieving symptoms, balancing rest and activity, and maximising potential. In primary care, this might involve advice on pacing, prescription medication, or basic lifestyle management counselling. A proportion of patients might benefit from more structured specialist approaches, such as graded exercise or cognitive behavioural therapy.

The success of any specific approach is dependent upon many factors, not least the way in which the approach is applied. In cases where an approach does not succeed or is found harmful, it is important to distinguish those where the approach is not appropriate for the individual from those where the approach is inappropriately or poorly applied. In addition, the Working Group note the following general principles that govern good practice:

- The decision to recommend a particular approach is best guided by the individual's illness and circumstances.
- The content and development of any such approach should be mutually agreed by both clinician and patient and informed by up-to-date specialist knowledge.
- Ideally, a decision to refer from primary care would be mutually agreed and guided by the degree of uncertainty surrounding the patient's illness or its management.
- Specialist therapies (e.g. graded exercise and cognitive behavioural therapy) are likely to be most effective when supervised and regularly monitored by therapists who have appropriate training and experience.
- All interventions need to be administered with thought and care and in accordance with revised Department of Health recommendations on informed consent.
- It is not appropriate that participation in a particular treatment regimen is made an absolute condition for continuation of sickness/disability payments.

The Working Group deemed it helpful to highlight specific therapies that had reasonable evidence of effectiveness. Given the prevailing uncertainty surrounding the condition and its therapies and the limitations of the existing range of research highlighted in the York review, we recognised that the evidence we sought needed to encompass both the precision of findings from rigorous randomised controlled trials and the breadth of clinical experience and patient reports. To do this, we used a trident approach to review and synthesise three lines of evidence: research findings, patient reports, and clinical opinion. We also considered resource implications, although cost-effectiveness is the least studied of all aspects of CFS/M.E. management.

Graded exercise

As a general principle, the Working Group agreed that both activity and rest can be harmful when overdone and yet be beneficial when carried out with the appropriate degree of balance. Graded exercise is a form of structured and supervised activity management that aims for gradual but progressive increases in aerobic activities such as walking or swimming. It is based on a principle – contested by some – that a principal factor maintaining the illness is inactivity, subsequent physical deconditioning, and its physiological consequences, which graded and supervised increases in exercise can help to reverse. In addition, it may act as a rehabilitative behavioural therapy by gradually exposing the patient to an

activity (exercise) that has been avoided. Gradual, supervised exposure within the individual's limits is thought also to help improve confidence in physical ability.

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 view that patients have a primary disease 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.

Research findings – The York review found promising results for graded exercise: all three randomised controlled trials so far found varying degrees of improvement in fatigue and disability with differing graded exercise regimens compared with no treatment and two control treatments. These trials all scored highly in the validity assessment, although, as with most clinical trials, the findings encompass only the range of patients able to meet the entry criteria. The York review found that people who were unable to attend outpatient clinics were excluded from these and other trials of treatment effectiveness.

In the trials, very few participants reported feeling worse with graded exercise, although the drop-out rate was just under a third in one of the trials – thought to be related to demands of the programme.

No randomised, controlled trials of graded exercise have been conducted in patients unable to attend outpatient clinics or in children. Several open studies suggest that graded exercise can be helpful to improve disability in more severely affected patients, so long as the treatment is carefully planned, regularly reviewed, and mutually agreed with the patient: however these studies lack the vigour needed to make/allow definitive comment on the role of this approach in severely affected patients as pointed out in the York review.

Patient reports – 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, particularly when such therapy is applied inflexibly or without mutual agreement with the patient. The non random survey of people who were severely affected found that out of 1214 who had tried graded exercise, 417 believed it was 'helpful', 187 reported 'no change', and 610 believed it had made their condition 'worse'. Similar adverse comments were also reported in patient group survey results from less severely affected patients, and no other treatment – pharmacological or non-pharmacological - received such negative feedback in patient surveys.

Clinical opinion – As with pacing, there is disagreement among clinicians about the value of graded exercise. Some clinicians consider graded exercise an effective therapy because of the evidence base, whereas others believe that CFS/M.E. involves a primary disease process that is not responsive to this type of approach, and that many of their patients are already functioning at or near to maximum levels of activity. However, the Working Group did agree that whenever graded exercise is being undertaken, activity levels should be initially based on current physical capacity. The programme should be mutually agreed between patient and therapist, it should be regularly adapted according to the clinical response and patients should be carefully monitored to ensure that exertion does not exceed target levels.

Resource implications – 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/M.E. patients. At present, very few therapists are available with such expertise.

Synthesis – The majority of the Working Group agreed that appropriately supervised, graded exercise therapy, applied by appropriately trained individuals, can benefit many, though not all, ambulant outpatients with CFS/M.E.

A successful outcome probably depends on the therapy being initially based on current physical capacity, mutually agreed between the therapist and patient, and adapted according to the clinical response. Appropriate education regarding the rationale and cautions of this therapy needs to be given to potential candidates for graded exercise. Patients who drop out of therapy need to be followed up swiftly to review the reasons and reassess their management plan.

The place of this therapy for more severely affected patients is currently uncertain, but a suitably modified (initially low intensity) exercise or activity programme may reverse the adverse consequences of pervasive inactivity, if this is perceived to be a key factor in the individual's illness.

Cognitive behavioural therapy

Cognitive behavioural therapy (CBT) is known to be helpful to some patients with physical and psychiatric illnesses to improve quality of life and day-to-day functioning. Re-enablement based on the cognitive behavioural model aims to empower patients to identify, understand, and modify their belief systems and behaviours, to maximise their own functioning and well-being with support and guidance from the therapist. It involves personal actions – i.e. 'what we do' and 'what we think' – that can affect physiological processes; for example, smoking, excessive alcohol intake, and stress can all contribute to illness. Application of a cognitive behavioural model to CFS/M.E. has been found successful in most patients in the trials.

It is important to note that a specific or shared belief system is not essential to apply the principles of cognitive behavioural therapy to CFS/M.E. However, the wider uncertainty surrounding the nature of CFS/M.E. does impact on perceptions and delivery of the therapy in individuals. Difficulties can also arise when therapist and patient share differing beliefs about the individual's illness, and the nature of CFS/M.E. Patients may have an understandable apprehension about increasing activity, so it is important that changes are mutually agreed and the patient is supported through the process.

The specific model and components of CBT vary between services, disciplines, and between therapists. The core components of a cognitive behavioural approach to CFS/M.E. would include energy/activity management, establishment of a sleep routine, goal setting, and psychological support. The general principles of this holistic approach can be administered by a range of therapists and nurses with experience of CFS/M.E., provided they have had appropriate training in the techniques.

Research findings – The York review found that CBT showed positive results in adults able to attend outpatient clinics. Three of the four randomised, controlled trials evaluating this therapy found a positive overall effect of the intervention, with the majority of those who had the therapy demonstrating varying degrees of improvement in both function and fatigue. These studies scored highly on validity assessment in the systematic review.

Few patients reported feeling worse after treatment in the trials, but few reported complete recovery. The best results seem to be obtained by therapists with knowledge of CFS/M.E. In one trial, global improvements were maintained after five years; however, there was no difference (between intervention and control groups) in fatigue, physical functioning, and other measures. Few adverse events were reported from the trials. Drop-out rates varied; one trial had drop-out rates in all three study groups (including the control group), with a 20% rate in the group of patients assigned CBT, who started therapy after randomisation. Other trials had low drop-out rates of around 10% in both study groups.

There have been no published randomised controlled trials of CBT for children or for the severely affected, although open studies suggest it may be helpful for the latter if applied appropriately.

Patient reports – These suggest wide variation in both the practice of and the individual response to CBT. Although there is general acceptance that the therapy can help some patients, some comments point to difficulties with inflexibility in the therapists' views or in the treatment plans. Some patients are reluctant to receive what they perceive to be a 'psychological treatment' for a 'physical' disorder. A persistent concern is that CBT is viewed by some clinicians as the sole proven treatment strategy. A further observation was that services are often unavailable locally or available only after a long wait.

In one patient-group survey, only 7% of respondents found the therapy 'helpful', compared with 26% who believed it made them 'worse'. The remaining 67% reported 'no change'. Harm was suggested by the report to occur if activity scheduling was too rigid, if the therapist displayed scepticism of the patient's views or experiences, or if they implied that their illness was 'all in the mind'. Patient reports indicate that patients find a holistic, practical, occupational therapy based service to be an acceptable approach. While mental health workers and therapists from other disciplines may also offer acceptable

services, it has been suggested that therapists accustomed to working solely with psychiatric populations may need additional training and experience to engage and work appropriately with patients suffering from CFS/M.E.

Clinical opinion – There was disagreement among clinicians as to the precise value and place of CBT, which partially reflected the varying models of the therapy and disease. However, there was agreement that when applied appropriately, with mutually agreed approaches and goals, it can undoubtedly benefit some patients. Some clinicians, using trial evidence and clinical experience, feel that it is beneficial to the majority of patients, whereas others feel it only benefits a minority. 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/M.E.

Resource implications – Outside specialist referral centres, it is currently difficult to find therapists with the necessary experience.

Synthesis – The Working Group accepts that appropriately administered CBT can improve functioning in many ambulatory patients with CFS/M.E. who attend adult outpatient clinics. Preferably, the therapist should have experience in CFS/M.E. or have some training in this field. Patients who might benefit can expect to receive a logical explanation of why CBT might help them, based on their specific history and general principles. Where such services are not available or the patient decides against a trial of therapy, patients might be managed by usual clinicians, using the principles of and informed by the practice of CBT with other approaches.

CBT for people with CFS/M.E. is currently unavailable or very difficult to obtain in much of the UK. Local expertise would be increased by the training of more cognitive behavioural therapists and by increased education on and experience of CFS/M.E. for existing therapists. The value of a trained therapist who has a good understanding of CFS/M.E. is that they are competent to raise concerns about the way the patient handles their illness, so the patient is empowered to manage their illness and its consequences more effectively. Good practice involves a flexible approach which encourages useful change, undertaken with mutual respect between therapist, the patient, and their family or carers.

Whether CBT is useful for children or adolescents is not known, although some clinicians believe that selected patients may benefit from a trial of the therapy by appropriately trained therapists. The place of the therapy for patients more or less severely affected than those who participated in research is currently uncertain.

Further research is needed to identify which CFS/M.E. patients derive most benefit from the therapy as well as trials that compare CBT to other rehabilitative approaches (pacing, graded exercise, etc), to delineate essential aspects of successful rehabilitation. Findings of such research would assist decisions on referral – e.g. on whether priority needs to be given to those patients who are experiencing obvious difficulties in coping with either the emotional, social, or activity management of their illness.

Pacing

'Pacing' is an energy management strategy in which patients are encouraged to achieve an appropriate balance between rest and activity. This usually involves living within physical and mental limitations imposed by the illness, and avoiding activities to a degree that exacerbates symptoms or interspersing activity with periods of rest. The aim is to prevent patients entering a vicious circle of overactivity and setbacks, while assisting them to set realistic goals for increasing activity when appropriate. Although the research evidence base for this therapy is very limited, many voluntary organisations and a proportion of clinicians consider that pacing has an important place to play in the management of CFS/M.E.

Pacing is based on the 'envelope' or 'glass ceiling' theories of CFS/M.E., which suggest that energy is finite and limited, and that the best way for a patient to manage their illness is to live within this envelope – i.e. not constantly breaking through the ceiling (some therapists advise never going beyond 70% of a patient's perceived energy limit). The underlying hypothesis is that if patients use their energy wisely, their limited energy will increase gradually. The therapy involves daily monitoring of energy and activity levels, reviewing the effects, and making appropriate adjustments. An individual approach is planned after a full assessment of previous healthy functioning and an

agreement of the baseline activity possible for the individual. Little evidence exists to indicate harmful effects, although clinical wisdom suggests that the strategy is not universally appropriate and some clinicians consider that pacing may perpetuate illness. The underlying principle might be viewed as being somewhat contradictory to the underlying principles of more active rehabilitative strategies.

Pacing accommodates various stages (acute, stabilisation/transition, and recovery) and degrees of severity (mild, moderate, severe) reported by patients with CFS/M.E. During an acute phase, appropriate rest then convalescence is advised. The first goal of subsequent stabilisation or transition phase(s) is to establish a baseline of sustainable activity, from which gradual stepwise increases in activity are encouraged. The individual is assisted to find an appropriate balance between various physical, mental, and emotional activities and to review and adapt their activity schedule if setbacks occur. For patients who enter a recovery phase, the principles of pacing can be applied to a return to work or education. For those who remain severely unwell and make no substantial progress, pacing therapy may also involve passive physiotherapy and other measures that can help prevent complications of prolonged immobility. The principles and practice of pacing are detailed in the 1994 Task Force report.'

Research findings – Research on pacing is sparse. One controlled trial found that six sessions of pacing therapy were no more helpful than 'guided support' in helping fatigue, depression, and symptom scores. This non-randomised study had several limitations and is unlikely to be representative.

Patient reports – Considerable support exists for pacing among patients and voluntary organisations, particularly for those who are more severely affected. A survey of more than 2000 members of a voluntary organisation who were or had been severely unwell showed that 89%, of group members found pacing 'helpful'. Similar findings are reported from surveys of less severely affected patients. Voluntary organisations believe that sufficient periods of rest are particularly beneficial in the early stages of the illness.

Clinical opinion – Disagreement exists among clinicians who treat patients with CFS/M.E. over the value of pacing. Many clinicians, including some in the Working Group, routinely recommend the approach while others are less convinced of its benefits, their experience suggesting that pacing may prolong a patient's illness. The Working Group noted that disagreement also exists over what is included in the term 'pacing'.

Resource implications – Advice to patients about pacing principles involves few additional resources. The basic principles are readily available in lay language from the voluntary sector.

Synthesis – Despite the lack of research on pacing, the Working Group recognises that this form of energy management is popular with patients, voluntary organisations, and some clinicians. The Working Group notes some general principles that may assist clinicians to help some patients manage their energy. The principles of, and tools used in, pacing, as well as those of the more active strategies, can be incorporated into a care plan for CFS/M.E. patients in both primary and secondary care.

Because of the shortage of good research evidence of the effectiveness of pacing, there is an urgent need for randomised controlled trials of pacing therapy, particularly in early illness (for example, in comparison with rehabilitation therapies such as CBT and/or graded exercise, and other forms of support such as counselling).

The use of counselling

Counselling describes both a skill used by clinicians in their daily work and a structured form of therapy. The principle is to create a supportive environment by the way in which the practitioner relates and responds to the patient, to provide them with the opportunity to explore, clarify, and make progress on personal issues with the goal of increasing resourcefulness towards improving well-being. Clinical wisdom suggests that some form of counselling on coping with a long-term illness is an important part of the ongoing approach to management of CFS/M.E. Clinicians and patients have sometimes been disappointed by the lack of guidance and the non-directiveness from some counselling styles.

Further research is warranted in the form of a larger, randomised, controlled trial to examine the possible benefits of counselling compared with other rehabilitative approaches in patients who have CFS/M.E.

Symptom control

Patients with CFS/M.E. characteristically have many symptoms. Although some of these may be tolerable with explanation and reassurance, some symptoms are intrusive and unpleasant. Moreover, some may act to cause a descending cycle, exacerbate the impact of the illness, and impede recovery and/or adaptation. Sleep, mood disturbance, and pain are notable in this regard, because they are common and have substantial impact, yet are often treatable. In some women, pre-menstrual or menstrual exacerbation of symptoms is reported as is use of hormone replacement in those patients with low levels of serum oestradiol. As part of the diagnostic process, each symptom should be carefully assessed and, where appropriate, further investigation should be undertaken to characterise the process and rule out other illness.

Clinicians can access their usual 'toolkit' of symptomatic measures where appropriate, adapted to patient need. Substantial efforts should be made to specifically elicit and manage difficulties with pain, sleep, and mood, not least because they are common and without treatment may compound each other. Management of more intrusive symptoms could involve advice on and support for adaptations in behaviour or diet, for example, or the use of medication(s) to treat or to prevent the symptom(s). In many cases, the clinician will consider approaches that are used when the same symptoms occur in other disease settings. The options, with their rationale, advantages, and possible side-effects, should be explained. This enables the patient and/or carers to decide whether or not they would like to try one or more such approaches and, if so, when. They will generally be quite clear about whether symptoms are sufficiently intrusive and/or frequent to justify symptom-control strategies. It is often worth suggesting that such interventions be used as a therapeutic trial for a defined period (unless severe intolerance occurs), during which the impact of the approach to the particular patient can be evaluated. Ultimately, discussions can be held on whether or not to continue.

Specific therapies can be chosen based on advice from relevant guidelines or reviews. In some cases, that advice will need to be adapted to CFS/M.E. and refined based on the individual patient's previous experience.

Since patients with CFS/M.E. are often relatively intolerant of medication, it is usually wise to start with lower doses and to make use of agents that are less likely to have adverse effects; where choices are available. If the initial approach does not succeed or is not tolerated, variations or alternatives can be attempted after discussion and agreement. If intolerance to medication is a major difficulty for the individual, other strategies are worth exploring with the assistance of specialist therapists, as appropriate.

[More detailed information for clinicians is given in Annexe 6]

Complementary approaches

In general, from individual comments and surveys by charities, patients find that alternative practitioners are more understanding and have a gentler approach to the illness than clinicians; they treat the person as an individual, and encourage self healing.

Practitioners most commonly consulted were chiropractors, nutritionists, especially allergy specialists, homeopathy practitioners, reflexologists, and herbalists. Patients reported that some of these approaches were helpful to alleviate some symptoms.

A proportion of patients feel alienated from clinical professionals by early responses to their symptoms, illness experience, and disability. Actual or perceived dismissiveness, incomprehension, or even disbelief are encountered, and have profoundly negative impacts. Such attitudes can also lead the patient to seek help from alternative and complementary therapists, without feeling that they can obtain advice about such therapies from orthodox clinicians. Thus, patients may come to rely excessively on unproven, unregulated approaches, rather than the regulated, evidence-based services that can and should be available through the NHS. Many complementary therapists are supportive, and they often provide time and personal attention, while some report achieving positive benefits with various approaches. However, there is concern that some therapists can instil confusing or misleading health beliefs, recommend unnecessary, unvalidated tests or potentially hazardous therapies, or encourage the patient to spend considerable sums of their limited resources.

Complementary approaches are popular with patients. The Sounding Board events and surveys undertaken by the voluntary organisations indicate that patients report benefit from several different therapies, partly owing to the perceived approach of the practitioners. However, the limited research evidence is acknowledged by voluntary organisations, and patients participating in the Sounding Board events expressed concerns about some complementary practitioners who make unrealistic claims of success, as do other orthodox clinicians. Charges for complementary approaches can also be prohibitive for patients who experience financial difficulties.

Clinicians may feel they lack the knowledge to advise patients on complementary therapies. Such therapies do impact – positively and negatively – on health and clinical care, so clinicians should be aware of their use by the individual. The patient can be advised to adopt a similar approach to complementary therapies to that they would adopt for symptom control.

AfME's response

Overview of treatment and management

The report makes some important points with which we agree:

- No management approach to CFS/M.E. has been found universally beneficial, and none can be considered a cure.
- However, general principles can be outlined to guide management.
- Most people with CFS/M.E. can expect some degree of improvement with time and treatment, so a positive attitude towards recovery needs always to be encouraged.
- Each individual is best managed according to a unique flexible management plan, in which specific strategies and therapies are tailored to their particular circumstances.
- All clinical interventions carry a potential risk of harm, especially if applied incorrectly; for CFS/M.E. in particular, imposed, rigid programmes can be actively harmful.

The report identifies a number of approaches that may help in the absence of a cure.

In considering our response we have drawn not only on individual reports from members but on two surveys, the results of which are shown below. These were of members of self-help groups (funded by AfME and the M.E. Association) and of those who are or who have been severely affected (funded and conducted by AfME).

Comparison of treatment approaches

Groups' research/severely affected survey

	sample	helped	made no difference	made worse
Pacing				
Groups	257	88%	9%	3%
Severely affected	2,180	89%	9%	1%
Graded exercise therapy				
Groups	209	39%	22%	39%
Severely affected	1,214	34%	15%	50%
Cognitive behavioural therapy				
Groups	113	55%	32%	13%
Severely affected	285	7%	67%	26%

Graded exercise

Graded exercise at its best is a sensitively applied programme, agreed between the doctor or therapist and the patient.

Successful programmes do not force people into exercises beyond their means, but establish a baseline – likely to be different for each person – and start gently. They also stop when patients need a break from the programme because they have reached a limit, and then continue after an agreed pause.

The best practitioners do not just focus on physical rehabilitation, but take a broader approach to activity. To identify programmes based on the best principles we would prefer that they be referred to as 'graded activity'.

Our surveys found wide variations in the responses to exercise programmes and the report acknowledges the controversy.

One reason that people have found it harmful is that some practitioners have not recognised the physical limitations of CFS/M.E. Although well-intentioned, they wrongly push their patients toward a recovery without listening to them and their reactions to the exercise, nor do they allow for pauses during the recovery process.

In our experience it is very rare for someone not to want to get better, and members report more problems from pushing themselves beyond their limits and then 'crashing', than from trying to do too little.

Therefore while we recognise that graded exercise can benefit some, it can cause harm, particularly if misapplied. We call on practitioners to adopt the best practice, listening to their patients and modifying activities to the capacity of the individual.

We therefore welcome the report's conclusion that:

'A successful outcome probably depends on the therapy being initially based on current physical capacity, mutually agreed between the therapist and patient, and adapted according to the clinical response. Appropriate education regarding the rationale and cautions of this therapy needs to be given to potential candidates for graded exercise. Patients who drop out of therapy need to be followed up swiftly to review the reasons and reassess their management plan'.

Cognitive behavioural therapy (CBT)

In considering the role of CBT it is critical to acknowledge that it does not pretend to be a cure, nor can its usefulness be used to claim that the illness was not physical in origin. It is widely used as a therapy in other conditions – including cancer.

The aim is to support rehabilitation rather than provide an instant cure (in the same way that plastering and resting a broken leg is not an instant cure).

Recovery from CFS/M.E. may be impeded by over-vigorous exercise, a too early attempt to resume normal activities, environmental factors, beliefs and fears about what is happening, demoralisation, frustration and depression.

CBT aims to address such thoughts and behaviours, helping people to recover. Contrary to some caricatures, practitioners are likely to start by advising patients to reduce their activities to a safe baseline and then work gradually toward recovery.

Our surveys suggest a wide variation in the response to CBT, suggesting that while it may benefit some (55% of those in the groups survey) it appears to be of little help to the severely affected (7% were helped/26% were made worse).

CBT should not be seen as a panacea, but we agree that many capable of attending adult out-patient clinics might be helped by CBT.

We would also agree that as in all aspects of this illness it should be 'undertaken with mutual respect between therapist, the patient, and their family or carers' and that there should be more trained therapists with experience in CFS/M.E.

Given the inadequate distribution and experience of therapists the recommendation that CBT be made widely available is unlikely to be achieved in the short term.

Pacing

This is a self management technique in which appropriate rest is balanced with improved knowledge of those activities that can be safely undertaken, including physical, emotional and mental activities.

The aim is to steadily improve, avoiding the damaging cycle of 'boom and bust' i.e. overdoing it and then crashing for long periods.

We reject the outdated caricature of pacing as limited in its objectives, and strongly recommend that people follow the principles of pacing with the aim of maximising their recovery from CFS/M.E.

Our surveys show that this is an approach found helpful by the overwhelming majority of those who have tried it. We welcome its inclusion within the report. We are dismayed that this approach has not been systematically studied by researchers. We offer to support any future studies.

Counselling

Given the inadequate provision of CFS/M.E. therapists, we support the provision and evaluation of counselling.

However we note criticisms that some counselling services may be over passive and we recommend the training of counsellors in CFS/M.E.

Symptom control

We welcome a proactive approach to the management of symptoms, particularly those such as pain and sleep disturbance, whilst recognising that some people are often relatively intolerant of medication, particularly in 'normal' doses.

We would now welcome more guidance to GPs on the specifics.

Complementary approaches

We welcome the recognition of the contribution and popularity of complementary approaches.

Some people may approach complementary practitioners because of 'actual or perceived dismissiveness, incomprehension, or even disbelief' of mainstream practitioners.

However, regardless of the reason why they were approached, our surveys consistently highlight the value of complementary therapies, particularly dietary and nutritional approaches, and we would welcome research in this area.

We are also concerned that some practitioners, through over-enthusiasm at best, encourage patients to use energy and money that they cannot afford in the search for a non-existent cure.

	sample	helped	made no difference	made worse
Groups' survey				
Alternative Medicine	215	39%	18%	8%
Other	90	39%	7%	10%
Severely affected survey				
Nutrition	1,953	61%	36%	3%
Other	878	76%	11%	14%

Section 4 Children and young people

Key messages

- CFS/M.E. represents a substantial problem in the young - 'children do get it', though many recover, even after prolonged illness.
- Important differences exist between children and adults in the nature and impact of the disease and its management.
- The condition potentially threatens physical, emotional, and intellectual development of children and young people, and can disrupt education and social and family life at a particularly vulnerable time of life.
- Clinicians face additional difficulties in supporting and managing the younger patients and their families and parents/carers.
- An especially prompt and authoritative diagnosis is needed in the young, while the possibility of other illnesses and complications must also remain in mind.
- Ideal management is patient-centred, community-based, multi-disciplinary, and co-ordinated, with regular follow-up. Community paediatric services need to be available for most children and all with prolonged school absence.
- The clinician who co-ordinates care needs to consider educational needs and impact on the family and parents/carers as early as practicable.
- Care is best delivered according to a specific, flexible, patient-focused treatment plan, designed and reviewed regularly with patient and family.
- Future services need to be developed around the needs of the child or young person and their family.

Nature and impact of CFS/M.E. in children and young people

Ill health imposes great demands on children and young people, so it is remarkable how many meet the challenges positively. Isolation from peer groups and loss of schooling cause a young person concern even if for short periods. When their condition is less well known, or when the young person meets disbelief or perceives professional hostility or criticism of his or her parents/carers, the impact of the illness is compounded. No more is known about CFS/M.E. in children and young people than in adults, but this should not prompt professional indifference – quite the opposite. The Working Group notes that the Royal Colleges have a continuing role to play in this respect. We would welcome 'bridge-building' initiatives between children and young people, their parents/carers, voluntary organisations, and paediatricians and child psychiatrists through their respective Royal Colleges.

Young people with CFS/M.E., especially of long duration, are vulnerable to negative effects on growth, including physical, emotional, and intellectual development, which may perpetuate impairment. The potential influence of any chronic disorder on education is of particular concern, as is the broader effect of the illness on parents/carers and family life. The relative lack of professional certainty over CFS/M.E. especially compounds difficulties for children with learning difficulties or those from minority groups, who also can be affected by CFS/M.E. In general, diagnostic criteria for CFS/M.E. are poorly defined in children, and the disease may present differently in those with coexisting disadvantage or disability.

Epidemiology

During the past decade, CFS/M.E. has become more commonly diagnosed among school-age children and even in children as young as five, although evidence suggests increased onset at secondary school age and around 14-15 years. Information on the disease burden in young people is scanty. CFS/M.E. clearly represents a substantial and widespread problem in the young. Few children in ethnic minority groups have been diagnosed with CFS/M.E., although more children seem to be accessing services.

Clinical profile

In general, CFS/M.E. that develops in a child or young person is recognizably the same clinical entity that develops in adults, with some differences. Children usually have a symptom pattern similar to adults, but they are particularly prone to abdominal pain, nausea, and variations in appetite, leading to weight gain or loss. Younger patients do not always experience the delayed onset of symptoms after increased physical or cognitive activity, but they generally do have a prolonged recovery period after activity. However, even in those with a mild form of the illness, physical activity is usually limited and loss of schooling occurs.

As with adults, symptoms wax and wane over time and in severity, and are affected by the individual's circumstances, previous healthy functioning, and responses to the illness. Aetiological and pathological considerations, including psychological factors, seem similar to those in adults, but children seem to be more vulnerable to the misconception that the disease is "all in the mind" or worse, that it does not exist. In addition, children do not always listen to caution from adults, teenagers may deny they have the illness, and very young children are often not able to understand the fluctuating nature of the condition. The expected duration of the illness in younger people is unknown because, as in adults, it is unique to the individual. However, most studies suggest that prognosis is better for children and young people than for adults, and many children recover even after long illnesses.

Severely affected children and young people

Some children and young people with CFS/M.E. are so severely affected by the disease that they become bed-bound, with a similar degree of cognitive and physical impairment to that experienced by patients with severe neurological conditions. Sensitivity to light, sound, and touch are characteristic symptoms in this group, together with visual deficits, hypotonia, and myoclonic jerks. Other aspects of the condition, such as nutrition, may also be severely affected. Care of such children and young people presents particular challenges. Diagnosis may be difficult and require particular care. In general, such patients would benefit from mobilisation of full community supportive services. Additional support and services may be required (e.g. tube feeding). Such support may need to continue for months or years.

Social impact

Within a family, any individual affected with CFS/M.E. has a profound impact on family life, particularly when that individual is a young person. The family unit experiences increased stress, stopping of normal activities, and in some instances the inability of other family members to accept the illness. The need for ongoing care means that parent(s) may have to give up work. In turn, the young person's progress towards increasing independence is impeded, children become more reliant on their parents/carers, and separation from them can cause distress. Many young people lose contact with friends and peers, which means that often the individual's only peer-group contact is with siblings. Other children in the family can feel left out as attention is focused on the ill child. CFS/M.E. can cause social isolation and an end to 'normal' family life. Clinicians and other professionals caring for the child can play a valuable part in minimising the impact of the disease on the family. Referral to the Disability Social Work Team should also be considered, to assess the need for support to the child and to help the family access disability related services.

Management

CFS/M.E. needs to be managed and services developed in keeping with general principles applicable to any chronic disease in the young: around the needs of and in partnership with the young person and their family. The uncertainties that surround CFS/M.E. are particularly difficult for children and young people, in whom an incorrect diagnosis presents an additional risk. Clinicians face additional difficulties in supporting and managing younger patients and their families, including issues over off-licence or off-label prescribing and obtaining consent to research or treatment in minors. Fortunately, children's health services are well placed to give optimum care for CFS/M.E. Many child patients and their families speak warmly of the support they have received.

Diagnosis

A diagnosis of CFS/M.E. in the young must be especially prompt, accurate, and authoritative, and second opinions are needed if doubt exists. As with other medical conditions that lack a diagnostic test, the diagnostic process for CFS/M.E. is the familiar one of assembling positive clues from the history and examination, while simultaneously ruling out other conditions, usually by laboratory and imaging investigations.

Other conditions that present with school absence are important differential diagnoses in the young, since they can mimic or complicate CFS/M.E. Such disorders need to be considered early and excluded or treated. The possibilities including physical illness such as hypothyroidism, musculoskeletal, neurological or cardiac disorders and mental and social conditions, particularly depression, but also eating disorders, refusal syndromes and rarely child abuse. Primary and secondary/psychiatric comorbidity will need recognition and management. Some children with chronic unexplained symptoms will not fit a unifying diagnosis but will still have medical and other needs to be met.

Almost all healthy children and young people are in full-time education. Given the potential impact of illness on education, the timescale for establishing a working diagnosis and management plan needs to be minimal, whatever the cause. When a child or young person has suffered excessive tiredness and/or other symptoms leading to fragmentary school attendance or absence for at least four weeks, active steps should be undertaken to identify the cause from a list of diagnoses that includes CFS/M.E. Excessive tiredness or 'fatigue' may not be a presenting problem in children with CFS/M.E. and might only emerge from careful history taking.

Approach to management

An ideal approach to management is patient-centred, and involves early recognition of CFS/M.E. by primary care services and confirmation by a specialist if appropriate. A treatment plan can then evolve depending on the degree of incapacity, with follow-up by the clinician(s) at an appropriate level for the incapacity, and according to local expertise and specialist interest. The plan needs to be developed with the patient and family, and revised according to feedback. Valuable clinical support can be offered to assist the family in keeping a diary, managing the child's limited energy, and developing a balanced approach to activity.

Desired outcomes and an approximate timetable for their achievement need to be agreed with all concerned. Setbacks or an inability to reach certain goals are not uncommon and all concerned need to be aware of this possibility, to avoid inadvertent criticism or censure. Ultimately, as recovery proceeds, an individually tailored reintegration programme for return to education and social functioning can be developed that is mutually agreed and non-coercive. Throughout, the child or young person needs to be listened to, understood, and allowed as much control as possible over their care. The principles of obtaining consent should be followed as set out by the Department of Health (see www.doh.gov.uk/consent) and due weight given to the child's assent or otherwise. The Gillick principles may need to be considered.

Few chronic medical conditions in childhood are managed by a single discipline and many require specialist follow-up. The hallmark of successful chronic disease management in children is integrated multi-disciplinary support, provided locally and usually co-ordinated by a paediatrician in partnership with family/carers and children. Involvement of a social worker early in the assessment process may be helpful to support families and professionals. Most children who are missing school can be cared for and managed in their homes, with follow-up in primary care or by a specialist such as a community paediatrician. Given the variability in professional expertise and education on CFS/M.E., the specialty of the co-ordinating clinician is not as important as the need for someone to adopt that role. If needed, hospital follow-up can be with a general paediatrician or other specialist mutually agreed by the child, their family, and GP. In general, a child who has prolonged school absence needs to be under the care of a specialist.

Other specialists, including child psychiatry when appropriate and professions allied to medicine are important in management. Affected children and young people will benefit from psychological support in some form. Joint work or referral to the CAMHS

may be helpful. Early referral to occupational therapy or physiotherapy services can be made if a specific need (e.g. for equipment) is identified early on. More expertise is required in school nursing and health visiting services for children and young people with CFS/M.E.

In general, local services are preferred, although non-local services might be accessed for respite care and in specialist/hospital care for second opinions and for complicated cases. Hospital admission is mainly reserved for difficult diagnostic assessment and for dealing with severe complications, serious intercurrent illness, or other specific problems. Whether convalescent in-patient services are needed for children and young people with CFS/M.E. is debatable. An acute ward is not the optimum environment for an adolescent with a long-term medical condition, but few other options now exist.

[The report goes on to outline the role of primary care, further care and follow up.]

Education

Nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning. A critical element of the child's management is assessment and provision of educational needs. An educational plan is not an optional extra but an integral part of therapy, just as play is for the younger child. A young person who is likely to have special needs, including home tuition, should be identified early in the diagnostic process, preferably by a GP or paediatrician. The coordinating clinician is then responsible for early referral to the Education Welfare Service to ensure that education is minimally disrupted. Adequate provision of continuing education needs close liaison between GP, community paediatric services, education services, the young person, and their family.

Some young people will be too severely affected by their illness to participate in any form of education, even at home. A resumption of education, in whatever form, should be managed in keeping with the general principles of activity management. Specifically, a young person with CFS/M.E. should never be forced to study but instead should be encouraged to set a pace that is likely to be sustainable, then have their progress regularly reviewed.

With support and reassurance, both schools and families can reach a position where the child is attending their school for short periods, is working in a separate area quietly if need be, can rest or work as their ability to concentrate fluctuates through the day, and can maintain some contact with their peers.

Gradually they can be reintegrated into the mainstream education system. The advantage of this approach is that it minimises the isolation of the child once he or she is able to get out of the house. It does require sensitive negotiation with the school and a tolerance on all sides.

Some more severely disabled children may need home tuition and/or distance learning on a longer-term basis. In addition to the time of a tutor or therapist, this may require information and communications technology, which can also help improve social contact.

Transition to adulthood

Children with CFS/M.E. grow up: the onset of adolescence and adulthood needs to be anticipated and the potentially retarding effects of a chronic medical condition such as CFS/M.E. on emotional, physical, sexual and social development should be minimised. This is a unique period of a person's life. Services for young people with CFS/M.E. should be tailored to their progress to adulthood: in particular arrangements for transition from paediatric secondary care to adult medical services need to be put in place well before it happens.

Child protection

On occasions, families of child sufferers with more severe CFS/M.E. have been the subject of child protection concerns. The Working Group notes that neither the fact of a child or young person having unexplained symptoms nor the exercising of selective choice about treatment or education for such a patient by the parents/carers and/or young person constitutes evidence of abuse. Nonetheless, children with CFS/M.E. may suffer harm, and this is part of the differential diagnosis. It is important to listen to the child, as well as to family members and parents/carers, to respect their experiences, and to give due weight to their views, especially the child's. The young person should be given the

opportunity to speak with the clinician, with or without their parents/carers.

In cases of CFS/M.E., evidence clearly suggestive of harm should be obtained before convening child protection procedures or initiating care proceedings in a family court – Social Services should be made aware that medical opinion in this area is divided, and consideration should be given to obtaining a further opinion from an expert medical practitioner with a specialist knowledge of CFS/M.E. [The Department of Health guidelines] *Working Together to Safeguard Children,* sets out the inter-agency arrangement to protect and safeguard children's welfare. This should be followed when there are concerns that a child may be, or is likely to, suffer significant harm.

Managing the impact on family/carers

All professional involvement with family and carers requires a clear awareness of the implications for parents/carers of uncertainty over their child's illness. Clinicians who are sympathetic and responsive to the increased parental anxiety engendered by diagnostic uncertainty and other specific fears are likely to minimise additional impact on the child. A background of disbelief and misattribution can pave the way for parents/carers experiencing a sense that their parenting is under scrutiny and liable to criticism, and for feelings of doubt, blame, or guilt. Clinicians need to take steps to empower parents/carers through communication over, and agreement on, the nature of their child's illness and the management plan that follows from this.

As with other chronic childhood illness, professional work needs to be founded on a clear awareness of the crucial role of parents/carers in undertaking the main care of the child, and aim to equip them adequately to support the child's progress. Several factors can affect parents' capacity to support and care for their child, all of which could influence progress and all of which may change during course of the illness.

Practitioners can support parents/carers by recognising the need to offer them opportunities to speak when the child is not present, though the child's consent and agreement should be obtained before this goes ahead. Parents/carers are likely to be concerned with protecting the child from a sense of being a burden, from the problematic implications of confused perceptions of the illness, and from the consequences of their own anxieties. It may be difficult for parents/carers to ask for help if it is not offered, since it is the child who is the patient. Risks for the main carer mirror those for the child (social isolation, work difficulties, loss of leisure, coping with the misperceptions of others, perceived blame, loss of confidence, depression, anxiety, etc).

Clinicians and other practitioners may be well-placed to equip parents/carers to improve the child's and their own situation.

Awareness of these issues needs to be matched by awareness of the importance to the child's care of parents' confidence in perceiving their own child's needs. It is important that parental confidence is actively protected, since it may be made vulnerable by both lay and professional responses to the illness. Careful listening and respect for parents'/carers' opinions are important factors. Although a family environment will inevitably impact on the course of any chronic childhood illness, the lack of blame needs to be specifically stated, and this is the key message that can open doors to achieving necessary support for the child and family.

AfME's response

We welcome recognition of the impact of the illness on the young and the importance of prompt diagnosis and a multi-disciplinary approach to care.

'Listening to the young person and their family, hearing, and understanding what they say is vital'. We could not have said it better.

We also welcome the report's recognition of the impact on young people's physical, emotional, and intellectual development, together with negative effects on their education, social and family life.

The actions of some well-intentioned, but ill-informed professionals have caused harm. We therefore particularly welcome the statement that:

'In cases of CFS/M.E., evidence clearly suggestive of harm should be obtained before convening child protection procedures or initiating care proceedings in a family court. Social Services should be made aware that medical opinion in this area is divided, and consideration should be given to obtaining a further opinion from

an expert medical practitioner with a specialist knowledge of CFS/M.E.'

Services

A multi-disciplinary assessment is key to the provision of a supportive package of health care and social care provision. Although care packages need to be individually tailored, where appropriate they should include visits from primary care teams and assessment and provision of equipment and practical assistance.

Specialist referral would usually be to a local consultant with an interest and expertise in CFS/M.E. Patients may also need to see other specialists if consideration of differential diagnoses requires assessment. Sufficient tertiary specialists in CFS/M.E. are needed to support primary and secondary care for the most difficult clinical problems, and to act as a resource for teaching, training, and research. Currently, there are too few identified and resourced specialists at secondary and tertiary level in much of the country, and the few that exist are overburdened; they are also inappropriate for care of the most severely affected, who cannot travel, or even less severely affected patients, for whom travel over long distances is liable to cause setbacks.

Children should usually be at least known to community paediatric services, and many should be referred to a paediatrician because of the impact of the illness on their education and their social relationships.

Education and support, plus measures to tackle the broader impact of the disease, should be initiated as early as practicable in management. This will often include assistance on how to contact other services, including in the voluntary sector.

[The report goes on to highlight in detail the need for equipment and support from social services]

While patients have access to the normal range of primary, secondary, and tertiary care services, few are specifically tailored and staffed with appropriate expertise to meet the specific needs of this patient group. Specialist services for children and young people, including in-patient facilities, are limited to a few nationwide. The Working Group confirmed deficits reported by patients and support organisations by inquiries to Regional Offices. A substantial number of patients are referred from primary care for a consultant opinion to one or more of several system-based specialists (general physicians, immunologists, neurologists, haematologists, and psychiatrists). Referrals also occur to tertiary centres for assessment and management.

Where the limited number of services have developed, this has been due to either the enthusiasm of clinicians who have been instrumental in "championing" the development of NHS services or the involvement of the charitable/voluntary sector.

The lack of locally based services is a problem to both patients who need a service and to commissioners of health services who wish to reduce the cost of out-of-area treatments.

Service Need

On the basis of a reasonable estimate of adult population prevalence of 0.4%, a general practice with a population of 10,000 patients is likely to have 30 – 40 patients with CFS/M.E., about half of whom may need input from services. The proportion of the latter patients who are severely affected by the disease is thought to be up to 25%. This group, who may be house-bound or bed-bound, have a considerable level of need yet they face considerable barriers to accessing services.

The burden of illness and service needs arising for children and young people are less clear. Much of the burden of care may rest on existing child health services, although there is a need for greater education on CFS/M.E. and services specifically designed around the needs of the young people.

AfME's response

It is no surprise to us that the report found major gaps in services for people with CFS/M.E.

We now call on government to urgently fund and provide the services identified as necessary, in primary care, secondary and tertiary care.

We also call on government to urgently redress the isolation and invisibility experienced by those most severely affected.

Action for M.E.'s policy response to the Chief Medical Officer's Report on the Treatment and Management of CFS/M.E.

We welcome the report, and its recognition of the impact of CFS/M.E.

Although there is still no definitive cause (or causes) the report recognises that it is a real illness with a substantial impact on individuals and society.

It highlights the challenge to the professions and we welcome the statement that 'existing controversy cannot and should not be used as an excuse for inaction or unsuitable practice'.

Publication of the report represents potentially the most significant event to date in the field.

In particular we welcome the findings on:

- **diagnosis**
- **research needs**
- **service needs**
- **remedying the neglect of the severely affected**
- **children's services**
- **child protection**
- **practical issues such as the operation of the benefits system**
- **the practical approach to treatment in the absence of a cure**

We give an unqualified welcome to the report's wide ranging recommendations and call on government to take action to implement them in full, with the necessary funding.

We are also pleased to place on record our thanks to the Chief Medical Officer, the officers, secretariat and members of the Working Group that produced the report.

The field has in the past been blighted by controversy, yet during the preparation of the report much common ground was established among those with differing opinions on the illness and its treatment and management. We look forward to further progress in reconciling differing perspectives.

We are grateful for the frequent references to the positive contribution of the voluntary sector and will continue to work with all those in the field to the benefit of those with CFS/M.E.

While we note that there is agreement about the limitations of the evidence base, it is encouraging that the report has drawn extensively on patient evidence as well as clinician experience.

AfME's Chief Executive Chris Clark explains to Brian Dow, Press and Campaigns Manager, what happened behind the scenes and the implications for the future

How did the Chief Medical Officer's report first come into being?

In July 1998, the out-going Chief Medical Officer, Sir Kenneth Calman, made an important statement:

'I recognise that M.E. is a real entity. It is distressing and debilitating. It affects large numbers of people and poses a significant challenge to the medical profession'.

He then set about commissioning a Working Group to report on the most effective methods of treatment and management for CFS/M.E. The in-coming Chief Medical Officer, Professor Liam Donaldson, decided that he would go ahead with the report and so the Working Group was formed.

So there were many different individuals involved – and we must also thank the Linbury Trust, which had a pivotal role in providing funding for the report.

What was the aim in getting involved?

Put simply, it was an unmissable opportunity to improve the lives of people with M.E.

How did our involvement work out in practical terms?

It has been hugely time consuming for all of us: listening, talking, explaining (both inside and outside the meetings) and gathering and submitting evidence such as the *Severely Neglected Report*, which produced information of a quality not previously seen and was the largest study of people with M.E. To make sure that the views we were feeding in were an accurate reflection of our members and the wider M.E. community we also commissioned an independent survey, of members of groups. We also took a leadership role at an event at the Department of Health which was a methodical collection of the views of patients.

Many of us at AfME have also met a large numbers of groups or their representatives and on almost every occasion have checked out with them whether our views on the issues were on the right tracks. And of course we are a charity led by people with M.E. so there has been constant dialogue about where we stood collectively and individually on all the major issues.

The remit was to 'evaluate the most effective forms of treatment and management'. Did that go far enough?

Not in the sense that we would all have wanted to find answers to issues such as causation and cure. However, it was not part of our work and we would have been doomed to failure because the research is not there yet so it was a reasonable first step target.

Some people think the CFS/M.E. title that was used in the report was a fudge.

Although we regard M.E. as important, clearly no title is perfect and there is little chance of agreement. I sympathise with one of the groups who said to me 'for goodness sake stop arguing about the name – give it a number and let's get on with getting the care we need'.

Is there no concern though, that you were too wide-ranging and could not focus on sub-groups?

No, the report is relevant to all our members, whether recovering or severely affected. Although AfME still thinks there are sub-groups, the research review found there was insufficient research on this, though the report is helpful in stressing throughout the need to care for people as individuals.

How was AfME's role in the report perceived by others?

In my opinion many clinicians in the field had viewed the patient voice as being extreme and unhelpful. That is no longer true and I hope we are seen as an organisation that puts forward its views constructively but assertively.

Being involved in the report brought AfME into close contact with individuals who had been regarded by some as our 'opponents' – what was this like?

I have to say that it was strange, coming into this field, to hear people described as 'opponents' and one of the things that has

worried me all along has been the polarisation of opinions, with people arguing at the extremes. I suppose it's inevitable in a field where there are few certainties, that opinions are voiced as passionate beliefs.

There are still differences of opinion, which include some important issues. But, crucially, there is now a huge amount of centre ground and we are talking with each other.

Did everyone sign up to the report?

There were a number of individuals who thought the Group would fall apart early on. In fact everyone made telling contributions up to the report being given to the CMO. Although some (including psychiatrists) did subsequently resign, the overwhelming majority of members did sign up.

Was the Working Group dominated by psychiatrists?

No, far from it. In fact the Group not only had doctors from other disciplines (including medical representatives from the charities themselves) but there was a large number of patient representatives on the group.

So what would you say to those who have complained about not being involved?

This has been the most inclusive process that I have come across in 30 years in health. That said, it doesn't mean that, were we to be writing the report on our own, it would look exactly the same!

How has AfME been changed by its involvement in the report?

In some ways very little – we remain dedicated to campaigning and our values and are still arguing for these. The way that we have changed is how we express our views, listening but remaining assertive. There are issues on which we could never give ground, but there are issues on which we have been prepared to listen and change where it is right to do so.

What do you think is the single most important thing to emerge from the report?

At last, Government recognises the extent and scale of the problem! Until you appreciate what you are dealing with, you can't tackle it properly.

In terms of the direct effect on our members and the wider M.E. community, the key findings are the need for early diagnosis, proper services, meeting the needs of the severely affected, the socially excluded and the young and research, research and research!

We don't want, and never have wanted, more than our fair share of services – what we want is equality, and the report will help.

How will this report actually change what goes on in the average GP's surgery?

It's going to take time for the practical aspects to filter through the NHS but somebody turning up in their GP's surgery would expect in the future to receive prompt diagnosis of M.E. and early advice. We'd now expect them to hear about the voluntary organisations and the experience and information they can offer.

We'd expect people to be received by clinicians with better understanding and more sympathy, and that a therapeutic relationship between clinician and patient is established so that the patient has more information and control of the options presented to them.

We'd also expect them not to have to fight their way for a referral to an NHS centre if they need ongoing support. We'd expect there to be NHS centres for ongoing support. And for those who are unable to access such services, we'd expect there to be outreach and domiciliary care that actually meets their needs.

Will people be forced into rehabilitation approaches such as graded exercise?

Absolutely not. The report is not only clear about potential benefits and limitations, but also the need for informed consent. The report is also clear that the receipt of benefits and insurance should not be conditional on participation. Furthermore we are delighted that pacing is now recognised as an alternative approach.

How long will it take before the picture really begins to improve?

It's going to vary in different parts of the country. There is a clear call within the report for urgent action in the areas where change is needed, so there is no reason why the situation should not begin to improve soon. Having said that, a sense of realism is important – it takes time and effort to train therapists and recruit specialists, and it's likely that some areas will act faster than others. There is a continuing role for us and local groups in making sure that now the Government has said what is needed, it is delivered.

This might be best described as the end of the beginning.

But surely the prejudice towards M.E. patients that has been experienced in some quarters won't be changed overnight?

I wish I could believe that every single sceptical doctor, nurse, therapist and member of the public will suddenly have their minds changed, but that's not going to be the case. What should and will happen though is that the day after publication, if a doctor uses the immortal words 'I don't believe in M.E.' the patient has the power to say 'I'm very sorry but the Chief Medical Officer says that it does exist and here's the evidence'.

Can GPs choose to ignore the findings of this report?

No, GPs certainly cannot ignore it. There is now guidance where previously there was not, and if a health professional is not complying with guidance issued by the Chief Medical Officer then he or she would need a pretty good reason for doing so.

There are also radical changes going on within the NHS around issues of clinical governance. The expectations of doctors in the 21st century are different.

But we are not an anti-doctor charity and there are a great many doctors whose care of patients is excellent – we hear this from members themselves. Let's also recognise that this is a mystifying illness and doctors need training and information.

What are the issues it has not solved?

It hasn't identified the cause of M.E. nor has it identified a magic pill.

By itself the report can't create a service in every part of the country; that challenge now passes on to local health services.

Take another key issue that affects people's lives – benefits. The report wasn't established to advise on the operation of the benefits system. Nevertheless the Working Group, because of the impact of the benefits system on people's health, made a separate report to the Chief Medical Officer who sent it on to the Chief Medical Adviser to the Department of Social Security.

This was a powerful piece of work and although we are disappointed that it has remained confidential, we'd still like members to know that action has been taken.

Will it change the public's perception of the illness?

Not by itself, but it is a very important part of the process. When we are dealing with journalists in the future we will be able to point to the Chief Medical Officer's report and what it says about the illness. This is no longer the case of a charity self pleading – we now have official recognition at the highest level.

What will Action for M.E. do now?

First we have to make sure that people hear its key messages. This is a massive exercise for us, but it would be a disaster if the report simply gathered dust on the shelves.

We will also update all our information and use it to influence what happens next.

Then we have to help inform and shape how the report is implemented. We will need to work nationally and with local groups to make sure that new services are created, that training is provided and research is properly informed by the needs and experiences of patients.

And we will need to find out if anyone is lagging behind, and if so, make a noise! Alongside this we have to help ensure that the report is not just about England, but proves informative throughout the UK. All in all, we are going to be very busy!

See overleaf for what you can do to help.

What you can do now

Now that the report has finally been published, Action for M.E. will be working hard to achieve the changes for which we have been waiting so long – more research, improved treatments and better services. However, we need your help too.

There are many ways in which you can help us bring about change. As more of us get involved, then the stronger our voice in pressing for the services that are needed. If you are unable to help, then please do ask your friends and family to support us.

- put up one of Action for M.E's posters in your GP's surgery or your hospital clinic. You can also ask them if they have seen the CMO's report. If not, give them a copy of this report so they are aware of the implications for their patients
- send your local MP a copy of this report. You can also ask if your MP is a member of the All Party Parliamentary Group on M.E. and if not ask them to join
- contact us to ask for information on how you and your local M.E. group can campaign for a locally-based M.E. service. We are developing a campaign pack to help you with ideas
- organise a fun event to raise funds for our essential campaigns and services – and raise awareness of M.E. at the same time. Or keep it simple and join one of Action for M.E.'s own events
- make a donation to help run our expanded information and self-help services, and to help our campaigns reach more people and make a real difference
- encourage your friends and family to support Action for M.E. – as members, donors or by helping your local group

Just fill in the form on this page and return it to us at the FREEPOST address below

I want to help bring about change

Please send me:

insert numbers

- ☐ posters .....
- ☐ copies of this report .....
- ☐ Guidance on the management of CFS/M.E. for GPs
- ☐ information about how I can help fundraise for Action for M.E.
- ☐ information about joining or setting up a local group
- ☐ I would like to make a donation to help Action for M.E. bring about change.

I enclose my cheque or postal order for £..... made payable to *Action for M.E.*

or

please deduct £..... (minimum £10) from my Visa/Mastercard/ Switch/CAF card

Card number

Expiry date Issue number (if applicable)

or Valid from date

Signature Today's date

Name

Address

Postcode

Membership number

☐ I would like to help reduce Action for M.E.'s administrative costs. Please do not send me a receipt for my donation on this occasion.

Using Gift Aid means that for every pound you give, we get an extra 28 pence from the Inland Revenue, helping your subscription go further. Please help us by ticking the appropriate box below. (To qualify for Gift Aid, the amount you pay in income tax or capital gains tax must at least equal the amount we will claim in the tax year.)

giftaid it

☐ I am a UK taxpayer and I want Action for M.E. to treat all donations I've made since 6 April 2000, and all donations I make from the date of this declaration as Gift Aid donations, until I notify you otherwise.

☐ I am not a UK taxpayer and currently unable to participate in the Gift Aid scheme.

Thank you

Please send this form to: Action for M.E., FREEPOST (SN1610), Wells, Somerset BA5 1YE.

☐ We would like to keep you in touch with the activities of Action for M.E. and Action for M.E. Trading Ltd. If you would prefer not to receive this information, please tick this box.