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Chronic Fatigue Syndrome/ME

This paper discusses the controversy surrounding Chronic Fatigue Syndrome/ME. The history of the condition, suggested causes and research are considered. Conflicting views on cause and treatment have resulted in uncertainty for patients. A Department of Health working group has been set up to promote a better understanding of the illness, and to advise on aspects of clinical management.

Alex Sleator

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Summary of main points

This paper discusses the controversy surrounding chronic fatigue syndrome/ME. This is a clinically diagnosed condition with a variety of symptoms, prominently chronic disabling fatigue which is made worse by physical or mental exertion. Other symptoms include impairment of short term memory and concentration, sleep disturbance, muscle and joint pain and a profound malaise.

The illness has a long history, but in spite of this the cause and pathology of the syndrome remain undetermined, generating much debate in scientific literature. There may, in fact, be a variety of different causes for the syndrome which involve a complex interplay of factors.

Researchers are currently examining a range of factors which may play a part in triggering the illness or perpetuating symptoms. These include virus infection, immunological disturbances, changes in muscle energy production, and brain dysfunction (changes in hormones, chemical transmitters and blood flow). Psychological and social factors that may play a part in predisposition to and maintenance of ill health and disability in some cases are also being considered.

Uncertainty about the cause of the condition and effective treatment leads to frustration amongst adult and child patients who may suffer debilitating ill health over a number of years. Patient groups are dismayed by misunderstandings and prejudice which they believe surround the illness and have engendered a climate of disbelief which adds to the distress experienced by the sufferer. Difficulties may arise in obtaining appropriate schooling and disability benefits.

However, there is now a consensus of opinion that CFS/ME is a definite clinical condition.

Several reports issued since 1994 have raised the profile of the issue and have informed the debate. Differing emphasis on the physiological and psychological aspects of the condition have given rise to controversy. The 1996 report of the Royal Colleges¹ laid considerable emphasis on psychological factors which may influence the illness and this gave rise to strong criticisms from some commentators.

The Department of Health has set up a working group on CFS/ME which will aim to promote a better understanding of the illness, to produce advice and information on aspects of clinical management, and to set out the evidence on which this information is based.

¹ Chronic fatigue syndrome. Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners October 1996/CR54, Revised 1997

CONTENTS

I	Introduction and Terminology	9
II	History of the Condition	10
III	Nature of the illness	12
	A. Definition and criteria for diagnosis	12
	B. Numbers of cases	14
IV	Independent reports on CFS/ME	16
	A. National taskforce reports 1994 and 1998	16
	B. Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners 1996	18
	1. Causes	18
	2. Management	19
	3. Government response	20
	4. Criticisms of the Royal Colleges Report	20
V	Possible causes and research	22
	A. Viruses	22
	B. Other suggested precipitating factors	23
	C. Immune dysfunction	24
	D. Abnormalities of muscle structure and function	25
	E. Psychiatry and physiological brain dysfunction	25
	F. Psychological aspects of CFS	28
VI	Management of CFS/ME	29
	A. ME Association guidelines	29
	B. Exercise	30

C.	Cognitive behaviour therapy (CBT)	30
VII	Children with CFS/ME	32
A.	Education for children with ME²	33
VIII	Government response to CFS/ME issues	36
A.	Social and economic costs	36
B.	Benefits	37
1.	Range of benefits³	37
2.	Obtaining benefits	37
C.	Parliamentary interest	38
1.	Research funding	38
2.	Provision of services	40
3.	Working group	41
IX	Appendixes	42
A.	Membership of the National Task Force on CFS/PVS/ME (1994 Report)	42
B.	Membership of the National Task Force on CFS/ME (1998 Report)	43
C.	Membership of the joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners	44
D.	Membership of Department of Health CFS Working Group	46

² Christine Gillie, Social Policy Section, November 1998

³ Pat Strickland, Social Policy Section, November 1998

I Introduction and Terminology

The syndrome⁴ of chronic fatigue and disability, associated with a variety of different symptoms and often with a history of preceding infection, has attracted considerable controversy as to its nature, causing division in the medical profession and alienating many patients from their doctors. The controversy and uncertainty is reflected in the various terms which are used almost interchangeably for the condition.

Myalgic encephalomyelitis or ME is the name used more popularly. Some authorities dislike this term as it implies a specific brain pathology which is not found in these patients. Encephalomyelitis literally means inflammation of the brain. Myalgia refers to muscle pain. *Post viral fatigue syndrome (PVFS)* or *post infectious fatigue syndrome (PIFS)* are other terms used when ME-like symptoms have their onset after a viral infection. US patient groups favour the term *Chronic fatigue and immune dysfunction syndrome (CFIDS)*

Chronic fatigue syndrome (CFS), a descriptive term encompassing all the above as well as chronic fatigue syndromes in general has been increasingly used over recent years and is preferred in most medical circles because of its neutrality. It was endorsed by the 1996 report of the joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners which preferred *CFS* to its alternatives as being accurate and free from unproven aetiological⁵ claims.⁶

There are, however, detractors who dislike the term as implying psychiatric causation, and as leading to an underestimate of the severity of the condition. Patient groups consider that 'fatigue' can be an inadequate term for the utter exhaustion and malaise that they experience.

We find the name Chronic Fatigue Syndrome derogatory and trivialising of an illness where fatigue is only one of a multitude of symptoms...⁷

In using the term in the following pages, no such causation or underestimation of severity is implied, but rather the lack of knowledge of causation, and the term is used interchangeably with ME.

The ME Association retains the use of ME for historical reasons, while recognising that 'encephalomyelitis' is not technically correct. It accepts CFS as the official name, and therefore also uses ME/CFS,⁸ as well as PVFS.

⁴ A syndrome is a combination of signs and/or symptoms that form a distinct clinical picture indicative of a particular disorder.

⁵ Relating to assignment of a cause.

⁶ Chronic fatigue syndrome. Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners October 1996/CR54, Revised 1997, para 3.1

⁷ BRAME Blue Ribbon for the Awareness of ME meeting, 14 May 1998

⁸ *Perspectives Magazine* of the ME Association, Issue 63 1997 p7

II History of the Condition

ME/CFS is not a new illness. Reports of a chronic fatigue disorder in medical literature date back to 1750.⁹ In the 1860s, people were said to suffer from neurasthenia, and through Victorian times the condition was recognised and much discussed.

Over the past sixty years a number of outbreaks of illness characterised by extreme fatigue have been documented, some of which appeared to mimic atypical polio, and which appeared to be infective in origin, and contagious.¹⁰ Paralysis was an important feature of the outbreaks. Often these episodes occurred in closed communities, or affected hospital workers. A number of names have been given to these outbreaks, including epidemic neuromyesthenia (USA), Tapanui flu (New Zealand), and Royal Free Disease (UK).

This latter outbreak affected about 300 nursing and medical staff at the Royal Free Hospital in 1955. It appeared to be caused by an infective agent, although this was never isolated. When the outbreak was written up in the *Lancet* the term Benign Myalgic Encephalomyelitis was applied.

The 'benign' part of the name was soon dropped and the term Myalgic Encephalomyelitis was progressively widened to include cases without paralysis or clear signs of encephalomyelitis. It was also applied to cases where known viruses, eg Coxsackie B and Epstein Barr (EB) virus,¹¹ were detected, and where the condition was thought to be a complication of infection by those viruses. Over recent decades the term ME has been applied to sporadic cases with similar clinical features, although there has been debate about whether the epidemic and sporadic groups are related.¹²

The unifying belief behind the range of uses of the term ME was that the condition it denoted was primarily physical or organic, rather than a psychogenic disorder.¹³ This belief underlies the preference for this term by many affected individuals, in spite of adoption of the more neutral term Chronic Fatigue Syndrome in medical circles.

In 1970 the *British Medical Journal* published a paper by two psychiatrists, Dr CP McEvedy and Dr AW Beard¹⁴ which concluded that the Royal Free outbreak was largely due to hysteria. The effect on medical opinion was far reaching, and remnants of disbelief still prevail.

⁹ ME Association

¹⁰ The clinical syndrome variously called Benign Myalgic Encephalomyelitis, Iceland Disease and Epidemic Neuromyasthenia. ED Acheson *The American Journal of Medicine* April 1959 p569-595

¹¹ The virus responsible for glandular fever

¹² Epidemiology: A Critical Review PG Wallace *British Medical Bulletin* 1991 vol 47 No 4 p942-951

¹³ Report from National Task Force on Chronic Fatigue Syndrome (CFS) Post Viral Fatigue Syndrome (PVFS) Myalgic Encephalomyelitis (ME) September 1994 p15

¹⁴ McEvedy CP and Beard AW 'Royal Free Epidemic of 1955 - A Reconsideration' *British Medical Journal* 1971, 1, 7-11

In the mid-1980's the condition was disparagingly termed "yuppie flu" implying a social class connection, and many doctors regarded it as a purely psychological condition. It is now known to be widespread geographically and across social class. Over recent years, and following considerable pressure from patient groups to raise the profile of the condition, there has been increasing recognition of the scale of debilitating illness involved.

ME charities have produced extensive case studies with the aim of presenting the patients' perspective. CHROME¹⁵ issued a report in 1996 which presented case reports from 169 severely affected ME patients and with the aim of monitoring them over a period of ten years. The report discusses the patient's viewpoint:¹⁶

On the whole patients' views of their own experiences have been energetically opposed, with systematic monitoring of those chronically affected not being considered relevant. Indeed, the view has been put that chronicity is a result of bad management and the patients' belief that they are suffering from an illness which prevents them from returning to normal activity ...

¹⁵ CHROME Case History Research On ME. (registered charity)

¹⁶ The Story from below part 1 First year report on the disease characteristics of 169 patients with chronic ME. CHROME May 1996

III Nature of the illness

ME/CFS is a potentially severe and disabling illness which has a definite beginning, and is diagnosed by the clinical picture rather than by laboratory tests.

The key symptoms are a profound disabling fatigue, an ongoing 'flu-like' malaise and various neurological problems (clumsiness, problems with memory, concentration and balance and disturbances of temperature control which causes pallor and sweats). Other prominent symptoms include muscle and joint pain, non-refreshing sleep pattern, sore throats and enlarged glands. Patients with CFS may become exhausted after only light physical exertion, and must often function at a level of activity substantially below their capacity before the onset of their illness. Some patients suffer mood swings and many will develop a depressive component to their illness.

The course of the illness differs widely among patients. Some recover completely with time, while others seem to get progressively worse. Often, the illness follows a cyclical course, alternating between periods of illness and relatively good health. CFS can persist for years and many patients find that severity of symptoms varies from day to day, and must adjust their level of activity accordingly.

The onset frequently occurs between the ages of 20 and 40, and females slightly outnumber males. However, any age group can be affected, and the condition is increasingly recognised in children. Contrary to earlier beliefs, there is no association with social status, although some comment on a strong representation from teachers and health care professionals.¹⁷ It has been recognised that diagnosis of CFS among some groups may reflect differences in culture and factors such as access to medical care. In the US, for example, the national Centres for Disease Control and Prevention (CDC)¹⁸ are addressing the question of possible under-reporting in non-white populations.

A. Definition and criteria for diagnosis

Chronic Fatigue Syndrome could be used to categorise a wide heterogeneous group of patients whose predominant complaint is undiagnosed fatigue. Attention has therefore been focused on reaching a consensus for diagnostic guidelines. This is very important for research purposes so that studies of the epidemiology,¹⁹ cause and treatment can be measured against consistent parameters.

A working definition of the syndrome suggested by the 1996 Royal Colleges of Physicians, Psychiatrists and General Practitioners report is:

¹⁷ Myalgic Encephalomyelitis: Post-Viral Fatigue Syndrome *Guidelines for the Care of Patients*, 2nd Edition, p7 April 1995 Dr Charles Shepherd, Medical Advisor, ME Association

¹⁸ The facts about Chronic Fatigue Syndrome. Centres for Disease Control and Prevention, National Centre for Infectious Diseases, Atlanta March 1995. <http://www.dds.nl~meweb/cdcfacts.txt>

¹⁹ The study of the distribution and determinants of disease in human populations

A syndrome characterised by a minimum of six months of severe physical and mental fatigue and fatigability, made worse by minor exertion. Other symptoms such as muscle pain (myalgia), sleep disorder and mood disturbances are common. Other common causes of chronic fatigue must be considered before the diagnosis can be made.²⁰

Two sets of diagnostic criteria were endorsed by the 1996 Royal Colleges report:

- The 1994 CDC criteria, introduced by the Centre for Disease Control in Atlanta²¹
- The Oxford criteria, produced as the result of a consensus conference held in the UK in 1991²²

The report was unable to choose between these "until further research establishes their validity".

The independent National Task Force in their 1998 report on NHS Services for CFS/ME²³ prefers the 1994 criteria.

The following chart compares these definitions²⁴

Case definitions for chronic fatigue syndrome

	CDC-1994	UK
Principle symptoms	Severe disabling fatigue not relieved by rest	Severe disabling fatigue affecting physical and mental functioning
Minimum duration	6 months	6 months
Functional impairment	Substantial	Disabling
Cognitive or neuropsychiatric symptoms	May be present	Mental fatigue required
Other symptoms	Four required	Not specific
New onset [not a lifelong condition]	Required	Required
Medical exclusions	Exclude clinically important conditions	Exclude known physical causes of chronic fatigue
Psychiatric exclusions	Melancholic depression Substance abuse Bipolar disorders ²⁵ Psychosis Eating disorder	Psychosis Bipolar disorders Eating disorder Organic brain disease

²⁰ Chronic fatigue syndrome Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners October 1996/CR54 Revised 1997 Appendix 2: Glossary

²¹ Fukuda K, Straus S, Hickie I, et al. The chronic fatigue syndrome: a comprehensive approach to its definition and study *Ann Int Med* 1994;121:953-9

²² Sharpe M, Archard L, Banatvala J, et al. Chronic fatigue syndrome: guidelines for research. *J R Soc Med* 1991;84:118-21

²³ NHS Services for people with Chronic Fatigue Syndrome/Myalgic Encephalitis the National Task Force on CFS/ME 1998

²⁴ Based on Chronic fatigue syndrome Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners October 1996/CR54 Revised 1997 Appendix 3

Similarities in these definitions include the requirement for a substantial functional impairment in addition to the complaint of fatigue. The American criteria attach particular significance to certain somatic²⁶ symptoms such as sore throats, painful muscles and lymph nodes, four symptoms from a choice of eight being required. The British definition, in contrast, does not emphasise somatic symptoms, instead insisting on both physical and mental fatigability.

Post-infectious fatigue syndrome (PIFS)²⁷

The Oxford criteria recognise a subgroup - PIFS - which either follows an infection or is associated with a current infection (causation is still a matter for research). To meet the criteria for PIFS patients must both meet the criteria for CFS and demonstrate:

- Definite evidence of an infection at onset or presentation (this requires more than a patient's self-report)
- The syndrome present for a minimum of six months after onset of the infection.
- The infection has been corroborated by laboratory evidence

WHO classification

The World Health Organisation International Classification of Diseases (ICD-10), classifies the condition under *neurological disorders* at Reference 93.3,²⁸ and uses the terms post-viral fatigue syndrome and benign myalgic encephalomyelitis.

B. Numbers of cases

The difficulty in defining and diagnosing CFS leads inevitably to confusion in quantifying the numbers of cases involved, and there are no official statistics yet available. Figures are available from studies in general practice, but there has been no population study in the UK²⁹

Estimates of the numbers of cases of CFS/ME in the population vary according to the criteria used. The liberal 1994 Oxford criteria produced an estimate of 2.6% of primary care attendees, but this figure almost certainly includes many patients who were also either anxious or depressed.³⁰ Conversely, the 1988 "excessively restrictive" criteria (these criteria excluded psychiatric disorders) produced an estimate of 0.1%.³¹ The Royal Colleges Joint Working Group concluded that the prevalence of CFS/ME was between 1-

²⁵ Such as manic depressive illness

²⁶ Relating to the body rather than the mind

²⁷ Myalgic Encephalomyelitis: Post-Viral Fatigue Syndrome *Guidelines for the Care of Patients*, 2nd Edition, April 1995 Dr Charles Shepherd, Medical Advisor, ME Association

²⁸ ICD-10 Neurological disorders G93.3 (volume 1, section: Other disorders of the nervous system, pages 422-424),

²⁹ Epidemiology of CFS Simon Wessely *A Research Portfolio on Chronic Fatigue* p5 Ed Robin Fox for The Linbury Trust Pub. Royal Society of Medicine Press Ltd 1998

³⁰ Epidemiology of CFS Simon Wessely *A Research Portfolio on Chronic Fatigue* p5 Ed Robin Fox for The Linbury Trust Pub. Royal Society of Medicine Press Ltd 1998 p3-4

³¹ These criteria were replaced by the 1994 CDC criteria as they was considered too restrictive

2%, falling to 0.1-0.7% if psychological disorders are excluded.³² It seems that around 0.5% may be an acceptable estimate of patients who fulfil CFS criteria and nothing else.³³

Assuming primary care attendees reflect UK population at large, this suggests that the prevalence in the population may be from 60,000 (0.1%) to 400,000 (0.7%), or if we accept the estimate of 0.5%, a good figure to use may be 300,000; using a rate of 2.6% gives an upper (probably excessively high) estimate of 1.5million cases.

Charities give a variety of estimates broadly in agreement. The ME/CFS Charities Alliance gives figures of 150,000 cases, while the Persistent Virus Research Foundation suggests 100,000.³⁴ A meeting of the patient group BRAME was given an estimated prevalence of 300,000 sufferers in the UK.³⁵

³² Chronic fatigue syndrome Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners October 1996/CR54, revised 1997 para 13.3

³³ *ibid* Appendix 4 para 5

³⁴ *The Lancet* 1996; vol 348 12 October 1996 p971

³⁵ BRAME Blue Ribbon for the Awareness of ME meeting 14 May 1998

IV Independent reports on CFS/ME

Three independent reports on CFS/ME have been released in the UK since 1994. Two of these were prepared by the National Taskforce on ME/CFS, and a third by a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners.

A. National taskforce reports 1994³⁶ and 1998³⁷

In 1992 ME organisations (ME Association, Action for ME and Westcare³⁸) asked the Department of Health to issue guidelines on the diagnosis and management of ME. In response the Department suggested that a Task Force should be set up. An independent group termed the 'National Task Force on CFS/PVFS/ME' was subsequently established, largely through an initiative of Westcare, supported financially by the Department of Health and with assistance from the Wellcome Trust. The Task Force, under the Chairmanship of Sir David Tyrrell, undertook a review of literature on the subject and drew upon the research and experience of its members. The objectives of the report issued in 1994³⁹ were:

- To provide background information about the conditions, assembling much of what is known and agreed about them
- In doing so to demonstrate that there is now a broadly agreed basis for positive action
- To make suggestions for the way forward
- To provide a focus for future action

The report⁴⁰ recognised the reality of the syndromes which cover a spectrum of disease, and which causes substantial disability and suffering. It acknowledged the costs of significant health problems both to society and to affected individuals, and the widespread uncertainty about chronic fatigue syndromes.

The importance of nomenclature was addressed. The important point was made that without a standard and consistent form of reference, research will sample different populations.

The Task Force recommended that the following issues should be addressed in future work:

- Clarify the differences between the various chronic fatigue syndromes
- Educate professionals and the public to accept the existence of these diseases
- Train relevant professionals to identify and manage them
- Take active steps to improve services to these patients
- Actively encourage research

³⁶ Membership of taskforce in Appendix A

³⁷ Membership of taskforce in Appendix B

³⁸ A registered charity

³⁹ Report from National Task Force on Chronic Fatigue Syndrome (CFS) Post Viral Fatigue Syndrome (PVFS) Myalgic Encephalomyelitis (ME) September 1994

⁴⁰ *ibid* p17

NHS services

The subsequent Royal Colleges report (see below) also found that there is a significant "unmet need" for care of CFS patients, and recommended that Health Authority/Health Board/Healthcare Trust should identify and support necessary changes in health services and provide appropriate guidance to commissioners and providers.

The most recent independent report in the UK was released in September 1998 by the National Taskforce on *NHS Services*. The aim of the report is ⁴¹

to offer guidance and recommendations on the type and extent of services for people with CFS/ME.

The report comments on an inadequate service provided to some CFS/ME patients, with only ten specialist units in the UK, with long waiting lists and huge regional disparities. The report presents relevant information to inform commissioners about the condition, together with information about current services and existing evidence of their benefit. The conclusions reached by the report in brief are:⁴²

- It is no longer defensible to neglect patients with CFS/ME on the grounds that CFS/ME is not a real illness or that nothing can be done.
- The huge disparity of services for CFS/ME compared to other established conditions is not consistent with declared Government objectives of equity of treatment.
- The current neglect and mismanagement of patients with CFS/ME is costly and wasteful.
- Provision of care for people with CFS/ME is a service obligation which can no longer be ignored.

The report calls for patients to have access to specialist services and suggests an initial minimum specialist service to cater for 0.1% of the population (500 cases in a district of 500,000). It states:

This represents an incontrovertible minimum of people who urgently need a service and who are not being properly catered for by any other existing service.⁴³

⁴¹ NHS Services for people with Chronic Fatigue Syndrome/Myalgic Encephalitis. The National Task Force on CFS/ME 1998

⁴² *ibid* Conclusions p 48

⁴³ *ibid* p6

B. Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners 1996⁴⁴

Following the 1994 report of the National Task Force the Chief Medical Officer of the Department of Health requested a report from the Academy of Medical Royal Colleges to advise on matters such as diagnosis, clinical practice, aetiology (causes), and service provision for this condition. A report was issued in 1996 by the joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners. The report built on the work of the Task Force, whilst stating that the Committee were not in agreement with all its findings. It was revised in 1997.

The report discusses nomenclature and prefers the term Chronic Fatigue Syndrome to its alternatives as being accurate and free from unproven etiological claims. It states that:⁴⁵

"The term chronic fatigue syndrome can be operationally defined for clinical and research purposes. The term CFS also allows clinicians to communicate effectively with patients and to propose a management plan while admitting that our understanding of the syndrome is incomplete."

A working definition of the syndrome suggested by the group is:

a syndrome characterised by a minimum of six months of severe physical and mental fatigue and fatigability, made worse by minor exertion. Other symptoms such as muscle pain (myalgia), sleep disorder and mood disturbances are common. Other common causes of chronic fatigue must be considered before the diagnosis can be made.⁴⁶

1. Causes

Comments of the Royal Colleges report are included in the discussion of possible causes and research. The findings of the working party are summarised here.

The report of the joint working group finds no consistent evidence that CFS is associated with muscle disorder in the majority of sufferers, save that resulting from inactivity consequent to the condition, and that evidence for structural or functional abnormality of the brain is weak. It states that there is no evidence that infections have a primary *causal* role in the vast majority of cases, although they do appear to *precipitate* the disorder in some. A number of viral agents, including glandular fever and viral meningitis may be involved. Viral infections may be only one of several possible precipitating factors in CFS, which should be regarded as multifactorial in origin.

⁴⁴ Chronic fatigue syndrome. Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners October 1996/CR54 Revised 1997

⁴⁵ *ibid* Summary Chapter 3

⁴⁶ *ibid* Glossary

The evidence also suggests that likelihood of CFS is increased where there is evidence of excessive fatigue and/or psychological illness before acquiring an infection. The report suggests that the link between infection and CFS may be a behaviour change on the part of the individual, rather than any direct linkage. The working group also find that CFS cannot be considered either "physical" or "psychological" - both need to be considered simultaneously to understand the syndrome. They consider that the depression which is found in half of patients cannot simply be regarded as secondary to the disability and uncertainty associated with CFS.

The report suggests that future research needs to consider predisposition (eg. personality, lifestyle or prior depression), the trigger or precipitant (eg. viral illness) and maintaining factors (eg. absence of a clear diagnosis, attribution, reduced exercise tolerance, societal focus on undetected infectious agent and advice to stop work).

2. Management

Management of this condition is a contentious issue, which is not surprising in view of the controversy that surrounds its diagnosis and causation. The joint working group comment:⁴⁷

"...At present treatment should address psychological disorder, misunderstandings about the nature of the condition, avoidance of activity, exercise intolerance and sleep disorder. Recent trials of graded exercise and/or cognitive behavioural treatment indicate that these are helpful in management. Further research is needed to identify non-responders and to examine whether they might have a different pattern of etiological factors. The success of these trials emphasises the importance of doctors encouraging and supporting their patients while they gradually extend their activities. This runs counter to the advice, still given to many patients, that activity is harmful and needs to be restricted.

We wish to emphasise the importance of early and positive treatment in primary care with access to specialist facilities only when necessary. A small proportion will need to be managed within the secondary sector, such provision must be appropriate, ie. able to provide multidisciplinary assessment and treatment, and to be able to carry out the principles of physical and psychological rehabilitation."

While antidepressants are an accepted therapeutic treatment for patients with a depressive element to their condition, the Royal Colleges report finds no systematic evidence to support other therapeutic claims. It sees no role for immunoglobulins, antihistamines, or other immunotherapy:⁴⁸

⁴⁷ Chronic fatigue syndrome. Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners October 1996/CR54 Revised 1997 para 13.9 - 13.10

⁴⁸ Chronic fatigue syndrome. Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners October 1996/CR54 Revised 1997 para 9.23

There is no compelling evidence linking immune dysfunction with disability, and no convincing evidence that any agent is effective. Experimental treatment such as immunotherapy should be given only as part of controlled clinical trials. We see no role for vitamin or dietary supplementation, and are unconvinced by the efficacy of magnesium or evening primrose oil.

3. Government response

The findings of the joint working group have helped to put the condition on an official footing, and to emphasise the importance of acceptance of the reality of the condition and of early treatment. The Chief Medical Officer wrote to all general practitioners drawing attention to the report. In reply to a Parliamentary Question the Secretary of State for Health, Tessa Jowell, said:⁴⁹

Ms Jowell: The Chief Medical Officer of the Department of Health wrote to all general practitioners in his quarterly newsletter in February of last year drawing their attention to chronic fatigue syndrome (CFS)/myalgic encephalomyelitis (ME), and specifically referring to the report published by the Medical Royal Colleges in 1996 and the report from the national task force on CFS, Post Viral Fatigue Syndrome and ME which was produced in 1994. It was intended that drawing attention to both reports in this way would provide a broad base of information to which GPs could refer for help in regard to the treatment and care of people who suffer from CFS/ME.

4. Criticisms of the Royal Colleges Report

The report drew a fiercely critical response. Commentators⁵⁰ have suggested that the working group was heavily weighted with psychiatrists, giving it a natural bias towards psychiatric rather than physiological explanations for the condition.⁵¹ An editorial in the *Lancet* endorsed the view of patient groups that the report was too ready to dismiss for lack of evidence a major role for viral cause of CFS or for structural or functional abnormalities in muscle or brain. It states the report was 'biased and inconclusive'.⁵²

These criticisms were rejected by the Royal Colleges. The *Lancet's* article was condemned, in a letter to *the Lancet*, as 'misleading and tendentious', and the report of the working party strongly defended:⁵³

"In the opinion of our three Colleges, our report represents a balanced, evidence-based discussion of the issues"

⁴⁹ HC Deb 19 June 1998 c 337-8W

⁵⁰ Frustrating Survey of Chronic Fatigue *Lancet* vol 348 12 Oct 1996 p971

⁵¹ Membership of the committee is listed in Appendix C

⁵² Frustrating Survey of Chronic Fatigue *Lancet* vol 348 12 Oct 1996 p971

⁵³ *Lancet* vol 348 16 Nov 1996 p1384 correspondence

Such was the depth of feeling that a public petition was laid in Parliament on 26 November 1997:⁵⁴

The Countess of Mar: My Lords, I beg to present a Petition from Mrs. Doris Jones, which prays that this House will take note of the Petition organised by Fighting for Truth⁵⁵ which calls for the rejection and withdrawal of the Royal Colleges' report on chronic fatigue syndrome (CR54) and further prays that this House will call upon Her Majesty's Government to review the scientific evidence upon which diagnosis and treatment of ME are based.

⁵⁴ HL 26 November 1997 583 97/98 c 1000

⁵⁵ ME pressure group

V Possible causes and research

The cause of CFS/ME has not been identified, but it is likely to be multifactorial, and there are numerous theories. Researchers are currently looking into the role of infection, immunological disturbances, changes in muscle energy production and brain dysfunction (eg changes in hormones, chemical transmitters and blood flow). Attention is also given to psychological and social factors that may play a role in predisposition to and perpetuation of ill health and disability in some cases. The condition is increasingly thought to be the result of a complex interaction of cerebral dysfunction, trigger factors and social attitudes.⁵⁶

The Linbury Trust, one of the Sainsbury Family Charitable Trusts, which has been a major funder of research into CFS/ME, has published (1998) *A Research Portfolio on Chronic Fatigue Syndrome*.⁵⁷ This document gives an account of developments in research into the causes and treatment of the condition, and would provide further information for the interested reader. Some commentators have, however, raised the issue that there may be a psychiatric bias in the research portfolio. Dr E G Dowsett,⁵⁸ has stated:⁵⁹

Of the 19 current or ex-Linbury Trust grantholders invited to contribute to this research portfolio, 12/19 are psychiatrists or psychologists and of the 13 accounts of work in progress, 9/13 (including all those on therapy) are written by members of the profession. Of the 4 remaining papers written by physicians (on Muscle), endocrinologists (on Circadian Rhythms) and microbiologists (on Immunology and Virology) at least one group still adheres to the "psychiatric dimension".

Factors which may be responsible for precipitating ME/CFS and perpetuating the illness have been the subject of research and debate in the scientific literature. Some of the factors that may be involved are outlined below.

A. Viruses

Most patients state that the illness began with a viral infection, and the symptoms are often consistent with this. Figures as high as 75% are quoted for cases where the illness follows a viral infection.⁶⁰ Numerous viruses are known to cause severe fatigue during acute infection. However, viral infection in the population is very common, many people get 4 or 5 minor viral infections in a year.⁶¹ Therefore chance associations are hard to exclude.

⁵⁶ *British Medical Journal* 306; 12 June 1993 p1557

⁵⁷ *A Research Portfolio on Chronic Fatigue* Ed Robin Fox for The Linbury Trust Pub. Royal Society of Medicine Press Ltd 1998

⁵⁸ Honorary Consultant Microbiologist, South Essex NHS Trust

⁵⁹ "Chronic fatigue" and the Linbury Trust Research Portfolio Dr E G Dowsett MB ChB. Dip. Bact. Honorary Consultant Microbiologist - South Essex Health Trust <http://www.community-care.org.uk/ME/fort/linrev.html>

⁶⁰ Dr McCluskey Chronic fatigue syndrome: its cause and a strategy for management *Comprehensive Therapy* 1998; 24 (8): 357-363

⁶¹ Kleinman A, Straus S (eds). *Chronic Fatigue Syndrome*. Chichester: John Wiley, 1993 p171

The Royal Colleges report states that at present there is no convincing evidence that *common* viral infections, of the kind seen frequently in primary care, are a risk factor for CFS, with the exception of the fatigue syndrome that follows Epstein Barr virus (the agent responsible for glandular fever).⁶² Other workers have demonstrated an increased risk with other (less common) viruses that cause viral meningitis,⁶³ (often an enterovirus in the UK), and the organism that causes Q fever (*Coxiella burnetii* - a type of rickettsia) is also associated with an increased risk.⁶⁴

Since the epidemic outbreaks, such as the Royal Free Episode, there has been speculation that enteroviruses may have a significant role in the aetiology of CFS/ME in some patients. This is a group of viruses which normally live harmlessly in the gut, and are known on occasion to produce severe disease of the central nervous system, and of heart muscle. Poliovirus and Echo and Coxsackie viruses fall into this group.

Studies have detected evidence of enteroviral infection in the blood of substantially more CFS/ME patients than both healthy controls and those with acute viral infections. A further study offered evidence of a novel group of enteroviruses, which could possibly pay some part in causing CFS/ME.⁶⁵

The Royal Colleges report argues that this does not distinguish between viral persistence as a cause, or alternatively as a consequence of CFS, and that the balance of evidence suggests that the *persistence* of enteroviruses is unlikely to play a role in the development of CFS/ME.

Other workers in the field disagree, and suggest a greater role for viruses, particularly enteroviruses, both in the initiation of the condition in some patients, and also in influencing the course of the illness through persisting infection at a cellular level.^{66,67}

B. Other suggested precipitating factors

The ME Association suggests⁶⁸ other possible precipitating factors or co-factors including immunisation^{69,70} mimicking the action of infection on the immune system, stress, inherited susceptibility and hormone levels.

⁶² Chronic fatigue syndrome. Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners October 1996/CR54 Revised 1997 Chapter 5, summary

⁶³ Hotopf M et al Chronic fatigue and minor psychiatric morbidity after viral meningitis: a controlled study *J Neurol Neurosurg Psychiatry* 1996; 60: 504- 9

⁶⁴ Ayres J et al Post-infectious fatigue syndrome following Q fever *QJ Med* 1998: 105-23

⁶⁵ Chronic fatigue syndrome Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners October 1996/CR54 Revised 1997 para 5.5

⁶⁶ Behan PO, Behan WMH, Gow JW et al, 1993

⁶⁷ Wiley, Chichester (Ciba Foundation Symposium 173) 1993 p146-159

⁶⁸ *Perspectives* Research Update p26 ME Association 1997

⁶⁹ Children with ME guidelines for School doctors and General Practitioners p2 Alan Franklin FRCP DCH *ME Association* 1994

⁷⁰ Kleinman A, Straus S (eds). *Chronic Fatigue Syndrome*. Chichester: John Wiley, 1993 p172

Chronic fatigue has been associated with a wide range of conditions, and research in these fields may yield useful information. Veterans returning from the Gulf War have reported a wide range of symptoms, including chronic fatigue, and suspicion has fallen on the use of organophosphate pesticides (one of a number of avenues of investigation). There have been suggestions that this group of pesticides may also be implicated in ill health in farmers.

A review of the scientific and medical literature carried out by the MRC Institute for Environment and Health (IEH) doubts that chronic, serious health effects result from low level exposure to organophosphates.⁷¹

Although there is at present insufficient evidence to eliminate the possibility that subtle (ie. not subjectively apparent) effects may be produced by low-level exposure to organophosphorus pesticides, based on the published evidence it can be concluded that such exposures are not likely to be responsible, in themselves, for any adverse health effects large enough to be subjectively apparent.

However, this is again an area of uncertainty, and further studies on the effects of organophosphorus compounds on human health are currently being carried out.⁷²

A Joint Working Group of the Royal College of Physicians and Royal College of Psychiatrists set up to examine the clinical aspects of long term low dose exposure to organophosphate sheep dips acknowledged that some studies have identified subtle cognitive impairment (impaired attention and reaction times), greater psychiatric ill-health and minor sensory changes. However, it considers that there are methodological weaknesses in the studies, and it also considers that further research is needed to elucidate the role of organophosphates in the health problems identified.⁷³

The Committee on Toxicity of Chemicals in Food, Consumer Products and the Environment (COT) has set up a special Working Group to examine the IEH report and other related scientific evidence and is expected to report early in 1999.

C. Immune dysfunction

Links between CFS/ME and preceding infections have led to investigation of immune system involvement in the persistent ill health of CFS. Persistent infections and consequent chronic symptoms may be related to an inadequate immune response, either as cause or effect. Abnormal cytokine levels (chemical messengers produced as a result of inflammation, which regulate the cells of the immune system), interacting with the nervous system, could be related to fever, myalgia (muscle pain) and sleep disturbance.

Research studies have found results consistent with chronic low level activation of the immune system together with depressed cell-mediated immunity (a function of specific

⁷¹ Organophosphorus esters: an evaluation of chronic neurotoxic effects. MRC Institute for Environment and Health, University of Leicester, June 1998

⁷² HC Deb 19 October 1998 c 902-3W

⁷³ Organophosphate sheep dip: Clinical aspects of long-term low-dose exposure. Report of a joint working party of the Royal College of Physicians and Royal College of Psychiatrists November 1998/CR67

lymphocytes, or white blood cells).⁷⁴ It is difficult to draw conclusions from these findings, and the cause of the disturbance remains unknown. The question of cause and effect remains.

The Royal Colleges report suggests that observed abnormalities could be attributed to "immunological perturbations in the aftermath of a viral infection, or to neuro-immunological influences, in turn related to behavioural and psychological factors in individual subjects".⁷⁵ It cautions against over-interpretation of the abnormalities found in immunology, until further controlled research has clarified immunological influences on symptoms in CFS.

D. Abnormalities of muscle structure and function

Weakness and pain in the muscles are prominent features of CFS/ME. Extensive investigations have been carried out to determine whether some abnormality of muscle function, biochemistry or structure is at fault. Most observers would now accept that the condition is not a primary disorder of muscle.⁷⁶ However, in some CFS patients, abnormalities have been demonstrated in the mitochondria of muscle cells (the part of the cell where energy is constantly produced).⁷⁷ The significance of these findings remain controversial. The Royal Colleges report concludes that, in the majority of sufferers, any muscle abnormalities are probably due to the effects of inactivity. Others working in the field maintain that there could be important and possibly treatable biochemical problems at a cellular level.

This distinction is very relevant to management of CFS/ME. An active programme of graded exercise to reverse deconditioning of the muscles brought about due to inactivity is seen by the Royal Colleges as an effective means of treating patients and gradually improving symptoms and mobility. Some patients and physicians, however, take the view that excessive exercise, particularly during the acute phase of the illness, exacerbates the condition and makes the patient feel very ill.

E. Psychiatry and physiological brain dysfunction

There is an increasing understanding that the distinction between physical and psychological or psychiatric illness is becoming progressively more blurred. For instance, many 'psychiatric' conditions, including depression, have been shown to have demonstrable physiological and neurochemical disturbances. People with Chronic Fatigue Syndrome generally experience both physical and psychological symptoms.

⁷⁴ Disturbed Immunity Phillip Cash and dBeatriz Gimenez *A Research Portfolio on Chronic Fatigue* p5 Ed Robin Fox for The Linbury Trust Pub. Royal Society of Medicine Press Ltd 1998 p 19-23

⁷⁵ Chronic fatigue syndrome Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners October 1996/CR54 Revised 1997 para 6.4

⁷⁶ Perspectives Research Update Issue 63 *ME Association* 1997

⁷⁷ Behan WMH et al 1991

However, it is now acknowledged that between one quarter and one third of those who fulfil criteria for CFS do not fulfil any criteria for any psychiatric disorder.⁷⁸

This is an area of controversy. Some doctors still take the view, vociferously denied by patient groups, that ME/CFS is a manifestation of a primary depressive illness, hysteria or a somatisation disorder (multiple physical symptoms often caused by depression or anxiety) and it is difficult to dispel the notion that CFS the physical disease is seen as legitimate, while CFS the psychological illness is seen as malingering.⁷⁹

- Depression

It has been accepted that CFS can occur without depression, but at the same time depression and/or anxiety represent a strong risk factor. They are not the same condition, but do appear to be associated.

The ME Association state that about a quarter of patients will develop a depressive component to their illness,⁸⁰ while the report of the Joint Colleges states that depression is found in half of patients.

Depression can arise in any form of chronic illness, including CFS. In depression there is a disturbance in brain chemistry. Common chemical messengers, such as serotonin and noradrenalin, which help to control mood, normal mental functioning, appetite and sleep can be disturbed.

Depression can lead to a cycle of

Depression → inactivity → deconditioning → sick role behaviour

It is not unreasonable to suppose that this cycle may account for some of the symptoms of CFS. However, CFS/ME has a number of symptoms which are not found in depression (eg. recurrent sore throats, enlarged glands, problems with temperature control, acute onset), and most of the normal features of true clinical depression are not seen in people with CFS/ME. Also, research into neurotransmitters, such as serotonin, in the brain appear to follow a pattern distinct from that in depression.⁸¹ Further work is being carried out to gauge the importance of these abnormalities.

However, evidence also suggests that the likelihood of CFS is increased where there is excessive fatigue and/or psychological illness before acquiring an infection. The Royal

⁷⁸ Chronic fatigue syndrome Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners October 1996/CR54 Revised 1997 para 7.6

⁷⁹ Psychosocial aspects Trudie Chalder *A Research Portfolio on Chronic Fatigue* p 24-27 Ed Robin Fox for The Linbury Trust Pub. Royal Society of Medicine Press Ltd 1998

⁸⁰ ME Association

⁸¹ Neurochemistry Anthony J Cleare *A Research Portfolio on Chronic Fatigue* p 24-27 Ed Robin Fox for The Linbury Trust Pub. Royal Society of Medicine Press Ltd 1998 p38-43

Colleges working group finds that CFS cannot be considered either "physical" or "psychological" - both need to be considered simultaneously to understand the syndrome. It comments that the depression which is found in half of patients cannot simply be regarded as secondary to the disability and uncertainty associated with CFS, and further research is needed in this area.

Dr Charles Shepherd, Medical Advisor to the ME Association, gives three factors affecting the chances of developing depression in ME/CFS:⁸²

- a) whether your underlying personality or family history places the individual at increased risk;
- b) to what extent adverse external factors such as problems with benefits, education, employment, doctors etc are building up and
- c) changes in brain chemistry which could be occurring as a direct result of either viral infection or immunological changes affecting the central nervous system and chemical transmitters.

- Hypothalamic-pituitary-adrenal axis (HPA) dysfunction

This is a promising area of study. The HPA axis is a term used to describe the complex interaction of the hypothalamus and pituitary gland, closely related structures in the brain, and the adrenal glands, situated above the kidneys, which produce hormones such as cortisol. Feedback mechanisms regulate the interaction between the nervous system and hormone release.

Suggestions of persistent low levels of the hormone cortisol in some CFS patients (in contrast to a major depression) are being investigated. One hypothesis⁸³ puts forward the idea that a short-lived infection, with or without the presence of stress, results in a disturbance of the HPA which then persists for a long period after elimination of the infection. Persistent dysfunction of the HPA then interferes with normal brain functioning, particularly where steroid regulation is involved. Altered functioning in these systems could then account for many of the psychological and some of the physical symptoms that patients describe.

- Sleep disturbance

The hypothalamus also controls the 'body clock' - the circadian rhythms that control functions such as feeding, metabolism, secretions of many hormones, and mood. This system is as yet incompletely understood, but many of the cardinal symptoms of CFS, poor concentration, poor quality sleep and myalgia, are also apparent in people who have lost the normal circadian rhythm through night shift work or jet lag. A hypothesis has been put forward that circadian rhythm is less effectively controlled in CFS patients,

⁸² *Perspectives* Medical Matters March 1998 ME Association

⁸³ Report from National Task Force on Chronic Fatigue Syndrome (CFS) Post Viral Fatigue Syndrome (PVFS) Myalgic Encephalomyelitis (ME) 26 September 1994 Appendix D p102

perhaps initiated at the time of an acute infection or through stress, and exacerbated by lack of daily routine, inactivity and sleep disturbance - in effect a vicious circle.⁸⁴ A recent study⁸⁵ suggests management strategies should involve re-learning a normal sleep pattern, and that phototherapy and melatonin may be useful in treatment in the future. Melatonin is not licensed for treatment in the UK, and it has been stated that it should only be given in the context of a controlled trial.⁸⁶

- Modern technology provides methods of studying brain structure and function, and these have been employed in the study of CFS. Population based neuro-imaging studies are in their infancy and results have been inconsistent. MRI (magnetic resonance imaging) has revealed white matter abnormalities in some CFS patients. These require careful interpretation. They may indicate the presence of some other neurological condition. Alternatively, it appears that this sensitive technique can reveal 'abnormalities' which are of little consequence.⁸⁷
- Interesting work has looked at the blood flow to different parts of the brain (using SPET or single photon emission tomography) and has found decreased blood flow to the brain stem in CFS patients compared to controls, with depressed patients showing intermediate values.⁸⁸ The Royal Colleges report again suggests that replication of these findings is necessary, and this is a technically difficult area to study.

F. Psychological aspects of CFS

Psychological and social factors which impact on the illness have been researched. The way an individual views his illness and his ways of coping with ill health, together with perceived strength of emotional and practical help available to him are thought to be factors which may affect an individual's predisposition to developing CFS/ME, and perpetuation of chronic ill health. This is discussed in the Research Portfolio on Chronic Fatigue Syndrome, together with the need for further research into predisposing, precipitating and perpetuating factors.⁸⁹

⁸⁴ Circadian rhythms Gareth Williams Jim Waterhouse p44-49 *A Research Portfolio on Chronic Fatigue* Ed Robin Fox for The Linbury Trust Pub. Royal Society of Medicine Press Ltd 1998

⁸⁵ Chronic Fatigue Syndrome: Its Causes and a Strategy for Management D R McCluskey *Comp Ther* 1998;24 (8): 357-363

⁸⁶ Circadian rhythms Gareth Williams Jim Waterhouse *A Research Portfolio on Chronic Fatigue* Ed Robin Fox for The Linbury Trust Pub. Royal Society of Medicine Press Ltd 1998 p48

⁸⁷ Chronic fatigue syndrome. Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners October 1996/CR54 C Revised 1997 Para 7.13

⁸⁸ *ibid*

⁸⁹ Psychosocial aspects Trudie Chalder *A Research Portfolio on Chronic Fatigue* p24-27 Ed Robin Fox for The Linbury Trust Pub. Royal Society of Medicine Press Ltd 1998

VI Management of CFS/ME

A condition whose cause is undetermined naturally gives rise to a multitude of potential treatments and management strategies. There is general recognition that an holistic and multidisciplinary approach is valuable.

Research based evidence for specific treatments is limited but increasing. However, the relative benefits of specific regimes is still controversial. Conflicting views about the value of different approaches to treatment has resulted in great confusion for both patients and doctors. To address these uncertainties the Department of Health is setting up a working party on CFS/ME which will hope to provide clarification on the value of specific treatments and the evidence on which its advice is based.

A. ME Association guidelines

A variety of patient groups provides information and support to patients. The ME Association has issued guidelines for the care of ME/CFS patients and sets out principles on which to base management:⁹⁰

- Establish the correct diagnosis
- Belief [in patient's symptoms], explanation and support
- Appropriate use of drugs and other treatments for symptomatic relief
- Advice on sensible changes in lifestyle and diet
- Liaison with schools, colleges and employers
- Support with obtaining DSS benefits and welfare rights
- Pros and con of the private medical sector and alternative therapies
- Value of joining a self-help group

These guidelines emphasise that there is no single effective treatment. They report that trials have found positive benefits from high dose evening primrose oil, injections of magnesium sulphate, and high dose immunoglobulin, but advise that these findings should be viewed with caution as most of the studies have only involved small numbers of patients. They discuss also the use of antiviral agents, calcium antagonists, antidepressants, vitamin and mineral supplements and cognitive behaviour therapy (see below) and graded exercise regimes (inter alia).

Useful advice on symptomatic relief, lifestyle modification and practical advice (driving, insurance, employment and benefit problems) are also tackled.

The perception that orthodox medicine has little to offer leads many patients to try alternative therapies. Dr Charles Shepherd, medical adviser to the ME Association,

⁹⁰ Myalgic Encephalomyelitis: Post-Viral Fatigue Syndrome Guidelines for the Care of Patients 2nd ed Dr Charles Shepherd ME Association 1995

considers that some of these approaches do help, and the reason may lie in the sympathetic and optimistic attitude of the therapist rather than the value of the therapy being prescribed.⁹¹

The Royal Colleges report emphasises the importance of a multidisciplinary approach, and of accepting a patient's symptoms and forming a therapeutic alliance with the patient. However, it endorses only a graded exercise regime and cognitive behaviour therapy as specific therapies of proven efficacy, with antidepressant therapy for those with depressive disorders.

B. Exercise

A randomised controlled trial of "graded exercise therapy" carried out at St Bartholemew's Hospital found that 74% of patients were "much better" or "very much better" after one year.⁹²

The Royal Colleges report endorses the use of a programme of graded exercises to improve physical stamina and reduce muscle deconditioning which results from inactivity. It says that exercise should be introduced in a cautious, controlled and agreed manner, and that it should not be overambitious. Even so, there has been concern that an increase in activity should be carefully paced to follow the abilities of the patient, rather than be dictated by the schedule of the practitioner.⁹³

Patient groups emphasise the need for rest particularly in the early stage of the illness, whereas the Royal Colleges state.⁹⁴

We emphasise the vast literature on the adverse effects of rest...we believe that rest *per se* is contraindicated in CFS. If it has a role, it is only as one component of a strategy for a short period, measured in days or weeks.

C. Cognitive behaviour therapy (CBT)

Cognitive techniques are used to help patients re-evaluate understanding of their illness, combat depression and anxiety and look for underlying patterns of thought and assumptions that may contribute to disability. Behavioural techniques can be used to gradually and consistently increase activity, reduce exercise avoidance of activity and improve confidence and control. Studies of CBT have produced conflicting results. The

⁹¹ *ibid* p31

⁹² Fulcher KY, White PD, Randomised controlled trial of graded exercise in patents with the chronic fatigue syndrome. *British Medical Journal* 1997; 314;1647-52

⁹³ NHS services for people with chronic Fatigue Syndrome/Myalgic encephalomyelitis. The National Task Force on CFS/ME September 1998

⁹⁴ Chronic fatigue syndrome October 1996/CR54 Joint working group of Royal College of Physicians, Royal College of Psychiatrists and Royal College of General Practitioners Revised 1997 para 9.15

Royal Colleges find in favour of this form of therapy while the ME Association is doubtful about its value.

The National Taskforce has commented on encouraging results in trials of CBT, but says that very real problems exist over the way it is being used in some cases.⁹⁵

⁹⁵ NHS services for people with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis. The National Task Force on CFS/ME September 1998

VII Children with CFS/ME

A study in 1997 found that CFS was the single commonest cause of long term absence from school.⁹⁶ Although interpretation of the data in the study has been criticised,⁹⁷ it is clear that CFS/ME is increasingly recognised in children of school age.

The condition presents a similar clinical picture to that in adults, but the criteria for diagnosis may need slight modification - three months duration of symptoms may be more appropriate than six for a diagnosis to be made.⁹⁸ The illness can be severe, resulting in chronic disabling ill health. Loss of schooling and social contact often ensues.

As with adult CFS/ME there is dispute about the basis of the illness. The Royal Colleges Report emphasises the psychosocial elements of the condition. Depression, anxiety and school phobia may all be factors and there is great confusion about diagnosis and management. Patients and their families may be defensive about receiving a psychiatric 'labelling', which they may see as a denial of the severity of the illness.

There is a consensus that recognition and early treatment of the condition is very important, and that social, emotional and physical factors need to be taken into account when planning a management strategy. The Royal Colleges report advocates early rehabilitation with a graded programme of activity, both physical and mental. It advocates multidisciplinary care within general practice (involving general practitioner, school nurse, and school authorities, together with the support of local paediatric, psychiatric or psychology services where appropriate). It suggests referral to a specialist team be reserved for those with a specific psychiatric disorder, severe or prolonged disability, or family factors interfering with progress.

Summary of CFS in children (adapted from Royal Colleges report):⁹⁹

Diagnosis

- New onset of disabling physical and mental fatigue for more than three months

Investigation

- Full history and examination
- Tests to exclude other diagnoses

⁹⁶ Dowsett EG, Colby J Long term sickness absence due to ME/CFS in UK schools: an epidemiological study with medical and educational implications *J Chronic Fatigue Syndrome* 1997;3 29-42

⁹⁷ Managing chronic fatigue syndrome in children *British Medical Journal* vol 314 7 June 1997 p1635

⁹⁸ Chronic fatigue syndrome. Joint working group of Royal Colleges of Physicians, Psychiatrists and General Practitioners October 1996/CR54 Revised 1997 para 10.4

⁹⁹ Managing chronic fatigue syndrome in children *British Medical Journal* vol 314 7 June 1997 p1635

Management

- Intervene early
- Acknowledge the reality of the child's symptoms
- Insist on inseparability of the physical and psychological
- Explore family and psychosocial issues
- Liaise closely with school
- Agree with family a daily life activity and educational programme
- Consider home tuition only when even part time school attendance proves impossible

On some issues opinions diverge. Some patients are concerned about over-rigorous exercise. Early return to school advocated by the Royal Colleges report is seen by some families as unrealistic, and focusing on family issues which may promote 'sick role' behaviour in the child is seen as unfair.

Disagreements centred around the diagnosis and treatment of CFS/ME in children have led in some cases to bitter disputes and even court action. Parents have disputed the benefits of psychiatric treatment, and it has been reported that children have been put on the "at risk" register and have been threatened with child protection proceedings if they refuse treatment in a psychiatric unit.¹⁰⁰

A. Education for children with ME¹⁰¹

Entitlement to education for a child with ME is the same as that for any other sick child. The arrangements made will depend upon the individual child's needs. Such needs may be met by the mainstream school or it may be necessary to make provision "otherwise than at school".

Section 19 of the *Education Act 1996* places a duty on local education authorities (LEAs) to arrange suitable education for all children of compulsory school age who are out of school because of illness, exclusion from school or for some other reason.¹⁰² Suitable education for the purposes of this section means "efficient education suitable to (the child's or young person's) age, ability and aptitude and to any special educational needs he may have."¹⁰³

Guidance on the duty to provide education otherwise than at school where it is necessary to meet a pupil's needs, and the arrangements to be made for sick children generally, was contained in a Joint Department for Education, Department of Health and NHS Executive

¹⁰⁰ "Parents stop health chiefs putting boy with ME on 'at risk' register" *The Scotsman* 16 Oct 1998

¹⁰¹ Christine Gillie, Social Policy Section, November 1998

¹⁰² This responsibility was first imposed on LEAs under section 298 of the *Education Act 1993* and took effect from September 1994. The *Education Act 1996* is a consolidation Act.

¹⁰³ *Education Act 1996*, Section 19 (6)

Circular.¹⁰⁴ This is still the current guidance. The Circular emphasised educational continuity, multi-professional working, liaison between the different parties, and access to a broad and balanced curriculum. The guidance did not specify how much education should be provided and in what form. A PQ answered earlier this year referred to the guidance:

Mr. Burstow: To ask the Secretary of State for Education and Employment what guidance is issued by his Department to local education authorities concerning the management of children with ME/CFS.

Ms Estelle Morris: Guidance on good practice in arranging provision for sick children is contained in DfEE Circular 12/94, "The Education of Sick Children". Circular 14/96, "Supporting Pupils with Medical Needs in School", sets out schools' legal responsibilities for pupils with medical needs. Good practice guidance was also made available in October 1996 to help schools put policies and procedures in place.¹⁰⁵

The type of provision made for a child with ME is a matter for the judgement of the school and the LEA. The duty to provide suitable education under section 19 and the issue of funding for home tuition was at the centre of a recent case taken to the House of Lords. In *R v East Sussex County Council ex parte T*¹⁰⁶ the House of Lords had to decide whether the LEA was acting lawfully when, purely for financial reasons, it cut the home tuition it was providing for a chronically sick child with ME and mild dyslexia from five to three hours per week. The cut was made because the LEA had decided to reduce its home tuition budget. Lord Browne-Wilkinson ruled that the duty under section 19 of the 1996 Act was owed to the individual child rather than to a class of children and that there was nothing in the section that suggested that resource questions were relevant to the question of what is suitable education. There was no reason to treat the resources of the LEA as a relevant factor in determining what constituted suitable education although if there was more than one way of providing suitable education the LEA would be entitled to have regard to its resources in choosing between such different ways.

Some of the main issues surrounding the education of children with ME were explored in a pamphlet published by Blue Ribbon for the Awareness of ME (BRAME). One of the contributions to it noted that provision for children with ME varies enormously. Some form of home tuition may be provided, including tuition using distance learning methods and information technology.¹⁰⁷

A child with ME may have "special educational needs" and require "special educational provision". However, ME might not, in itself, necessarily require special educational

¹⁰⁴ "The Education of Sick Children", *DfEE Circular 12/94*, May 1994. Also issued as DH LAC (94) 10 and NHSE HSG (94) 24 Circulars.

¹⁰⁵ HC Deb, 27 April 1998 c 24W

¹⁰⁶ *Education Law Reports 1998*, 237-350, No 3, p 251

¹⁰⁷ *Education and ME*, BRAME, May 1998, p 45

provision but a child with ME may suffer from another condition that requires special educational provision to be made. Whether it is appropriate for special educational provision to be made will depend upon the individual child's needs as assessed by the LEA. In 1993 new legislation on special educational needs was introduced; originally Part III of the *Education Act 1993*, it is now consolidated as Part IV of the *Education Act 1996*. Under the 1993 Act, the Secretary of State for Education issued a Code of Practice giving guidance to schools and LEAs on how to identify and assess special educational needs.¹⁰⁸

Under section 312 of the *Education Act 1996* a child has "special educational needs" for the purposes of the Act if he has a "learning difficulty which calls for special educational provision to be made for him". A child has a "learning difficulty" if:

- (a) He has a significantly greater difficulty in learning than the majority of children his age,
- (b) He has a disability which either prevents or hinders him from making use of educational facilities of a kind generally provided for children of his age in schools within the area of the local education authority, or
- (c) He is under [compulsory school age] and is, or would be if special educational provision were not made for him, likely to fall within paragraph (a) or (b) when of ... that age.

(3) A child is not to be taken as having a learning difficulty solely because of the language (or form of the language) in which he is, or will be, taught is different from a language (or form of a language) which has at any time been spoken in his home.¹⁰⁹

¹⁰⁸ DfE, *Code of Practice on the Identification and Assessment of Special Educational Needs*, 1994

¹⁰⁹ Section 312 (2) (3)

VIII Government response to CFS/ME issues

A. Social and economic costs

Total social and economic costs associated with disability in CFS/ME will be considerable. However, no official figures are available for the UK.

The National Taskforce has estimated current levels of expenditure on CFS/ME, including both health care costs and societal costs. They acknowledge that this gives only the order of magnitude of costs, and that more work needs to be done to enable greater precision in estimating UK costs:¹¹⁰

An Australian study in the early 1990s (Lloyd et al 1992) generated estimates of the direct and indirect costs of chronic fatigue syndrome to the community. When converted to current UK prices, this suggests a total annual cost per case of £5,095, about 20% of which is attributable to direct medical costs; the remainder represents indirect costs including welfare benefits, and loss of production and tax revenue. On a conservative estimate of the prevalence of around 0.3%, this would **suggest an overall cost to the community in the UK of around £1,000m per annum.**

These figures are borne out by the results of a postal survey of members of Action for ME and the ME Association (Bibby et al 1996). A similar estimate of the average direct cost of medical care was obtained (£690 per patient per annum), but a more comprehensive estimate of indirect costs to the community (including the full costs of social care to families and carers) produced a total cost estimate which was approximately double that of the Australian study.

CFS/ME sufferers have to cope with lost school and work days and restricted social life. Patient groups draw attention to the loss of quality of life incurred through ignorance about the illness among professionals and lay people, refusal of benefits, pensions and insurance.¹¹¹

Professor Simon Wessely, from the CFS Research Unit, King's College School of Medicine and Dentistry, discusses the impact of CFS on patients in primary care, as well as those who have presented at specialist clinics.¹¹²

You have to be blind not to notice the devastating impact of CFS in some of those who attend specialist clinics around the world, and various studies attest to its economic toll on individuals, families and society. But what about the larger numbers in primary care? It would be nice to record that these people are not so impaired, but this is not so. Our primary care study showed that they too had a

¹¹⁰ NHS services for people with chronic Fatigue Syndrome/Myalgic encephalomyelitis. The National Task Force on CFS/ME September 1998 p44

¹¹¹ BRAME Blue Ribbon for the Awareness of ME meeting 14 May 1998 Dr EG Dowsett

substantial burden of illness, and that the impact of CFS was greater in terms of personal, physical and emotional disability than that associated with angina, blood pressure, arthritis or chronic bronchitis.

B. Benefits

1. Range of benefits¹¹³

There is a range of benefits to which a person suffering from ME might be entitled. None of these depends on a particular diagnosis itself. Rather they depend on the person fulfilling other criteria. The main benefits involved are as follows:

- **Incapacity Benefit (IB).** This is a benefit for people who have made the required National Insurance benefits and who are assessed as incapable of work.
- **Disability Living Allowance (DLA).** This is for people who become disabled before the age of 65 and who need help with personal care or mobility. It is not means-tested, or dependent on National Insurance Contributions.
- Means-tested benefits such as **Income Support, Housing Benefit** and **Council Tax Benefit** which have special premiums for disabled people.

Other possible benefits include:

Attendance Allowance (AA), which is for people over 65 who are so severely disabled that they need help with personal care.

Severe Disablement Allowance, which is for people who are severely disabled and assessed as incapable of work, but who have not made contributions to get Incapacity Benefit.

Disability Working Allowance, which is a means-tested benefit paid to people in full time work with a disability or illness which puts them at a disadvantage in getting a job.

2. Obtaining benefits

Some CFS/ME patients have reported difficulties gaining disability benefits. ME charities regard a lack of recognition of the illness as a serious, chronic, disabling disease entity as a factor in these difficulties, and have worked to raise the profile and recognition of the illness. The Medical Director of the ME Association, Dr Charles Shepherd, lectures to Benefits Agency doctors.

¹¹² Epidemiology of CFS Simon Wessely *Research Portfolio on Chronic Fatigue* Ed. Robin Fox for the Linbury Trust. Pub. Royal Society of Medicine Press Ltd 1998 p4

¹¹³ Pat Strickland, Social Policy Section, November 1998

The Disability Handbook now has a chapter devoted to Chronic Fatigue Syndrome¹¹⁴ which the ME Association states has been changed to reflect the realities of illness and disability for those affected¹¹⁵. The Handbook is designed to be a source of reliable information on the care and mobility needs likely to arise in a variety of medical conditions. It is issued by the DSS and is used by Adjudication Officers in making decisions on DLA/AA and also by members of Disability Appeals Tribunals.

The Incapacity Benefit Handbook for Medical Service Doctors, written for doctors who provide advice to Benefits Agency Adjudication Officers in relation to Incapacity Benefit, also has a chapter on Chronic Fatigue Syndrome . This advises:¹¹⁶

There is no firm evidence to suggest that myalgic encephalomyelitis (ME) is a distinct entity from other forms of Chronic Fatigue Syndrome (CFS), nor is there firm evidence that CFS is a physical disease ...

The nature of the disability is such that it is rarely, if ever, possible to give advice on the basis of documentary evidence alone. At examination, because of the absence of clinical findings, full and detailed information about activities of daily living is essential, and accurate observation of the client during the interview and examination is very important. A mental health assessment will almost always be appropriate, bearing in mind the common claim that CFS leads to poor concentration. You will find it quicker and easier in the long run to approach the assessment on the basis that the mental health assessment section will need to be completed. If you do not complete a mental health assessment you must explain your reasons for not doing so.

C. Parliamentary interest

1. Research funding

There has been considerable Parliamentary interest in the problems of CFS/ME. An Early Day Motion on the subject of ME awareness was tabled by Paul Burstow in May 1998:¹¹⁷

That this House notes that 10th to 17th May was Myalgic Encephalomyelitis (ME) Awareness Week; recognises the often severe difficulties faced by ME sufferers, their carers and their families; notes with concern that between 1996 and 1998 no resources were allocated by the Department of Health or the Medical Research Council to investigate the physical causes of ME; and calls on the Secretary of State for Health to propose measures to increase awareness and understanding amongst health care professionals and the general public, to support research, and to provide care and support for ME sufferers, their carers and their families.

¹¹⁴ The Disability Handbook 2nd Ed. 1998 ch. 16

¹¹⁵ *Perspectives* ME Association 1997 p28

¹¹⁶ Incapacity Benefit Handbook for Medical Service Doctors 1996, chapter 17

¹¹⁷ EDM 1323 1997/98 14 May 1998 ME Awareness

Paul Burstow has also asked the Secretary of State for Health what research his Department has funded into ME/CFS in the last five years.¹¹⁸

Ms Jowell: A number of research projects into myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) have been carried out or are currently underway. These are:

"The role of noradrenaline in the neuropsychological pathogenesis of the chronic fatigue syndrome (ME)", funded by the Medical Research Council (MRC) and costing £37,000, is being undertaken by Dr. R. K. Morriss at the University of Manchester.

"Rehabilitation in the chronic fatigue syndrome (ME) -a controlled trial of cognitive-behavioural therapy", now completed and funded by the Department of Health for £59,034.

"Should General Practitioners manage chronic fatigue syndrome (ME)? A controlled trial", an ongoing research project funded by the National Health Service research and development programme for £64,433.

The Department has also funded a £65,000 project which considered whether a particular type of psychological treatment was effective in reducing disability in CFS/ME Patients and a £60,000 project which is looking at whether general practitioners are best placed to manage CFS/ME patients. In addition, the NHS Standing Group on Health Technology has recently identified the latest series of priority areas for which it anticipates commissioning primary research or systematic reviews. One of the topics identified is management strategies for chronic fatigue syndrome/ME.

The Government has also been asked what plans it has to commission research into the physical causes of myalgic encephalitis (ME)¹¹⁹

Baroness Hayman: The main Government agency for funding research into the causes and pathogenesis of health problems is the Medical Research Council (MRC) which receives its grant-in-aid from the Department of Trade and Industry.

The MRC is funding one study which is about to be completed at the University of Manchester entitled 'The role of noradrenaline in the neuropsychological pathogenesis of the chronic fatigue syndrome'. The MRC also supports a considerable amount of basic research that would underpin any search for the pathophysiology of myalgic encephalomyelitis.

The Department of Health has not commissioned any research in this area, and has no present plans to do so. We are however working with the Linbury Trust on issues related to the treatment and management of the problem.

¹¹⁸ HC Deb 27 April 1998 c53W

¹¹⁹ HL Deb 3 September 1998 c 27W

2. Provision of services

Provision of services has been seen by patient groups as a matter for concern and the independent National Taskforce has produced a document which discusses this.¹²⁰ Service provision has been raised in a Parliamentary Question in June 1998.¹²¹

Mr. Laurence Robertson: To ask the Secretary of State for Health what steps he is taking to promote awareness and understanding of myalgic encephalitis among doctors and the general public; what help is offered to people who suffer from the illness; and if he will make a statement.

Ms Jowell: The National Health Service provides a wide range of services to which sufferers of myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS) have access and such patients are seen within a wide range of community services and hospital specialities. Patients can discuss the options available to them with their general practitioner and they may also request an assessment of their needs by local authority social services departments. It is the responsibility of health authorities to decide how the needs of ME/CFS sufferers should be met and whether or not they should purchase dedicated services. All such decisions are made in the light of competing priorities. Raising awareness and understanding about ME/CFS is a major part of the work of the ME/CFS voluntary organisations. Since 1988, the Department has provided substantial funding to ME/CFS organisations, amounting to almost a quarter of a million pounds. Some of the ME/CFS organisations provide information packs to GPs about the condition, as well as to sufferers and their families.

The Government has also been asked what guidance the Department of Health gives to health authorities concerning CFS/ME. The Minister for Public Health, Tessa Jowell, replied:¹²²

There is no single effective treatment for chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). The condition varies significantly from one patient to another and therefore individual patients benefit from different treatment regimes. Therefore, we consider that it is more appropriate for clinical guidelines to be produced by clinicians themselves or through their representative professional bodies. Furthermore, the Medical Royal Colleges point out that, whilst CFS/ME should be managed by general practitioners, it is inappropriate at present to issue clinical guidelines given the lack of methodologically sound research.

¹²⁰ NHS Services for people with Chronic Fatigue Syndrome/Myalgic Encephalitis. The National Task Force on CFS/ME 1998 (see also section 1V)

¹²¹ HC Deb 10 June 1998 c. 605W

¹²² HC Deb 27 Apr 1998 c. 54W

3. Working group

In response to the uncertainties and contradictory reports and advice available to patients and doctors, the Department of Health is setting up a working group on CFS/ME under the Chairmanship of Professor Allen Hutchinson, Director of Public Health, School of Health and Related Research at Sheffield University. The working group will aim to promote a better understanding of Chronic Fatigue Syndrome/ME, to produce advice and information on aspects of clinical management of the illness, and to set out the evidence on which this information is based. There will be a main working group and a sub-group on children.

Announcing details of the working group, the Chief Medical Office, Professor Liam Donaldson, said:¹²³

"This initiative will provide us with a real opportunity to review the practical care and support for patients, carers and healthcare professionals alike. We have sought to ensure that the Working Group reflects a broad range of patient and professional opinion."

The key group will have two parts; a small inner group, which will survey the evidence and produce the good practice text, and a larger reference group, to comment on and contribute to the work. The composition of the working group, is detailed in Appendix D.

The group will be supported by the Linbury Trust, one of the Sainsbury Family Charitable Trusts, which has been funding research into CFS/ME since 1991. Work will start early in 1999.¹²⁴

¹²³ 1998/0487 CFS working group membership announced. Department of Health 4 Nov 1998

¹²⁴ Personal communication, Department of Health, October 1998

IX Appendixes

A. Membership of the National Task Force on CFS/PVS/ME (1994 Report)

Members of the Task Force¹²⁵

Chairman

Dr David Tyrrell Physician and Virologist (Retired)

Members

Dr Len Archard Reader in Molecular Pathology, Charing Cross & Westminster Medical School.

Dr Michael Denman Consultant Physician, (Rheumatology/Immunology), MRC Unit, Northwick Park Hospital.

Prof Ted Dinan Prof of Psychological Medicine, St Bartholomews Hospital.

Dr Declan Doogan Medical Director, Pfizer UK

Dr Leslie Findley Consultant Neurologist, Havering Hospitals Trust.

Dr Clare Fleming General Practitioner.
(Report Secretary)

Dr Alan Franklin Consultant Paediatrician, Essex Health Authority.

Prof Ariel Lant Prof of Pharmacology and Therapeutics, Chelsea and Westminster Hospital.

Dr Jeanette Naish GP and Senior Lecturer in General Practice, Joint Medical Colleges of St Bartholomew's & the London Hospitals.

Dr Derek Pheby Director, Cancer Epidemiology Research Unit, Bristol University.

Dr Colette Ray Senior Lecturer in Psychology, Brunel University.

Dr Richard Sykes Director, Westcare.
(Secretary)

Dr William Weir Consultant Physician, Coppett's Wood and Royal Free Hospitals.

Observers

Mr Sam Gallop Disability Living Allowance Advisory Board.

Dr Judith Hilton Senior Medical Officer, Department of Health.

Dr Hugh Nicholas Senior Medical Officer, Department of Health.

¹²⁵ Report from National Task Force on Chronic Fatigue Syndrome (CFS) Post Viral Fatigue Syndrome (PVFS) Myalgic Encephalomyelitis (ME) Appendix A, p 86 September 1994

B. Membership of the National Task Force on CFS/ME (1998 Report)

Task Force Services Group Membership¹²⁶

Members

Prof Peter Campion	Professor of Primary Care Medicine, University of Hull (Current chairman)
Dr Carlo Berti	Senior Medical Adviser, Pfizer LJK
Ms Trudie Chalder,	Senior Lecturer, Dept Psychological Medicine, King's College School of Medicine
Ms Diane Cox	Head Occupational Therapist, CFS Service, Havering Hospitals NHS Trust, Romford, Essex
Dr Clare Fleming	General Practitioner
Dr Ariel Lant	(Former chairman) Consultant Physician
Dr Anne Macintyre	Medical Adviser, ME Association
Mrs Mavis Moore	Chief Executive, ME Association
Mr Dick Patterson	Chairman, Dorset Group of the ME Association
Dr Virginia Pearson	Consultant in Public Health Medicine, North East Devon Health Authority
Dr Derek Pheby	Director, Unit of Applied Epidemiology, University of the West of England
Ms Kate Sweeney	Senior Physiotherapist, Coppett's Wood Hospital
Dr Richard Sykes	Director, Westcare
Dr William Weir	Consultant Physician, Coppett's Wood and Royal Free Hospitals

Representative of Royal Medical Colleges

Prof Simon Wessely	Director of CFS Research Unit, King's College School of Medicine
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Observers

Mr Sam Gallop OBE	Disability Living Allowance Advisory Board.
Ms Heather White	Department of Health

Secretarial support from Westcare:

Ms Kerren Davey, Ms Jo Francis, Ms Rosemary Lynn, Ms Helenna Michelska

¹²⁶ NHS Services for people with Chronic Fatigue Syndrome/Myalgic Encephalitis. The National Task Force on CFS/ME Appendix A p50 September 1998

C. Membership of the joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners¹²⁷

Sir Richard Bayliss
Consulting Physician, Westminster Hospital, London

Professor Leszek Borysiewicz
Professor of Medicine, University of Wales College of Medicine, Cardiff

Professor Robert Boyd
Professor of Paediatrics, University of Manchester

Professor Francis Creed
Professor of Community Psychiatry, University of Manchester

Dr Anthony David
Reader in Neuropsychiatry, King's College School of Medicine, London

Sir Anthony Dawson
Consulting Physician, St Bartholomew's Hospital, London

Professor Richard H T Edwards
Professor of Medicine, University of Liverpool

Professor Elena Garralda,
Professor of Child and Adolescent Psychiatry, St Marys Hospital Medical School, London

Mr John James
Chief Executive, Kensington, Chelsea and Westminster Health Commissioning Agency

Dr Sean Lynch
Senior Lecturer in Psychiatry, St James's University Hospital, Leeds

Dr Anthony Pelosi
Consultant Psychiatrist, Hairmyres Hospital, East Kilbride

Dr Tim Peto
Consultant Physician in Infectious Diseases, John Radcliffe Hospital, Oxford

Dr Leone Ridsdale

¹²⁷ Chronic fatigue syndrome Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners October 1996/CR54 Revised 1997

*Senior Lecturer in General Practice, Guy's & St Thomas's Medical and Dental School,
London*

Dr Margaret Thompson
Consultant Child Psychiatrist, Southampton General Hospital

Dr Simon Wessely
Reader in Psychological Medicine, King's College School of Medicine, London

Dr Peter White
Senior Lecturer in Psychiatry, St Bartholomew's Hospital, London

D. Membership of Department of Health CFS Working Group¹²⁸

Chair: Professor Allen Hutchinson, Director of Public Health, School of Health and Related Research, The University of Sheffield

Deputy Chair: Naomi Wayne, Chief Executive Action for ME

Dr Trudi Chalder, Senior Lecturer, Department of Psychological Medicine, Kings College Hospital, London

Dr Anthony Cleare, Senior Lecturer (Linbury Trust Fellow), Department of Psychological Medicine, Kings College Hospital, London

Roma Gant, person with ME

Jonathan Hull, person with ME

Dr Nigel Hunt, General Practitioner, Rivermead Gate Medical Centre, Chelmsford

Simon Lawrence, person with ME, Co-ordinator for the 25% ME Group

Mavis Moore, Chief Executive ME Association

Dr Derek Pheby, Epidemiologist, University of West of England

Dr Alison Round, Consultant in Public Health Medicine, North & East Devon HA

Dr Charles Shepherd, General Practitioner, Medical Advisor to the ME Association

Patricia Smith, carer

Dr Peter White, Consultant Psychiatrist, St Bartholomew's Hospital, London

Children's Group

Chair: Judith Waterman, retired Speech and Language Therapist Officer, Clinical Advice Team, NHS Executive

Judy Acreman, Senior Nurse Therapist, Child & Family Services, Ashurst Hospital, Southampton

Jane Colby, Child Services Development Officer Action for ME

Dr Alan Franklin FRCP, FRCPCH, DCH, Honorary Consultant Paediatrician, Mid Essex HA, Paediatric Medical Adviser ME Association and West Care, Chairman Children's Focus Group on ME/CFS West Care

Professor Elena Garalda, Professor of Child and Adolescent Psychiatry, St Mary's Hospital Medical School, London

Anna Grace Lidstone, Co-ordinator and Editor TYMES

Rachel Lynds, Association of Youth with ME

Dr Anne McIntyre, Medical Advisor to the ME Association

Mavis Moore, Chief Executive ME Association

Jill Moss, Director Association of Youth with ME

Dr Nigel Speight, Consultant Paediatrician, Family Services

¹²⁸ 1998/0487 "CFS working group membership announced" Department of Health 4th November 1998

Directorate, Department of Paediatrics, Dryburn Hospital, London

Reference Group

Maureen Carmody, Clinical Nurse Specialist, Department of Psychiatry, Royal Southampton Hospital

Dr Betty Dowsett, Honorary Consultant Microbiologist, South Essex NHS Trust

Dr Leslie Finley, Consultant Neurologist, National ME Centre

Tanya Harrison, BRAME (Blue Ribbon for the Awareness of Myalgic Encephalomyelitis)

Professor Tony Pinching, Immunologist, St Bartholomews Hospital, London

Dr Chris Richards, CHROME (Case History Research on ME)

Marie Simmons, Senior Counsellor Westcare

Kate Sweeney, Senior Physiotherapist, Royal Free Hospital, London

Professor Simon Wessely, Professor of Epidemiological and Liaison Psychiatry, Director CFS Research Unit, King's College School of Medicine, London

Dr Adrian Winbow, Consultant Psychiatrist, Hayes Grove Priory Hospital, Kent

Dr Andrew Wright, General Practitioner, National Medical Advisor Action for ME and 11 patients and 4 carers