

Chronic fatigue syndrome

SUMMARY OF A REPORT OF A JOINT COMMITTEE OF THE ROYAL COLLEGES OF PHYSICIANS, PSYCHIATRISTS AND GENERAL PRACTITIONERS

ABSTRACT—Chronic Fatigue Syndrome (CFS) is not a single diagnostic entity. It is a symptom complex which can be reached by many different routes. The conceptual model of CFS needs to be changed from one determined by a single cause/agent to one in which dysfunction is the end stage of a multifactorial process. Although it is important to recognise the role of factors that precipitate the condition, greater understanding is required of factors that predispose individuals to develop the illness, and those that perpetuate disability.

The relationship between CFS, viral infections and psychological disorders is still not completely understood. There is no evidence that infections have a primary causal role in the vast majority of cases, although they appear to precipitate the disorder in some. Previous personality factors and psychological distress appear to be more important than common viral infections. They may also play an important role in perpetuating disability.

The evidence for structural or functional abnormalities of brain or muscle, or for a disturbance of coenzyme or immune function as primary aetiological factors in CFS is weak. Many of the findings may be epiphenomena related to the confounding effect of psychological distress, sleep deprivation or prolonged inactivity.

The issues surrounding CFS in children are similar to those identified in adults but there is less research based evidence. The principles of assessment are identical, with the addition of a consideration of family and school factors. Most children should do well with simple management strategies involving behavioural activation, goal setting and return to school. A small number may need more specialist care. Management of children with severe CFS requires genuine multidisciplinary working and a commitment to physical and psychological rehabilitation.

Most patients should be managed within primary care, not in the general hospital. At present treatment should include appropriate education about the nature of the condition, encourage activity and reduce exercise intolerance, and address relevant psycho-

logical and sleep disorders. Recent trials of graded exercise and/or cognitive behavioural treatment indicate that these are helpful in management. 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.

In April 1995 the Chief Medical Officer (CMO) requested that the Conference of Royal Colleges produce a report on the subject of CFS with specific reference to the issues of management and service provision. The initial reason for the request was to enable him to respond to a report produced under the auspices of the charity Westcare, which exists to provide support for sufferers from ME (myalgic encephalomyelitis) in the west country. That report was produced by a committee under the chairmanship of Dr David Tyrrell, and was published in September 1994 [1].

In order to respond to the CMO's request the Presidents of the Royal College of Physicians and the Royal College of Psychiatrists, and latterly the Royal College of General Practitioners nominated an expert committee. This met on several occasions between July and December 1995 under the chairmanship of Professor Francis Creed. The members of the committee were drawn from medicine, psychiatry, paediatrics and general practice. Each had relevant clinical experience of this subject, and nearly all were actively involved in original research in the area. The non-clinical member was Mr John James, chief executive of the Kensington, Chelsea and Westminster Commissioning Agency, who contributed a summary with the purchaser specifically in mind. Members of the committee were asked to produce a series of short working papers, covering infectious diseases, immunology, adult psychiatry, neuroimaging, epidemiology, neurophysiology, child psychiatry etc. Specific instructions were given that the committee would be guided by the principles of evidence-based medicine. This is particularly relevant in the field of CFS, where opinions are often held with considerable intensity at variance with the quality of the evidence. Any recommendations were to be accompanied by published evidence, supplemented where necessary by clinical experience.

This paper summarises the final report, which has been approved by the councils of the three Colleges.

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References to the original literature are found in the full report [2].

Background to CFS

Chronic fatigue and CFS are not new. The illnesses now considered under these labels have been recognised for many years. An historical perspective induces a certain humility—we have been here before. Many of the problems that confront both patients suffering from fatigue syndromes and the doctors attempting to understand and heal them have been addressed in the past, sometimes more successfully than at present. Why, therefore, was this report requested at the time it was? One reason is the recent rise to prominence of patients with the label myalgic encephalomyelitis (ME), itself linked to several well publicised claims from both sides of the Atlantic of a viral aetiology for otherwise unexplained fatigue. Although these claims now appear premature they attracted considerable interest from patients, doctors and the media.

Raising the profile of the chronically fatigued patient was helpful, but the accompanying controversy was not. The debate on CFS/ME is often accompanied by simplistic and inaccurate polemics, especially the contrast between 'real' and 'unreal' disease, the latter frequently being seen as synonymous with psychological disorder. The label of ME is itself contentious; it is currently attached to too wide a range of conditions to be meaningful.

Definitions—what's in a name?

The most accurate term for the syndrome under consideration is the chronic fatigue syndrome (CFS). This can be operationally defined, a prerequisite for clinical research. It is a short and accurate label, free from unproven aetiological claims. Like other operationally defined conditions, it can be graded according to severity.

The committee rejected the use of the term ME. Encephalomyelitis describes a distinct pathological process, absent from this condition. Use of the term erroneously endorses the existence of a specific pathology for which there is no evidence. It has been suggested that there is a wide group of disorders, which fall under the term 'CFS', which is predominantly psychosocial, and a core called 'ME', which is more severe, has a characteristic pattern of fatigability and is primarily of organic origin. We found no evidence to support this. That group within CFS with more symptoms, profounder fatigability, greater disability, and longer illness duration is the subset with the strongest associations with psychological disorder. Such an association does not indicate that psychological disorder is the cause of greater disability. However, suggestions that the greater the severity of symptoms or disability, the greater the chance of finding an 'organic' aetiology, are misguided.

Key points

The term chronic fatigue syndrome (CFS) can be defined for clinical and research purposes. The term allows clinicians to communicate effectively with patients to propose a management plan, while admitting understanding of the syndrome is incomplete. The term and similar terms are used to cover a wide variety of other complaints. They cannot be used for research and may mislead patients into believing a serious and specific pathological process affects muscles and brain. The value of research in this area is enhanced if future studies use standardised criteria including a measure of severity, for the purposes of comparison.

Epidemiology

The historical literature contains many examples of outbreaks of unusual illnesses, often in institutions, of which the best known was the serous episode that affected the staff of the R Hospital in 1955, and was the origin of the term 'myalgic encephalomyelitis'. The aetiology and mode of the contagion in these epidemics have not been satisfactorily explained, with competing infectious and psychological explanations proposed. There are clear distinctions between so called epidemic and sporadic cases of CFS. The case descriptions of epidemic cases differ from those of the sporadic cases that are the concern. The epidemics themselves have been defined, heterogeneous and often poorly resolvable with different case descriptions and different modes of transmission. It is improbable that a common explanation exists uniting these phenomena under the shared name. It is misleading to apply tentative conclusions from the study of epidemic cases to modern CFS.

The epidemiology of sporadic CFS is a source of confusion. Many reports of its national prevalence have been based on expert opinion of specialists. However, the characteristics of these patients do not reflect the position in primary care. The observation that sufferers tend to come from higher social classes and from certain professions most likely reflects selection bias and treatment seeking behaviour. Systematic studies of the community and primary care suggest that CFS is commoner than previously assumed and does not have a characteristic social class distribution, although most fulfilling the criteria do not seek help under the name of CFS or ME.

Key points

- *The population point prevalence of CFS in primary care is 0.1–0.9% using restrictive (US) criteria that exclude patients with psychiatric disorder, and 1.5–3.0% using the broader Oxford criteria.*

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- There is no clear link to social class or occupational group—these associations relate to attendance at tertiary centre clinics, not prevalence in the general population.
- There are no reliable data on incidence, except after EBV infection.
- Most primary care or community cases of CFS fulfil criteria for common psychological disorders; a proportion (25–40%) do not.
- Functional disability may be marked in CFS—the greater the impairment, the greater the psychological morbidity.

Aetiology

Virology

There have been many claims over the years linking viral agents with CFS. Currently, most patients seeking specialist help report that their illness began with a viral infection. The committee reviewed the various methods in which viral agents might be associated with CFS. The first is that the infecting agent might persist within the body in either an abnormal fashion or abnormal site. We were unable to find any compelling evidence that viral persistence is uniquely identified with CFS. Claims for enteroviral persistence as the cause of CFS have generally not withstood replication. CFS may be triggered by certain infectious episodes. The best evidence comes from longitudinal studies of the outcome of glandular fever, with additional evidence for some other, less common agents such as infectious hepatitis or viral meningitis. The risk of chronic fatigue and CFS after viral infection is significantly increased if there was evidence of excessive fatigue and/or psychological distress before acquiring an infection.

Key points

- At present there is no convincing evidence that common viral infections are a risk factor for CFS, with the exception of the fatigue syndrome that follows EBV. Viral infections may be only one of several possible aetiological factors in CFS, which should be regarded as being multifactorial in origin.
- Less than 10% of those with EBV infection develop CFS—the factors that distinguish these 10% from the remainder need to be explored.
- Studies in primary care have found that psychological distress, excessive fatigability and perhaps attributional style prior to clinical viral infection, are risk factors for the subsequent development of CFS.
- Future research needs to consider predisposing factors (eg personality, lifestyle, prior fatigue, prior depression, genetics), the trigger or precipitant (eg viral illness) and maintaining factors (eg absence of a clear diagnosis, reduced exercise tolerance, societal focus on undetected infectious agent and advice to stop work).

Muscle dysfunction

The report identifies ten studies dealing with muscle function and CFS. There is no consistent evidence of a primary disorder of muscle in most, and no evidence of any changes in muscle structure that could not be explained by the consequence of illness. This is consistent with the frequent observation that fatigue in CFS affects both physical and mental functioning, and is worsened by physical and mental effort.

Immunology

The Committee were aware of a considerable number of studies of possible immune dysfunction in CFS. There are technical differences between studies, perhaps explaining the inconsistent nature of the reported findings. The possibility that any changes might be secondary to confounders such as neurohormonal variables, sleep disorder or psychological distress has been insufficiently addressed. The presence of immunological dysfunction has not been associated with clinical status or clinical outcome. This is an area for more multidisciplinary research.

Psychiatry and neuropsychiatry

We agree that chronic fatigue syndromes often do not fit neatly into the conventional view that disease is either 'physical' or 'psychological' [1]. In this respect, CFS does not present a new or unique problem in medical practice. It illustrates the difficulty that modern medicine sometimes has in responding to disorders that have both physical and psychological components, and the limitations of an over-narrow biomedical model.

There are over 20 published studies concerning the possible role of psychiatric disorder in CFS. Between one half and two-thirds of individuals seen in either primary or specialist care with a diagnosis of some form of chronic fatigue syndrome also fulfil criteria for psychiatric disorder, chiefly depression, anxiety or somatisation disorder; in all studies, at least one third do not.

There are a number of explanations for these findings. The first is that psychiatric disorder is simply a reaction to physical illness. However, five studies that compare CFS with chronic neuromuscular or rheumatological disorders show that this is untenable.

The possibility of selection bias was also considered, but studies in primary care have shown similar associations. The report favoured three, overlapping explanations. The first is that CFS and psychiatric disorder share a common origin in both neurobiological and psychosocial dysfunction. The second is that the overlap is partly artefactual, since the operational definitions for CFS and the common psychiatric disorders themselves overlap. The third is of misdiagnosis. The key word is heterogeneity—we noted a recent study

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that suggested that in some patients symptoms were associated with psychiatric disorder, some with abnormal exercise responses and some with neither.

We also considered the welcome recent upsurge of neurobiological research into CFS, including studies of neuropsychology, neuroimaging and neuroendocrinology. At present no particular pattern can be discerned in the results. Formal disorders of intellect and memory cannot be confirmed in CFS, despite the severity of the subjective complaints, but a disorder of sustained attention seems probable. Functional neuroimaging shows abnormalities, but whether these are associated with psychological morbidity, or indeed are a consequence rather than a cause of cognitive difficulties, remains to be determined. There is no pathognomonic neuroimaging finding in CFS, nor is neuroimaging a diagnostic tool. Finally, we noted recent work on the neuroendocrinology of CFS indicating a disturbance of the hypothalamic-pituitary axis (HPA). Such work has considerable attraction, since the function of the HPA axis has relevance to the clinical characteristics of CFS. However, the nature of these abnormalities remains to be confirmed; recent research has suggested that some are secondary to other behavioural changes in CFS, such as sleep disorder.

Key points

- CFS cannot be considered either 'physical' or 'psychological'—both need to be considered simultaneously to understand the syndrome.
- The depression which is found in one half of patients cannot simply be regarded as secondary to the disability and uncertainty associated with CFS.
- The number of psychiatric symptoms increases with number of somatic (bodily) symptoms—the most severe forms fulfil criteria for somatisation disorder, in which disability is profound.
- Structural and functional neuroimaging and neuroendocrine investigations have not led to consistent abnormalities being demonstrated in CFS. More clearly established normal ranges are necessary to interpret the observed abnormalities. These changes may be characteristic to some subgroups, but may also be due to such confounding factors as sleep disturbance and prolonged inactivity.
- Reports of cognitive abnormalities are similarly inconsistent.
- Current findings in relation to muscle dysfunction and immune abnormalities are open to several interpretations. There is no compelling evidence for a substantial primary role of neuromuscular dysfunction.
- Further research should be encouraged into neurobiological aspects of CFS, using adequate case definitions, sample descriptions and assessment of confounders.

Presentation, assessment, investigation and

At the core of CFS is the concept of easy to profound fatigue, which is made worse by physical or mental exertion. Symptoms called 'key features' or 'typical' are not monic, and can be encountered not only in fulfil the operational criteria for CFS, but also conditions, physical or psychological. The diagnostic abnormal physical signs in CFS patients complain of sore throats, but clinic gitis is unusual. Some patients develop tender lymph glands. Clinically significant lymphadenopathy should not be accepted as CFS—a cause for it must be sought.

Patients need to be assessed using a biopsychosocial approach. Some doctors and patients require that biological and psychosocial need to be assessed with equal thoroughness. Many medical clinics are ill-equipped to offer a full social assessment. Generic mental health services also lack the relevant skills, or be unacceptable to the patient.

The report strongly endorses the role of primary care in the management of CFS. It emphasises the importance of early treatment in primary care to develop a beneficial therapeutic doctor-patient relationship and to attempt to prevent chronicity. There are still problems and mutual misunderstanding. We are aware of claims that some do dismiss the patient's symptoms with such phrases as 'pull yourself together', although such reports are rare.

In assessing patients with excessive fatigue, it is important to strike a balance between under-investigation and over-investigation. There is too often a tendency to investigate possible physical illnesses to the exclusion of possible psychological disorders to be investigated. The need for investigations will be determined largely by the results of a good clinical physical and psychiatric examination, all of which should be mandatory. Unless there are pointers in the clinical examination, detailed laboratory investigations are largely unhelpful in anyone with fatigue lasting more than six months. Studies of selected patients have revealed changes in some laboratory tests, but these are encountered only in a minority and are rarely substantial, and do not lead to any change in clinical management. Their significance should be assessed by researchers rather than clinicians. There are no laboratory tests that establish or confirm a diagnosis of CFS, and none should be performed for that purpose.

The following simple tests are a compromise between under- and over-investigation.

- Full blood count
- Acute phase protein changes (ESR, CRP)
- Liver function tests
- Urea and electrolytes
- TSH and free thyroxine

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- creatine kinase
- urine test for protein and sugar

The aims of assessment for patients presenting with symptoms suggestive of CFS may be summarized as follows (Table 1):

The prognosis for patients with the label 'ME' who reach specialist care is a cause for concern. The majority of those seen in specialist clinics continue to have persistent symptoms and/or disability on follow up. However, these findings are influenced by selection factors. The natural history of CFS in the community or primary care remains obscure.

No laboratory markers, virological or immunological, have been shown to predict outcome. On the other hand, four studies have found that poor outcome is associated with social, psychological and cultural factors. These include the strength of belief in a solely physical cause for symptoms, untreated psychological distress, and the use of avoidant coping strategies (such as reducing activity, dietary, social and other restrictions).

The report also considered the use and abuse of the diagnosis of CFS. At present a diagnosis of CFS can be of use in clinical practice as a structure for patient understanding and a model for treatment. If a doctor chooses to use the label, he or she must be also able to give appropriate management. Whatever label is chosen, it is essential that the doctor accepts the patient's distress as genuine. No patient should ever feel their credibility is doubted. There is no place in the clinical consultation for such statements as 'there is nothing wrong with you' or 'it is all in the mind', just as there is no place for such statement as 'you have ME—there is nothing I can do'.

Key points

- *Profound fatigue, made worse by minimal physical or mental exertion, lies at the core of CFS but there are no other cardinal features, abnormal physical signs or laboratory tests which can confirm the 'diagnosis'.*
- *Biopsychosocial investigation is essential—this is best provided in primary care. Secondary care units should provide facilities for such assessments when required.*
- *Unless there are atypical features, limited investigation for alternative diagnoses is appropriate and should be accompanied by assessment of patient's disability, psychological state and illness beliefs.*
- *Untreated, the prognosis for those seen in specialist care is of concern. The prognosis in primary care remains uncertain, and requires further research.*

Management

Good clinical management relies on the biopsychosocial approach. The doctor should give relevant information, seek to solve problems, look at coping strate-

Table 1. Aims of assessment

- 1 To clarify the nature of the complaint and consider alternative diagnoses
- 2 To assess the current disability
- 3 To elicit the beliefs and fears of patient and family about symptoms, diagnosis, and treatment
- 4 To elicit the beliefs of patient and family about the role, benefits and consequences of rest and activity
- 5 To identify psychological distress
- 6 To formulate the problem in terms of predisposing, precipitating and perpetuating factors
- 7 To provide a basis for negotiating a management plan

gies and use a multidisciplinary approach. Depression or anxiety, when identified, should be treated.

The committee was aware of the frequent misgivings and misconceptions that continue to surround the subject of activity, exercise and rest in CFS. The report strongly affirms that cautious, controlled increases in activity remain the cornerstone of the management of CFS. Overcoming the consequences of reduced or variable levels of activity by a programme of controlled increase in activity, often over a time-scale measured in weeks or months, is a crucial part of good clinical care. Rest 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. Activity can be restored in a number of ways. Simple exercise programmes are used in several centres, supported by two randomised controlled trials. There is no evidence that cautious exercise leads to permanent damage or disability in CFS. However, the intensity of exercise should be chosen in the light of the subject's current capabilities based on knowledge of the degree of physical unfit-ness and deconditioning. The setting of realistic goals that can be increased in a stepwise manner is important. Over-ambitious or aggressive exercise programmes, or following advice to 'exercise away the fatigue' are likely to fail. This can be understood by reference to exercise physiology and the neuromuscular response to unaccustomed activity, and does not imply any pathological process specific for CFS. Many CFS sufferers adopt a pattern in which brief bursts of activity, inevitably followed by a worsening of the symptoms of pain and exhaustion, in turn give way to periods of prolonged rest and avoidance of activity.

Effective psychological and physical management may involve replacing varying activity level with a consistent programme of rest and activity, avoiding extremes of both. Patients should be advised that such a programme of gradually increasing activity (in which each increment may be spread over several weeks) may

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cause a transient (activity associated) rather than a persistent, increase in muscle fatigue and pain.

Cognitive behaviour therapy (CBT) is another collaborative approach to rehabilitation that incorporates elements of attributional change (looking for alternative explanations for symptoms), activity management and graded target setting. A recent systematic review of three randomised controlled trials concluded it is a promising and cost effective approach recommended for the outpatient management of CFS.

The prevention of disability, particularly in primary care, requires encouragement to be active. Prolonged rest is associated with secondary disability. We are therefore concerned about such advice as the need to reorganise life in order to 'live within your limits', which carries a risk of perpetuating disability. Certain illness beliefs may have an adverse effect on outcome—such as the fear that any activity which causes an increase in fatigue is damaging; that 'doing too much' causes permanent muscle damage; and that CFS is irreversible or untreatable. Such inaccurate beliefs might fuel avoidance of activity, and then be powerfully reinforced by the pain and fatigue which inevitably follow each attempt to resume previous levels of activity. This in turn might lead to increasing restriction of activity, frustration, loss of control and demoralisation.

There is also anecdotal opinion suggesting that rehabilitation needs to take account of the 'stages' of illness which usually implies that during 'active' phases of illness patients need to restrict their activity. We know of no evidence to support this. Two classic randomised controlled trials suggest that early exercise in the aftermath of a proven viral illness is not only safe, but beneficial.

Many sufferers make significant lifestyle changes as a result of illness. These may include altering their response to stressful events, adjusting their work and leisure goals, altering their coping strategies, and reassessing their priorities and values. These need to be acknowledged, but in the context of encouraging recovery and preventing relapse, rather than reinforcing further withdrawal.

Drug therapy

The list of treatments for which therapeutic claims are made in the context of CFS is a source of concern. There is no systematic evidence supporting any drug regime for CFS. We found no role for immunoglobulins, antihistamines, other immunotherapies or antiviral agents. Experimental treatments such as immunotherapy should be given only as part of controlled clinical trials. The committee saw no role for vitamin or dietary supplementation, and was unconvinced of the efficacy of magnesium or evening primrose oil.

Antidepressants are used by a variety of clinicians involved in the care of patients with CFS. At present

most of the favourable evidence comes from controlled studies. Two placebo-controlled studies of fluoxetine are inconclusive—one study showing evidence of efficacy the other finding no evidence. At present we continue to endorse the use of antidepressants in those CFS patients with depression whilst accepting that the evidence is inconclusive for other indications.

Key points

- *Acceptance of the patient's symptoms and establishing a therapeutic alliance are the starting points for the management of CFS.*
- *Gradual, planned, mutually agreed and monitored increase in exercise, forms the cornerstone of management. Excessive rest and the pattern of alternating under-activity are counterproductive.*
- *Cognitive behaviour therapy has been shown to be effective in recent controlled trials.*
- *Some patients need help to adjust their previous lifestyles to one of consistent and more moderate activity.*
- *More randomised controlled trials of treatment, in primary care, are required.*

Children

CFS does occur in children and adolescents, but there is no firm information on its prevalence. We are aware of no evidence that severe forms are more common in children than adults. The symptoms encountered in children are similar to those in adults. The one point of divergence between children and adults is that the six months duration criterion may be too long for children; three months may be more appropriate. CFS in children may, as in adults, be triggered by certain infections such as glandular fever, but there is no evidence to support abnormal viral persistence as a cause of long term disability.

Published studies of CFS in children, all from specialist centres, show the important contribution made by psychosocial factors. The symptoms of depression is important and common. As with adults, emotions such as frustration are encountered together with feelings of loss related to time away from school and impairment of social relations. Anxiety is also common. Many children attending specialist centres with a diagnosis of CFS are high achievers and often have anxieties about their school performance, which cause them to work excessively hard to achieve at the limits of their ability. Overall, we think that relevant psychological factors contributing to CFS in children may involve a complex family dynamic involving high expectation, limited communication on emotional issues and previous experience of illness. School phobia is important, both as a potential diagnosis and a complication of CFS. The

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resume school attendance does not exclude the diagnosis; children may have profound anxieties about attendance despite a strongly expressed wish to resume schooling.

Assessment:

It is important to appreciate the validity of the child's complaints. Children are as, if not more, sensitive to any suggestion their ill health might be spurious, or 'all in the mind'. Acknowledging the reality of the child's symptoms reduces the risk of a defensive reaction by either the child or family. Thus, although exploration of education, family and psychosocial issues is always indicated, this must always be done with tact and sensitivity, especially as many families continue to see the problems as solely 'organic'.

Investigation:

As in adults, it is essential that a full clinical history and physical examination is performed in every case, but the number of physical investigations should be kept to a minimum unless there are specific pointers in the history or examination. Laboratory investigations are usually unhelpful, with the exception of tests for infectious mononucleosis. Recent EBV infection can only be diagnosed by the presence of the VCA IgM antibody.

Management:

No randomised trials exist to inform appropriate management in children. Case series from specialist centres report the success of behavioural activation packages, often linked with a family therapy approach. Tuition at home should be reserved only for the most severely affected and should be for as short a time as possible, and always in close liaison with the school. In severely affected children, work with the family and liaison between health and education services is invariably required.

Outcome:

A recent paper reported the outcome of a case series of 50 children with severe chronic fatigue, most of whom recalled a triggering symptomatic infection. A programme beginning with careful assessment and engagement, followed by symptomatic relief, reduction of secondary gain, insisting on regular school attendance and the gradual resumption of activity despite ongoing fatigue, resulted in a good outcome in 94%. Such findings are uncontrolled and based on selected cases, but contradict unsupported statements such as 'the average length of illness in teenagers lasts about four and a half years'.

Service provision

Most children ought to be adequately managed by a combination of primary care, school nurse and school authorities, with the support of local paediatric, psychiatric or psychology services where appropriate. Referral to a specialist team may be indicated if there is evidence of specific psychiatric disorder, severe or prolonged disability, or family factors interfering with progress. In the absence of such factors, basic management involves reassurance, explanation, exploration and alleviation of school factors (learning difficulties, exam stressors, bullying), basic goal setting and monitoring with planned increases in activity and planned return to school. These can usually be provided by the GP or primary care team, who will need to monitor the child and family closely. Good clinical practice for severely affected children will usually involve access to a combined unit with facilities for assessment, treatment and rehabilitation. Such units will require close cooperation between paediatricians and psychiatrists. The necessary skills may involve psychology, occupational therapy, nursing, physiotherapy, dietetics and education.

Key points

- *The presentation and management of CFS in children is similar to that of adults. The time criterion for CFS may be shorter than for adults. Early rehabilitation is particularly important.*
- *Multiprofessional care is appropriate especially for more severe problems.*
- *There is an even greater lack of systematically acquired data in children than in adults with CFS and more research is required, particularly on treatment.*

Facilities and service provision

Overall, the report emphasises that the management of CFS is first and foremost the responsibility of the primary care team. The majority of cases can be managed satisfactorily in primary care provided that:

- the GP has sufficient understanding, sympathy, and skills to manage the condition
- other members of the primary care team (physiotherapist, social worker and/or psychologist) can be involved when necessary.

Nevertheless a small number of patients may develop severe, prolonged or complex disabilities that require specialist care. This is an area of unmet need which we see as broader than the narrow perspective of CFS, including chronic functional symptoms and syndromes such as irritable bowel, fibromyalgia, non-cardiac chest pain and chronic pain. All these overlapping syndromes are associated with morbidity and high resource consumption. Their management is

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unsatisfactory for both doctor and patient. There is a need for a reconfiguration of general hospital services to address these problems more effectively and efficiently [3].

Service provision for CFS should combine a physical and psychological multidisciplinary care approach. All models for delivering such care involve some form of multidisciplinary working and some form of rehabilitative management strategies. Table 2 gives the essential skills necessary for the task.

Implications for purchasers

In an appendix the report includes some implications for commissioners. The conclusions point out to

purchasers that it is likely that CFS is already consuming significant resources in both primary and secondary care, some of which has been to the benefit of the patient. Purchasers should be aware of recent developments in good clinical practice to improve this situation, whilst acknowledging the timing uncertainties surrounding the care of the condition.

Commissioners of services can take immediate steps to identify which specialist units in their region are best equipped to treat patients with established CFS. They should review with those units their knowledge and understanding of the issues raised in the Joint Commission Report, and to draw the findings in the report to the attention of GPs. More effective management particularly at the primary care level should avoid waste of resources.

Table 2. Essential skills/tasks for a multidisciplinary CFS unit. Ability to:

- 1 Take a full history and carry out an appropriate physical examination
- 2 Obtain information on emotional issues such as depression, anxiety, hopelessness and suicidal risk
- 3 Obtain information on attributions, coping strategies and previous experiences of treatment
- 4 Perform the minimum number of investigations
- 5 Provide appropriate and unambiguous reassurance when there is no evidence of relevant physical pathology
- 6 Provide appropriate and acceptable explanations for symptoms such as pain, fatigue, dizziness and so on
- 7 Plan individually tailored rehabilitation programmes aimed at increasing activity, improving confidence and restoring control
- 8 Recognise when and how to obtain specialist medical/psychiatric/psychological opinions
- 9 Remain informed about current evidence on CFS
- 10 Provide outcome data

References

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- 3 *The psychological care of medical patients: recognition of a need for provision*. London: The Royal College of Physicians/Royal College of Psychiatrists, 1995.

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CHRONIC FATIGUE SYNDROME

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