ME & CFS: A REPORT FOR THE WELSH ASSEMBLY GOVERNMENT

Produced by

WAMES (Welsh Association of ME & CFS Support)

February 2004

Introduction

There could be as many as 11,600 sufferers of ME and CFS in Wales - 0.4% of the population. [1]. Twenty five per cent of those could be severely affected (i.e. housebound or bedbound). All ages and both sexes can be affected. In a recent study it was found that the cost of the illness to Wales is £171 million in medical costs, benefits payments and lost earnings. [2]

1. Nature of ME

1.1 Terminology & history

ME is not a new illness. In the early part of the 20th century it was named after the geographical location where viral outbreaks took place, or by the term atypical poliomyelitis.

In the later 1980s psychologists, principally in the USA, attempted to reclassify the illness as Chronic Fatigue Syndrome (CFS). This term did not become accepted in the UK until it was endorsed by the Royal Colleges in 1996 [3], in spite of widespread opposition.

In the USA the illness is called Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) though new criticism of this terminology means that it is now under review.

The WHO has recently reaffirmed its classification of ME and CFS as 2 separate conditions with ME as a neurological illness and CFS as a mental health problem.

One of the problems that patients have with the term CFS is that it highlights only the fatigue element which is just one of the main symptoms. This fatigue is also often misunderstood as little more than extreme tiredness. The umbrella term ME/CFS and latterly CFS/ME has been adopted by some to denote a spectrum of disorders with a fatigue element, not necessarily all of physical origin.

When reading documents and research papers it is important to determine which meaning is behind the terminology used, before it is possible to compare results and theories.

WAMES opted to follow the WHO's classification when choosing a name for the association and when compiling this document, in order to distinguish between the neurological and psychological conditions of ME and CFS. We recognise however that confusion abounds and that there is not an agreed terminology in either the patient or medical world.

1.2 Cause/s:

Psychosocial theory

The causation theory held by some psychiatrists, notably Prof. Simon Wessely of King's College, is that CFS is the result of three problems:

- inactivity (which increases de-conditioning and exacerbates fatigue);
- physical attributions or a wrong belief that the illness is viral and incurable, which induces hopelessness);
- depression.

According to the King's College team, the persistence of all CFS is therefore the result of psychosocial factors, not biological ones. [4]

This is a difficult theory for patients to accept. On the one hand research shows that physical dysfunction persists and on the other, they see friends endure, or experience for themselves, the failure of the treatments that they are told should cure their condition (ie inflexible CBT and GET). This has led to close scrutiny of the writings of Prof. Wessely and his colleagues. Many inconsistencies have been noted and questions raised about the nature and quality of their research. An example of this kind of critique can be found at the 25% ME Group's website. [5]

Biological theory

Increasingly a number of researchers are becoming convinced that ME is one of a group of post-viral neurological disorders that include post-polio syndrome (PPS), Guillain Barre Syndrome (GBS) and Multiple Sclerosis (MS).

Many ME clinicians characterise the illness by the dysfunction that they have found in their patients. For example the National ME Centre, based in the Department of Neurology at Harold Wood Hospital in Romford, Essex, has, like others, come to the conclusion that:

"ME, or Chronic Post Viral Fatigue Syndrome, is primarily a brain disorder which typically occurs in a vulnerable individual, often at a time of stress, as a consequence of a viral or recurrent viral infection… Our concept is that chronic fatigue syndrome (ME) represents a profound disturbance of functioning of the nervous system (brain) and its connections with the immune system and endocrine system (hormone)." [6]

The acceptance of a biological origin and the continuation of obvious physical symptoms, does not mean that both physical and mental stressors cannot exacerbate the condition. In some cases, psychological problems serve to progress the illness. Clinicians vary in their assessments of the extent to which these other factors can influence the illness. Some believe that it will vary from patient to patient.

Environmental theory

It is becoming increasingly evident that a new range of illnesses triggered by exposure to invasive chemical toxins share a similar range of symptoms to those of ME and could result from similar nervous damage. These include organophosphate poisoning (OP), Multi Chemical Sensitivity (MCS) and Gulf War Syndrome (GWS). Symptoms can also develop following reactions to vaccinations and antibiotics. Recovery or significant improvement is claimed by some through nutrition therapy, allergy desensitisation, lifestyle changes etc. Some doctors suspect that chemical poisoning can weaken the immune system so that it is unable to cope adequately with a subsequent viral infection. [7]

1.3 Symptoms

In January 2002 the English CMO's report on CFS/ME was published (5), stating that CFS/ME is a chronic illness. The report had been commissioned before devolution so was originally intended to be applicable to the whole of the UK. It includes evidence of the extent of distress and disability that patients with an ME symptomatology can experience. It is a very long document but a useful guide has been published by AfME. [8]

There are many other documents which describe the effect that the illness has on patients and family. The following description describes the experience of most of our members:

"The condition is characterised by extreme debilitating and disabling exhaustion, muscle pain and a severe 'flu-like' malaise. People can experience a wide range of symptoms, the main ones include digestive problems, difficulties with concentration and memory, loss of balance, sleep disorders, mood swings, migraine-type headaches, persistent sore throat & swollen glands, visual disturbances and poor temperature control.

The major characteristic of the illness however is that symptoms become worse after physical and mental exertion, although the reaction can be delayed a day or more. The other annoying characteristic is that symptoms fluctuate, you just never know what to expect. There can be periods of remission and relapse leaving sufferers and families alike, confused and frustrated." [9]

The GP's guidelines based on the English CMO's report gives a similar description on page 2 under Symptoms [10]. The children's charity AYME has produced a Functional Ability Scale [11] which gives a good idea of the various levels of disability patients can experience.

1.4 Children & young people

Children as young as 3 or 4 have been diagnosed with ME. There are some differences in the way that children present with the illness. Onset is often more gradual in young children, and their daily behaviour is more variable, with no apparent initiating infection. Symptoms such as severe headache, abdominal pain, loss of appetite, and nausea are more common. They are also much more likely to be disbelieved and their illness can seriously disrupt their education, with long term consequences for their personal development and ability to be self-supporting. [12]

Young people describe the way the illness makes them feel on the AYME website. [13] West Wales sufferer Beth Llewellyn talks about her struggle with ME on the BBC website. [14] In his book *Faces of CFS*, Dr David Bell describes the symptoms and struggles of 10 of his adult and young patients. [15]

1.5 Prognosis

Prognosis is difficult to predict and we are not aware of any studies done on individuals (as opposed to mass outbreaks). Patient groups have found that some make a gradual return to full health, especially if they have had an early diagnosis and follow an appropriate management plan. Children are much more likely to make a good recovery than adults, if they receive appropriate support.

The majority will make variable progress struggling with relapses and remissions, and some may reach 70-80% of previous level of functioning. About 25% remain severely disabled.

2. Current state of research

Much that is written in the British medical press about CFS is by psychiatrists referring to a Functional Somatic Syndrome. There are in fact many doctors and scientists around the world who, through clinical experience or scientific research, are convinced that there is also an existing neurological condition, ME, classified by the WHO (ICD -10 G93.3). ME researchers often find it difficult to get published in the UK, even if they are eminent people and their work is peer reviewed. This makes it difficult for health professionals to get an accurate picture of the range of illness covered by the term CFS/ME. We hope that the criticisms in 2003, both from within and without the medical press, of the validation of research and the peer review process will lead to improvements in this situation.

2.1 York Review & Effective Health Care Bulletin

The Working Groups for the English CMO’s report commissioned a review by the University of York of the literature on CFS and ME. They based their report on this. This review later formed the basis of the Department of Health’s *Effective Health Bulletin* which assessed 7 different categories of intervention and recommended only 2 as being “evidence based” – Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET). [16] A more detailed study was then published in Sep 2002 [17]. The CMO’s report had recommended Pacing, in addition, as surveys of patients had found that they felt they had benefited most from this technique. The Bulletin recommended a study to evaluate pacing in comparison with CBT and GET, which is due to take place from 2004. [18]

Patients and ME charities have complained that the Review omitted much of the research into the physical nature of the illness and the ineffectiveness of rehabilitation approaches, while some poorly defined research supporting a psychiatric understanding of the illness was included, thus giving a misguided impression of the state of research. The Review and report did however highlight the urgent need for good quality research into all aspects of CFS/ME. In fact it commented that the very few existing studies were of poor quality (which presumably means that the evidence base for CBT and GET is weak). It also highlighted the fact that research has not been done with the severely affected and only one study looked at young people, raising questions about the applicability of the findings to all people with CFS/ME.

2.2 MRC Research Strategy

The 2003 MRC research strategy [19] also highlighted the urgent need for research but did not believe that research into the physical cause/s should be a priority. We are at a loss to understand how effective interventions can be found without this knowledge! They seemed unwilling to recommend new areas of research in the area of pathophysiology and were very selective about which research to follow up. We do not understand their rejection of the extensive research which has already pointed towards immunological and neurological dysfunction in ME, much of which has been “peer reviewed”. Some proponents of the psychiatric school of thought have also ignored this research however.

The issues of terminology, clinical & diagnostic assessment and health services provision were also, inexplicably, not considered priorities for research. The Research Advisory Group did however accept the seriousness of the condition and acknowledged the increasing evidence that a number of sub groups exist under the CFS/ME banner. The call for improved methodology in research and for studies to include young people and the severely affected was timely.

We accept the importance of studying interventions to help patients use the most appropriate management skills and find symptomatic relief. We query the value of further research into CBT and GET and would prefer to see research that might help a large number of ME patients, as classified by the WHO under ICD10 - G93.3. We understand however that some members of the Research Advisory Group have published papers on these theories and therefore have an interest in them. This perhaps explains some of the unsubstantiated conclusions made in the report about the strong link between depression and CFS (definition of term uncertain), psychological factors and illness severity and duration, and that fatigue/weakness is due to a ‘vicious spiral of immobility’. We would prefer to know how efficacious the drug and complementary therapies, and self-management packages are, which many patients are already using.

We feel that this Research report is a useful first step towards shaping future research but has many flaws and does not present a full picture of research into ME and CFS. In fact, the summary report of the consultation questionnaire, annex 2, pp 34 – 41, describes the strong feelings of ME patients, clinicians and researchers about the shortcomings of current research and their preference for prioritising research into physical causation of the illness.

2.3 Major textbook

The major scientific text on ME, *The clinical and scientific basis of ME/CFS*, by Dr Byron M Hyde et al [20] includes contributions by 72 of the world’s leading ME clinical specialists and researchers. It outlines the findings of the infectious origins of ME, effects on the muscles, heart, central and peripheral nervous systems, immune systems, neurological functions and blood cells. Any serious consideration of ME has to include this volume.

2.4 ME Research Groups

The major ME research groups in the UK are the *CFS Foundation* (previously the *Persistent Virus Research Foundation*) [21] and *MERGE* (*ME Research Group for Education and Support*) [22]. The *Ramsay Research Fund* has also produced some quality research in the past, but is winding down due to lack of funding.

2.5 CFS Research

Research into a broadly defined category of illness called CFS has been largely funded by the Linbury Trust over the years, with it’s sister organisations the Sainsbury Trust and the Gatsby Foundation. The majority of the Linbury fellows and most, if not all the funding was given to psychiatrists. In 1998 a collection of their research conclusions was published which promoted an understanding of CFS as a psychosocial illness. [23]

2.6 Guides to research

MERGE has produced a brief introduction to the problem of ignoring the research into physical illness. [24] It discusses the problems caused by the plethora of definitions in current use and the bias towards a psychological understanding. It also introduces the major research developments in the field of immunology and neurology. The MERGE website also contains a database of studies into ME and related illnesses, although it is restricted to data compiled from searches of easily accessible indexes.

Dr Ellen Goudsmit's guide to recent research results [25] includes those which are often “missing” from other reviews, and includes the possibility of a persistent enterovirus; abnormalities in muscles, brain, immune system and autonomic nervous system. She also includes studies which found GET to be unhelpful, and which found differences between ME and depression, FSS and other fatigue syndromes. In addition she publishes quarterly updates of ME/CFS research references on Axford’s Abode ME/CFS website. [26]

The Co-cure website also maintains an extensive list of completed research into ME and CFS. [27]

2.7 CBT & GET

The research carried out into these 2 interventions have caused more concern to the ME community than all the other research combined. – see 4.10

Psychologist Dr Ellen Goudsmit challenges the validity of much of the research into CBT and GET in articles on Axford’s website and quotes studies which contradict their findings, (she uses the term CFS to mean a physical illness):

- it’s not clear which sub group/s of patients participated but it is unlikely that many studies included patients with strict ME.
- depression does not affect outcome
- believing in a physical illness does not inhibit recovery
- relationship between inactivity and fatigue in CFS has not been proven
- pacing activity (as opposed to gradually increasing activity) has led to improvements
- there is no evidence that every patient with CFS hold the same beliefs about their illness.
- illness beliefs may be accurate and changing them would be inappropriate!
- in general, the level of activity among CFS patients is the same as that found in people with MS
- there is no evidence that CFS patients spend an unreasonable amount of time resting
- ‘inactivity’ does not lead to CFS symptoms in other sedentary groups, e.g. those recovering from a broken leg, prisoners etc.
- ‘inactivity’ does not explain cognitive deficits, intolerance to alcohol, sore throats, vertigo and the other less publicised symptoms of CFS.
- ‘inactivity’ does not explain some of the muscle function abnormalities which have been found
- lack of stimulation would produce global impairments in cognitive function, not the specific ones documented to date
- The majority of patients with CFS do not have a history of major depression, and rates of current depression generally resemble those of patients with MS or cancer. Depression is different from, and cannot explain CFS. The same is true for anxiety. [28]

2.8 Young people & severely affected

The main piece of research done into children and ME surveyed the13 epidemics affecting children that had been reported since 1934. They identified peak prevalence at puberty, a relapsing nature with chronicity, a predominance in girls, frequent summer and autumn onset, contact with contaminated milk, food or water and clusters of cases in schools and families. They also conducted a pilot study in 63 private schools and 5 LEAs in a variety of locations. They found that ME/CFS (physical illness) was the main cause of long term sickness absence from school for both staff and pupils, and that inappropriate school attendance was the major cause of relapse among ME young people. Some areas were also found to have clusters of viral infections and ME/CFS in schools. [29] [30]

There are no known research projects that have included the severely affected sufferer, although the 25% ME Group carried out a survey of its members in 2001 and found that over a 2-3 year period 31% had improved; 25% deteriorated; 13% returned to normal or had almost fully recovered; and the rest had remained relatively stable or experienced fluctuating periods of health. The most helpful strategies were considered to be: pacing activity with rest; adjusting diet; and alternative treatments. The most unhelpful strategies were: orthodox medical treatments; graded exercises; and CBT. [31]

3. Current state of health services

3.1 Wales

Mid & west Wales

We understand that the LHBs have adopted the old Dyfed Powys Health Authority policy of only funding CBT and GET as "treatments" for ME and CFS, and that GPs and consultants are expected to have diagnosed the patient and to be managing the patient's illness in a primary care setting.

In 2000 the patient support group completed a survey of members in the Dyfed Powys Health Authority area. The main conclusions were:

- 70% waited longer than a year before getting a diagnosis
- 23% changed GPs because they were not satisfied with their attitude or treatment.
- only 22% felt that their GP was knowledgeable about ME/CFS
- 33% were offered no treatments by doctors

The 2 things most often mentioned as important for ME/CFS sufferers were:

- an early diagnosis
- and an understanding GP who acknowledged the serious of the illness, was willing to listen and spend time helping looking for ways to help improve patients' health.

Although the group membership has grown greatly in size since then, feedback indicates that little has improved since 2000. Patients feel unsupported and sometimes rejected. Some feel pressurised into changing doctors and a few have resorted to legal threats. The survey results include comments made by patients. [32]

Over the years ME patients have asked their GPs to refer them to a range of specialists, such as Dr David Lewis, ex-paediatrician in Bronglais Hospital, and the CFS clinic in Cardiff, now no longer functioning. For years the only option for adults has been to travel to the National ME Clinic in Essex (which many patients can neither afford nor are able to cope with the journey) or for children to look for private consultations with English paediatricians.

The **Disability Resource Team** based in Llanelli has impressed patients with their understanding of ME. They offer a physiotherapy and OT service to a range of severely affected patients with neurological illnesses in their homes, but have a considerable waiting list.

The **Pain Management Centre** at Bronllys Hospital in Powys is due to pilot a new service for CFS patients in Wales from September 2004. [33] They describe it as a 4 week inpatient cognitive behavioural programme which will include graded exercise training, cognitive behavioural therapy, relaxation and education in improving sleep hygiene. The content will be based on their pain courses. They describe the aim of the programme as being to teach self-management skills from which the participants can devise their own management programme. The gentle exercise training they intend to employ does not appear to be exactly the same as Graded Exercise Therapy but past ME patients on the pain courses found that the graded exercise element caused relapse and the management programme was difficult to implement at home. Psychometric evaluations will be carried out to assess the effectiveness of the programme although the broad participation criteria they will use (CDC 1994) will make it difficult to tell how patients with strict ME patients responded. They are accepting referrals for adults with an existing diagnosis of CFS or ME who fit are mobile and can care for themselves, therefore limiting their intake to a very small range of existing ME and CFS patients.

North Wales

The **North Wales Chronic Fatigue support service** operates clinics in Connah's Quay and Caernarfon (originally set up by the North Wales HA) run by a physiotherapist, dietician, clinical psychologist and GP. They do not offer a diagnosis and their approach is based on a cognitive behavioural therapeutic model, which includes sessions in pacing, realistic goal setting and dietary advice. This model “assumes that illness related beliefs and cognitions play a central role in CFS and these beliefs in turn influence a person’s emotional, behavioural and physiological state.” [34]

They treat all patients with an existing diagnosis of CFS or ME in the same way and we have been told that they discourage patients from trying other approaches or contacting support groups. We have not seen a copy of the final report, which was due out in the summer of 2003, but psychologist Simon Neale gave a talk in September 2002 where he reported that the results showed that patients’ quality of life is “going from ‘bad’ to ‘a bit better’” and that patient functioning is “getting people a little bit better”

The North Wales ME support groups have a number of concerns about these clinics. Patients value the pacing theory taught by the clinics and say that they have benefited most by meeting other sufferers and exchanging experiences. However some feel that the clinics “don’t really understand ME”. Many experience major episodes of relapse in the months and years that follow, despite efforts to implement techniques learned at the clinics and many find the management plan is almost impossible to implement and maintain in the real world, where their family and work commitments take priority. After participating, patients often report that they are still looking for help in managing their ME and return to their GPs, who have nothing more to offer them. The support groups fear that the underlying assumption that people are not really ill, but only think they are, has led to unrealistic expectations being placed on ill people. The clinics also are only suitable for adults with quite a high degree of functioning, leaving many in the area unsupported and without a formal diagnosis.

South Wales

The **Children’s CFS Clinic** in Cardiff has seen children under 18 from Cardiff and the Vale who have already been given a diagnosis of CFS. They accepted referrals from paediatricians only. The assessment and management was carried out by a paediatrician, physiotherapist, mental health nurse and psychologist. The main management was graded exercise and psychological support. The review of the service consists of too few responses to judge it’s overall success but some of the past patients with ME are known to have found the regime very hard and inflexible. No account was taken of the tendency in ME patients for delayed reaction to activity, so the team often didn’t see the suffering they were causing the children. A number remain very ill. This clinic has now closed leaving no specialist services for young people with ME or CFS in the whole of Wales.

Dr Meirion Llewellyn continues to hold a clinic at the Royal Gwent hospital in Newport and also a private clinic in Gwent, although his Cardiff clinic has closed. Both have long waiting lists. His treatment protocol has not been published but he has described himself as a Consultant Physician in Infectious Diseases with an interest in ME and CFS, and he does not consider his NHS clinic in Gwent to be a specialist ME or CFS clinic. He advises the use of GET, CBT and antidepressants and past ME patients have found that this has not helped them and was even harmful in a number of instances.

A report on CFS/ME Services published by the Gwent Health Authority in January 2003 [35] highlighted the significant number of CFS/ME sufferers in the area and the need for better services, and named Dr Llewellyn as a specialist. It is unknown whether the LHBs are considering this in their needs assessment exercise.

Mike Sadlier, a physiotherapist at the UHW Hospital Cardiff offers a service to a range of patients, including CFS and ME patients based on Multi-Convergent Therapy principles. This includes CBT, GET and relaxation techniques. He conducted a pilot study into this method and concluded that it was effective. A full research study has been undertaken and is due to be published in 2003/4. He used the broad CDC 1994 criteria and the Oxford criteria to select patients so it is unclear whether ME patients were included in the study. The exercise element of this therapy has caused problems for ME sufferers. [36]

3.2 UK – wide

The problems experienced in this country are mirrored around the UK. It is estimated that up to 25% of the ME population are classified as severely affected, their level of disability and suffering rendering then house bound or bed-ridden. The AfME survey of 2001, *Severely neglected*, [37] describes the extent to which patients feel neglected by the healthcare professions. For example 33% had to wait more than 18 months for a diagnosis and 65% received no advice on managing their illness. 70% were never able or were sometimes too unwell to attend a surgery and 80% of the bedridden had been refused a home visit by a doctor.

Young people

There is also a lack of appropriate services for children, and no onward transition from children's to adult services in Wales, but the situation is rather more serious than that. Children have been bullied into inappropriate treatments and returning to school before they are ready, while their parents can be accused of abuse or Munchausen's syndrome. A number of young people and their parents have experienced these problems in south Wales and WAMES wishes to see this stopped.

The Tymes Trust dossier, *The forgotten children* [38], illustrates the type of intimidation and neglect children can face. The BBC Panorama programme from 1999 also features specific cases of people who were brave enough to speak out about their mistreatment. Parents and families can be and are ostracised by their neighbourhood when it is known that they have been accused of abuse, even if it appears to be false. [39]

English CMO's report

The report includes evidence from across the UK of:

- The extent of distress and disability the illness causes patients, family & carers
- Inadequate awareness & understanding from healthcare professionals
- Under provision of treatment & care, with patchy & inconsistent service delivery & planning
- The severity even for those most mildly affected, but especially the invisibility and special difficulties of those most severely affected [40]

4. Possible healthcare approaches

4.1 English CMO's Report & Medical Guidelines

The English CMO's report on CFS/ME, advises that most adult patients can be dealt with in the primary care setting and sets out guidelines for doctors. There is much that is disappointing in this report but it does provide a starting point and warns that existing controversy cannot and should not be used as an excuse for inaction or unsuitable practice. (section 4.1) "Clinicians need to apply current knowledge despite the remaining uncertainty; inaction due to ignorance or denial of the condition is unacceptable"

The main points:

- service networks should be established involving the principles of stepped care
- In the absence of more refined data, health care provision should be provided for the 0.4% of the population who have CFS/ME
- there is a need for education and training for healthcare professionals.
- GPs and medical specialists should at least be able to provide a diagnosis and initial guidance
- management plans should be devised in a primary care setting in partnership with the patient, adapted to their needs and applied flexibly.
- children need an especially prompt diagnosis.
- the management of a child's illness needs to be done by GP or paediatrician in partnership with patient, family, school etc. and care taken in the transition from childhood to adult life.
- there is a need for tertiary specialists to advise and support primary care colleagues
- the patient's carer and family usually also need support.

- clinicians should give appropriate and clear advice to employers, educators, social services, and providers of benefits, insurance, housing and pensions.
- appropriate domiciliary services should be included for the house or bed-bound patient.
- there is a need for public awareness campaigns.

The Welsh CMO briefly drew attention to this Report in her Update in July 2002 but we are not aware of any other publicity of the report or its contents. [41]

Brief guidelines for doctors, based on the report's recommendations have also been published by AfME and have been recommended by the Department of Health in England. [10] They recommend making a speedy provisional diagnosis and then confirming it based on pattern recognition of the characteristic symptoms and the exclusion of alternative diagnoses. The main problems with these guidelines are their briefness so we consider them an introduction to the report's recommendations, rather than an effective working tool for doctors. eg they talk about a spectrum of disorders but do not explain what they think they are or which of the 3 rehabilitation approaches (GET, CBT and pacing) might suit which condition, nor which management techniques might be suitable.

4.2 Scottish Executive's report

Following the publication of the English CMO's report, the Scottish Executive set up a Short Life Group to plan healthcare services. The Scottish CMO concluded that:

"*It is clear that this is a disorder which can be recognised, where a diagnosis can be given, and a range of interventions agreed upon, with a clear expectation of an improved outcome for most patients, and support for all*."

The key recommendations of the Short Life Group are:

- Local health needs assessment should form part of ongoing NHS Board programmes
  NHS Boards should develop plans, suitable for their local area, on how services for CFS/ME patients might be developed over the next two to three years
- A tiered approach to service development, specialist local support, and where necessary, the ability to refer complex cases to more specialist services
- Care management should be patient centred, and delivered locally by multi-agency teams. Care and management plans should be negotiated with the patient and carer and should involve partner agencies
- Provision for educating and training of all professionals, and the development of necessary skills for treating the disorder. Professional supervision is essential to maintain the quality of care [42]

4.3 Department of Health CFS/ME service for England

The Department of Health in 2003 announced funding of £8.5 million for developing services for CFS/ME patients in England:

- Establishing centres of expertise across the country to champion the development of services and improve clinical care;
- Setting up satellite multidisciplinary community teams to develop services within primary care to support GP's and other health professionals;
- Facilitating access to specialist assessment diagnosis and advice on clinical management to patients, families and health professionals;
- Supporting clinical research; and
- Providing education and training of health care professionals. [43]

An announcement has now been made about the centres that have been awarded funding. Some of these have already been operating a service based on a psychiatric cause for the illness and using GET as the main intervention. ME patients in England are concerned that their needs will not be catered for and that unsuspecting patients may be harmed by inappropriate interventions.

4.4 Other medical guidelines

The most exhaustive set of UK medical guidelines for ME is probably those by **Drs Shepherd,** (a GP) **and Chaudhuri** (a neurologist), [44] now out of print, but previously published by the ME Association. They are available online as a pdf file. They include a detailed look at nomenclature, pathoaetiology, diagnostic assessment and management. Research is introduced on the role of infection, immunological dysfunction, muscle problems, central nervous system involvement, ion channel dysfunction, co-existent psychiatric disorders and sleep disturbance. Advice on diagnosis covers clinical history, symptomatology, physical examination, investigations, mental health assessment and differential diagnoses. Diagnosis depends on the presence of exercise-induced fatigue, post-exertional malaise, myalgia, cognitive dysfunction and a on-going flu-like malaise. A range of pharmacological treatments, helpful and unhelpful are explored while the main non-pharmacological treatments recommended are pacing and management of sleep disturbance.

The recent guidelines from **Canada** are considered to be the most significant in the world. They recommend that in order to be diagnosed with ME/CFS, a patient must become symptomatically ill after exercise and must also have neurological, neurocognitive, neuroendocrine, dysautonomic, and immune manifestations. In short, symptoms other than fatigue must be present for a patient to meet the criteria. This case definition, also incorporates some of the current research on dysautonomia, cardiac, and immune problems. The section on Clinical evaluation sets out what to look for when taking the patient's history, during physical examination and which laboratory and investigative protocol to follow. It also lists the differences between ME/CFS and FMS or psychiatric disorders. Also included are guidelines on how to assess prognosis, occupational disability and rehabilitative potential. [45]

The late **Dr John Richardson** was a clinician with many years of clinical experience of ME patients. His guidelines compare illness following enteroviruses with those following poliomyelitis. His notes on physical examinations are detailed and suggested treatments include IgG infusions, Ampligen and Galanthamine. He ends by looking forward to the day when the triggering enteroviruses are identified and a vaccine is available. [46]

Microbiologist **DR EG Dowsett** also sees parallels between ME and non paralytic poliomyelitis and considers neurological dysfunction essential for diagnosis. Her treatment protocol begins with: removal of stress and additional exposure to infection at onset; conservation of energy; reduction of stress & life style changes. [47] Her leaflet for doctors also suggests lab tests and discusses prognosis. [48]

Paediatrician **Dr Alan Franklin's** guidelines for school doctors, nurses and GPs lists the slight differences between adults and children and believes that the management strategy should centre on the degree of disability. He urges extreme caution over exercise and school attendance until the patient has reached the third stage of remission and the possibility of relapse becomes less. Possible treatments include simple analgesics, anti-fungal antibiotics and amitriptyline although he advises care with the dosage. [49]

The report ***Childhood ME*** (aka *Children & ME*) has useful guidelines in the Medical section. It includes detailed lists of symptoms, differential diagnoses and investigations. The management approach centres on the management of both physical and mental activity, nutrition and diet and, like Dr Franklin, urges caution with the dosage of medication used for symptomatic relief. [12]

4.5 National ME Centre

This centre in Essex was set up under the guidance of Dr EG Dowsett at the Neurosciences Unit for the benefit of fatigue syndromes of all types. Over the years it has altered its stance and now uses the term CFS as an umbrella diagnosis, which includes the disorder designated Myalgic Encephalomyelitis (ME). It has found that the illness content of CFS patients varies from patient to patient. It recognises therefore the need to advise and recommend very individualised treatment packages.

It accepts referrals from GPs or hospital specialists throughout the UK. The purpose of the consultation is to confirm the diagnosis, assess treatment to date and advise through the general practitioner, a “management” package.

The management advice could be one of the following for example:

- Advice on medication and/or life style changes.
- A recommendation to be seen, by referral, to one of the therapists in the Chronic Fatigue Team of the Essex Neurosciences Unit for an outpatient programme.
- A recommendation for admission into one of the designated fatigue beds in the Essex Neurosciences Unit at Oldchurch Hospital for inpatient medical assessment, inpatient programme under the direction of the Fatigue team therapists. All programmes are holistic and orthodox and may include controlled activation, modified cognitive behavioural therapy, physiotherapy, appropriate counselling, dietary and nutritional assessment and treatment.
- A recommendation for referral to other specialists for advice of management e.g. rheumatologist, general physician, immunologist, psychiatrist. This would be important for those whose fatigue has an origin other than chronic fatigue syndrome (ME).

The waiting list for consultations and admissions is long and the journey is very trying and too expensive for some. Patients from Wales sometimes have to do the journey over 2 days, but the approach has been very helpful for some patients whose level of functioning has improved. [6]

4.6 AfME / Westcare Clinics

AfME now runs the Westcare UK clinics in 3 areas which aim to provide advice and information about effective management of ME. They do not offer a cure. The Gloucestershire clinics offer an initial consultation with the doctor and OT, which focuses on assessing the patient’s current level of functioning. They will then draw up a management plan in partnership with the patient. The clinic takes place in various towns across the county, according to demand. The expectation is that no patient should have to travel for more than 30 minutes to get to a clinic. Follow up sessions will normally take place in patients’ homes with one or more of a range of therapists including OTs and counsellors. The individual management plan and final report is then copied to the referring GP. [50]

They base their approach on a belief that CFS/ME “is a physical illness, or group of illnesses, of uncertain cause, which like other physical illnesses may be profoundly affected by social and psychological factors”. They do not consider the absence of a known physical cause to be sufficient grounds for attributing a psychological problem and believe there is sufficient evidence of a physical basis from biological research and the pattern and history of symptoms. This leads to a cautious attitude to using rehabilitation approaches. [51] [52]

4.7 Stockport Outreach Nurse

Stockport operates an ME Outreach Nurse Service which aims to provide home visits to the newly diagnosed, the severely and very severely affected, and families with child sufferers. They offer support and practical advice which is tailored to the individual for both the patient and the carer on symptom control, energy management and gently paced activity. This is followed up and reinforced by telephone contact. They recognise 3 distinct phases to the illness – acute, chronic and recovery – which influences the nature of the recommended management strategy. They also provide specialist advice and information to other primary care professionals.

While the NMEC and Westcare clinics use OTs to deliver care to ME patients, Stockport believes that there are advantages to using a nurse:

- They are highly skilled practitioners capable of planning, giving, supervising and evaluating individualised patient care.
- They are trained in the basis of pharmacology and are in a position to discuss with general practitioners the suitability or otherwise of certain drug treatments.

- They are well placed to assist individuals in reaching their optimal levels of self-care
- Their experience of nursing develops certain diagnostic skills that are absent in other allied health professionals [53]

4.8 GET, CBT and Pacing

GET has proved helpful to some chronic fatigue sufferers but harmful to many ME sufferers who have suffered major relapses. The English CMO's report (section 4.4.2.1) included patient evidence where 50% of respondents reported a worsening of symptoms following graded exercise programmes.

The value of **CBT** in providing some patients with an understanding of illness is not in doubt, although it has caused a lot of distress when used to re-educate supposed wrong illness beliefs. Patients have found they are unable to "think themselves better" and can face physicians' censure for "not co-operating fully".

Dr Shepherd points out that it is not always understood that there are *"different types of CBT being used in relation to ME/CFS - it is certainly not being generally delivered in a way that CBT is in other chronic illnesses such as cancer. One format, often administered in non-psychiatric settings, largely concentrates on helping patients with practical lifestyle advice (ie nutrition, sleep, activity management), and this usually achieves a high degree of patient satisfaction. At the other end of the spectrum is a type of CBT, usually delivered in a psychiatric setting, which involves 'challenging' or 'correcting' what many therapists believe are patterns of abnormal illness beliefs or behaviours. Not surprisingly, many patients are reluctant to take part if they perceive that the programme is going to be biased in this direction. We really do not know whether any of these quite expensive approaches to management involving CBT are more effective than good active management (or even simple counselling) in a primary care situation. As with GET, the evidence from patients presented in the CMO report was not consistent with the results of randomised controlled trials (only 7% found CBT to be 'helpful'; 26% reported it made them 'worse', and 67% reported 'no change')."* [54]

Dr Ellen Goudsmit, whose assessment of the inappropriateness of GET and CBT can be found on Axford's website [28], recommends the use of pacing instead of GET and a positive (optimistic) outlook combined with sympathetic counselling instead of the more expensive option of CBT. She sees the aim of pacing as "to remain as active as possible but to avoid the relapses resulting from over-exertion". This is achieved by limiting activity according to the patient's experience of what they can cope with and 'switching' activities to avoid tiring specific muscle groups. [55]

Condemnation of strict GET as an intervention for ME patients is widespread in the ME world, although a mixture of GET and pacing, sometimes called Adaptive Pacing Therapy or Graded pacing, has recently become acceptable to some. This seems to attempt to combine an acceptance of the dangers of over-exertion but introduces the concept of "gradual stepwise increases in activity", a concept alien to pacing proper. It's popularity may be partly due to the fact that it will be easier to do a controlled study of this than of the type of pacing that most patients use. An MRC trial due to begin in 2004 intends to study Adaptive Pacing Therapy. Dr Goudsmit points out that there is no evidence that pacing on its own benefits patients but needs to be part of a management programme.

4.9 Other Treatment Protocols

Out of desperation many ME patients, who can afford to, look for help outside the NHS. Individual treatments which Welsh patients have tried include: acupuncture, herbal & mineral supplements; magnesium injections, vitamin B12 injections, magnetotherapy, homeopathy.

There a number of specialist ME/CFS services which offer a variety of treatment or management approaches. Few have been assessed for effectiveness and some products or therapies have very dubious benefits. However some people have been so desperate they have spent thousands of pounds or run up debts looking for help.

4.10 Staff education & training

The major complaint from patients is that doctors know very little about the diagnosis and management of ME. **PGCE** courses often don't include training on ME though some of the Welsh training schemes have information on their websites about CFS. These often, present only a psychiatric understanding of the condition CFS The Bridgend scheme mistakenly refers to TATT (Tired All The Time) as being at one end of the spectrum and CFS at the other). Their website includes a number of helpful insights but when describing precipitating factors to the illness the emphasis is on psychological factors with disease and injury only being the cause 'sometimes'. The major perpetuating factors listed are also psychological. The recommended treatment includes some helpful suggestions like keeping a symptom diary and referring to self-help groups, but also advises gradual increase in activity and anxiety management. [56]

In contrast the Continuing Education module for nurses encourages students to explore the different understandings of and treatment approaches to CFS/ME They are also asked to consider the effect the classification of the illness might have on patients' and practitioners' attitudes. [57] PGCE courses have been run in North Wales using a variety of specialist ME speakers from England.

Tymes Trust Referral Scheme – Because of the shortage of ME specialists in the NHS in the UK, this children's charity offers a useful Professionals Referral Service so that it's members' doctors can talk to ME experts within the medical field, their child's teachers can talk to ME experts in the teaching profession, and so on. They also provide specialists within most professions who can help sufferers to sort out any misunderstandings they may have with professionals. [58]

Medical school and nursing courses still include very little, if anything, on ME, in spite of the acknowledgement by the Department of Health that CFS/ME is a serious and chronic illness. More needs to be done to remind Universities, Teaching hospitals and colleges that health practitioners need this education.

11.11 Self-help

Most patients have had to hunt out information about their illness for themselves. Two books have played a major role in this. They are both written by doctors who developed ME themselves. Drs Anne MacIntyre and Charles Shepherd cover the history, terminology, causes, symptoms, alternative diagnoses, research, management, practical and social aspects of the illness. [59] [60]

Many patients or their carers join one of the 5 local patient support groups in Wales such as MWWMEG [61] and UK charities eg Action for ME (AfME) [62], 25% ME Group (for the severely affected) [63], Tymes Trust [58] and Association of young people with ME (AYME) [64]. The Welsh Association of ME & CFS Support (WAMES) is the umbrella body for local support groups in Wales and also advises people on ME and matters where Welsh practice differs from the rest of the UK. A new bilingual Young People's support service was also set up in 2003. [65]

5. Conclusion

ME patients urgently need:

1. **Official recognition** - a national policy & medical guidelines for ME
2. **Accurate & speedy diagnosis from doctors**
3. **Appropriate illness management advice & domiciliary support**
4. ***Local* specialist advice**
5. **Specialist tertiary service**

References

1. 0.4 % was given in the English CMO’s report as a reasonable estimated incidence of CFS/ME for the whole of the UK. Sections 1.4.2 & 4.5.1
2. Cost to the nation report, by AfME, May 2003 http://www.afme.org.uk/res/img/resources/Costtothenation.pdf

Section 1

3. Chronic Fatigue Syndrome: report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners. Oct 1996
4. *Chronic Fatigue Syndrome: A Practical Guide to Assessment and Management* Sharpe, M. Wessely, S et al *Gen Hosp Psychiatry* 1997:19:3:185-199
5. *Denigration by design* http://www.btinternet.com/~severeme.group/contents.htm
6. The National ME Centre, Disablement Services Centre, Harold Wood Hospital, Gubbins Lane, Harold Wood, Romford, Essex. RM3 OBE www.nmec.org.uk
7. *Toxic causes of CFS*, by Dr Sarah Myhill http://www.drmyhill.co.uk/article.cfm?id=84
8. *The Chief Medical Officer’s Working Group Report on CFS/ME: a guide* AfME, 2002 http://www.afme.org.uk/res/img/resources/CMO%20Report.pdf
9. *ME Fact sheet* WAMES, 2003
10. *Guidance on the management of CFS/ME* AfME, 2002 http://www.afme.org.uk/res/img/resources/DoctorsGuide.pdf
11. *Functional Ability scale* AYME, 2002 www.ayme.org.uk/theme2/ability.html
12. *Children with ME* http://www.ayme.org.uk/theme2/children.html#intro aka *Childhood ME* http://www.youngactiononline.com/docs/chldhdme.htm
13. *What is ME like? Young members of AYME explain* http://www.ayme.org.uk/theme2/me-like.html
14. *Dance champ’s ME lobby* http://news.bbc.co.uk/1/hi/wales/3019445.stm
15. *Faces of CFS*, by Dr David S Bell. pub by DS Bell, 2000

Section 2

16. *Effective Health Bulletin: Interventions for the management of CFS/ME*. 2002 vol 7, no. 4. NHS Centre for Reviews and Dissemination, University of York. http://www.york.ac.uk/inst/crd/ehc74.pdf
17. *The effectiveness of interventions used in the treatment / management of chronic fatigue syndrome and/or myalgic encephalomyelitis in adults and children*. Bagnal et al NHS Centre for Reviews and Dissemination, University of York, Sep 2002 http://www.york.ac.uk/inst/crd/report22.pdf
18. Press release: *MRC announces 2 trials to assess treatments for CFS/ME*, May 15 2003 http://www.mrc.ac.uk/index/public-interest/public-press_office/public-press_releases_2003/public-15_may_2003.htm
19. *MRC CFS/ME Research Advisory Group CFS/ME Research Strategy.* May 2003 http://www.mrc.ac.uk/pdf-cfs_me_research_strategy.pdf Press release at http://www.mrc.ac.uk/index/public-interest/public-press_office/public-press_releases_2003/public-1_may_2003b.htm
20. *The Clinical & Scientific Basis of Myalgic Encephalomyelitis / Chronic fatigue Syndrome*, edited by Hyde, Goldstein & Levine Nightingale Research Foundation, 1992 http://www.nightingale.ca
21. CFS Research Foundation www.cfsresearchfoundation.org.uk
22. MERGE http://www.meresearch.org.uk/
23. *A research portfolio on chronic fatigue*, edited by Robin Fox for the Linbury Trust. Royal Society of Medicine Press, 1998
24. *Research report in Myalgic Encephalomyelitis (ME)/ Chronic Fatigue Syndrome (CFS),* by Dr Vance Spence in *25% ME Group Newsletter* no 10 Winter 2000 http://www.btinternet.com/~severeme.group/MERGE/research_report.htm

25. *Some facts about ME/PVFS/CFS,* by Ellen Goudsmit http://freespace.virgin.net/david.axford/facts96.htm http://freespace.virgin.net/david.axford/facts03.htm
26. *Quarterly updates of ME/CFS research references* on Axford's Abode ME/CFS website http://freespace.virgin.net/david.axford/melist2.htm#Medical Updates
27. Co-cure *Research updates* http://www.co-cure.org/infores.htm *Updates on CFS Clinical Theory and practice* http://www.co-cure.org/update.htm
28. *Summary of the CBT explanation of CFS*, by Ellen Goudsmit on Axford's website http://freespace.virgin.net/david.axford/cbt-expl.htm#Literature Update
29. *Long Term Sickness Absence due to ME/CFS in UK Schools: an epidemiological study with medical and educational implications*, by Dr EG Dowsett & Jane Colby http://www.youngactiononline.com/docs/meuksch.htm
30. *Does ME cluster in Schools?,* by Dr EG Dowsett http://www.youngactiononline.com/docs/doesme.htm
31. *25% group survey follow up results* http://www.btinternet.com/~severeme.group/general_questionnaire_followup.htm

Section 3

32. *Medical treatment for ME/CFS in mid & west Wales: survey results* 2000, by Mid Wales ME Group
33. Bronllys Pain Management Centre http://www.managingpain.org.uk/newcfs.doc
34. *Chronic Fatigue Syndrome – Service evaluation interim report* – April 2001. Inst. of Medical & Social Care Research University of Wales Bangor
35. *Services for people suffering from CFS/ME* [report from the Gwent Health Authority, January 2003]
36. *A preliminary study into the effectiveness of MCT in the treatment of heterogeneous patients with CF*S. Michael Sadlier et al Journal of Chronic Fatigue Syndrome 7(1) (2000) p93-100
37. *Severely neglected: ME in the UK membership survey* AfME, Mar 2001 http://www.afme.org.uk/res/img/resources/Severely%20Neglected.pdf
38. *The forgotten children: a dossier of shame* Tymes Trust, 2003 http://www.youngactiononline.com/
39. *Sick and Tired*, BBC T Programme, Nov 8 1999 http://news.bbc.co.uk/1/hi/audiovideo/programmes/panorama/archive/506549.stm

Section 4

40. *A Report of the CFS/ME Working Group: Report to the Chief Medical Officer of an Independent Working Group*, Jan 2003 www.doh.gov.uk/cmo/cfsmereport
41. *CMO Update* no. 33, July 2002 http://www.wales.nhs.uk/documents/CMO-update-33-e.pdf
42. *Outline for development of services for CFS/ME in Scotland report of the Scottish short life working group* Dec 2002 http://www.show.scot.nhs.uk/sehd/mels/hdl2003_02.pdf
43. Department of Health Press Release: *ME Awareness Week – the government announces £8.5 million for CFS/ME services*, Mon 12 May 2003 http://www.info.doh.gov.uk/doh/intpress.nsf/page/2003-0187?OpenDocument
44. *ME/CFS/PVFS an exploration of the key clinical issues*, by Dr C Shepherd & Dr A Chaudhuri http://www.meassociation.org.uk/explor.htm#TEXTTOP
45. *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols*, in *J of Chronic Fatigue Syndrome*, Vol. 11 (1) 2003, pp. 7-116,

    For a 30-page excerpt of this document, which includes the diagnostic part of the ME/CFS case definition in PDF format http://www.co-cure.org/ccpccd.pdf
46. *Myalgic Encephalomyelitis Guidelines for doctors,* by Dr John Richardson NRG, Apr 1999 http://www.btinternet.com/~severeme.group/papers/Newcastle_research_paper.doc
47. *The enigma and the paradox of ME* , by Dr EG Dowsett http://www.youngactiononline.com/docs/enigma.htm

48. *What is ME/CFS? (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome)* A Short Introductory Leaflet prepared by Dr E G Dowsett MB ChB.Dip.Bact. February 1998 http://www.youngactiononline.com/docs/whatisme.htm
49. *ME in children & young people*, by Dr Alan Franklin Tymes Trust, c. 2000
50. AfME (Westcare) http://www.afme.org.uk/howwehelp.asp?table=contenttypethree&id=6&pagetitle=Face-to-face%20services
51. *The physical and the mental in CFS/ME: principles of psychological help*, by Richard Sykes et al. Westcare UK, 2002
52. *CFS/ME: trusting patients' perceptions of a multi-dimensional physical illness*, by Richard Sykes & Peter Campion Westcare, UK 2002
53. *Stockport ME Outreach Nurse Service*, by Elizabeth Jackson & Gillian Walsh 2002
54. Dr Charles Shepherd's letter to MRC 29th Jan 2003
55. *Pacing for ME & CFS: the facts* 2002 [8 p.] Goudsmit, Dr E http://freespace.virgin.net/david.axford/me-pace.htm
56. Bridgend Vocational Training Services tutorial on TATT http://www.pencoedmedical.co.uk/tatt.htm
57. *An overview of Chronic Fatigue Syndrome*, E Jackson et al *Nursing Standard* 17:13, 45-53 Sep 24 2002
58. Tymes Trust www.youngactiononline.com
59. *ME Chronic Fatigue Syndrome: how to live with it*, by Dr Anne MacIntyre Thorsons, 1998
60. *Living with ME the chronic/Post-Viral Fatigue Syndrome*, by Charles Shepherd. Vermilion, 1999
61. MWWMEG leaflet (green) and 2 posters www.midwalesmegroup.org.uk (new site due 2004)
62. Action for ME www.afme.org.uk
63. 25% ME Group www.25megroup.org
64. Association of young people with ME www.ayme.org.uk
65. WAMES www.wames.org.uk