

# MEDICAL SERVICES

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PROVIDED ON BEHALF OF THE DEPARTMENT FOR WORK AND PENSIONS

Training and Development

## **Continuing Medical Education Programme**

### **Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) - Guidelines for the Disability Analyst**

**MED/S2/CMEP~0017**

Version 7 Final

Module: 6



# Medical Services

## Foreword

This training has been produced as part of a training programme for Health Care Professionals approved by the Department for Work and Pensions Chief Medical Adviser to carry out benefit assessment work.

All Health Care Professionals undertaking assessments must be registered practitioners who in addition, have undergone training in disability assessment medicine and specific training in the relevant benefit areas. The training includes theory training in a classroom setting, supervised practical training, and a demonstration of understanding as assessed by quality audit.

This training must be read with the understanding that, as experienced practitioners, the Health Care Professionals will have detailed knowledge of the principles and practice of relevant diagnostic techniques, and therefore such information is not contained in this training module.

In addition, the training module is not a stand-alone document, and forms only a part of the training and written documentation that the Health Care Professional receives. As disability assessment is a practical occupation, much of the guidance also involves verbal information and coaching.

Thus, although the training module may be of interest to non-medical readers, it must be remembered that some of the information may not be readily understood without background medical knowledge and an awareness of the other training given to Health Care Professionals.

Office of the Chief Medical Adviser

28<sup>th</sup> May 2014



## Document control

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### Superseded documents

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Section 3 Case study and questions rewritten

Section 4 rewritten

Section 5 updated with current disability analysis information

Section 6 rewritten with current Revised WCA information and new case study added

Section 7 rewritten and new case study added

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# 1. Introduction

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These guidelines form part of Atos Healthcare's programme for continuing medical education for Health Care Professionals (HCPs). They are designed to encourage consistency in our approach to complex conditions; provoke reflection on our own perceptions with regard to them; and foster awareness of current medical thinking.

Chronic fatigue syndrome / Myalgic Encephalomyelitis (CFS/ME) is a disorder, or group of disorders, which continues to cause considerable difficulties for clinician and disability analyst alike, due to the absence of clear causative factors, the lack of precise case definition and the variable and uncertain natural history. Since the terms "myalgic encephalomyelitis" and "post-viral fatigue syndrome" both carry implications relating to causation, the generic term CFS/ME is preferred.

The purpose of this module is to encourage HCPs working in disability analysis to adopt a common approach to this difficult and complex condition.

The disability analyst's particular focus in CFS/ME is the assessment and measurement of overall functional disablement. It is hoped that this training module will encourage HCPs to approach these cases in a way that is objective, thoughtful and structured.

The Decision Maker (DM) who receives the report and advice will have similar difficulty in interpreting the issues, and one of the HCP's central tasks is to evaluate the history, clinical findings and disability in any given case and present them in an impartial, objective way.

## 1.1 Objectives

By the end of this module HCPs should have:-

- An overview of CFS/ME including aetiology, diagnosis, management and prognosis
- Considered the assessment of CFS/ME in disability analysis, developing a consistent and focused approach
- Considered the assessment of CFS/ME in Revised WCA and DLA cases

## 1.2 How to use these Guidelines

After the introduction, there is a short questionnaire to complete. This is followed by a short case study to help HCPs to begin to think about some of the principles of assessment of claimants with CFS/ME.

The document contains an overview of the condition including diagnosis and management.

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This is followed by a review of the principles of disability analysis when assessing claimants with CFS/ME, with specific sections about Revised Work Capability assessments and Disability Living Allowance assessments (with case studies to complete). HCPs should read the whole document, however they need only complete the cases studies for the relevant benefit strand for which they are trained.

There is a reading list with further sources of information about CFS/ME.

At the end of the document there is a MCQ to be completed and returned to the local training support manager.

## 2. Current knowledge of CFS/ME

Before proceeding with the rest of the module, it would be helpful to complete the following short exercise. First read the question, and then tick the most appropriate box.

	Yes	No	Don't Know
CFS/ME is entirely psychological in origin			
CFS/ME is wholly physical in origin			
CFS/ME symptoms are usually associated with mild levels of functional impairment			
Most people with CFS/ME will recover to pre-morbid functional levels although it may take a long time			
Depression is part of the CFS/ME condition			
There is often overlap in the symptoms experienced in CFS/ME with the condition of fibromyalgia			
Muscle pain is not a symptom found in CFS/ME			
CFS/ME can be diagnosed with a biochemical marker			
CFS/ME has clear diagnostic guidelines			
The aetiology of CFS/ME has been clearly elucidated			
CFS/ME is always triggered by a viral infection			
Antidepressant medication is effective in the treatment of CFS/ME			
There is consensus about the management of CFS/ME			
NICE guidelines recommend offering cognitive behavioural therapy and graded exercise therapy but not adaptive pacing therapy in the management of CFS/ME			
Patient groups in the UK prefer adaptive pacing rather than cognitive behavioural therapy and graded exercise therapy in the management of CFS/ME			

### 3. CFS/ME Case Study

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Read the following case study information. Try to decide how to approach the face-to-face assessment of this claimant and the task of providing the Decision Maker (DM) with advice.

Mrs D is a 42 year old woman who provides the following history in her claim form:

She has been diagnosed with CFS. She lists her main symptoms as fatigue, muscle pains, sleeplessness and poor concentration.

The symptoms began about 3 years ago. She suffered a bad bout of flu (which she described as “severe flu”, with limb pains, headache, sweating and malaise) and has never recovered fully. She was working as an English teacher at the time. She initially had 2 weeks off work and then returned although she was not feeling fully recovered. Within a week she had to stop work because of overwhelming exhaustion and has never been well enough to return.

She has been seeing her General Practitioner since the start of her illness. After 6 months of no improvement, her GP referred her to a specialist CFS clinic, which she attended for 6 months or so. She now sees her GP every 3 months or so. Fatigue is the main problem but she has other problematic symptoms as well.

She sleeps poorly. She gets up if she feels well enough. Some days she showers and dresses, but some days she does not have the energy. Some days she either does not get up at all or returns to bed after an hour or so. She has been trying to do some cooking lately, but finds it very tiring and mostly her husband and daughter attend to all the routine household tasks. She rests at times during the day. She finds it tiring to walk anywhere and therefore rarely leaves the house.

She has found it very hard to cope with her symptoms and the worry that she might never recover. She had always been very fit and active until the onset of this illness. She enjoyed her job, although it was very stressful at times. She also used to run regularly and play golf and she misses her hobbies a lot.

A report from her GP attached to the claim form states “CFS diagnosed 3 years ago after flu'-like illness. Was referred to CFS clinic. Little improvement over time, ongoing significant fatigue.”

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Thinking about the information provided:

Are there special considerations that may guide a HCP's initial approach to assessing claimants with CFS/ME?

What areas of the history should HCPs concentrate on, and why?

If performing a physical examination, what areas of the physical examination should be concentrated on, and why? Are there any special considerations that need to take into account during an examination?

Should a mental state assessment be performed and if so what areas should be focused on?

## 4. Overview of CFS/ME

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In 2002 the CMO CFS/ME Working Group reported “In recent years, CFS has been the preferred medical term for this disorder, or group of disorders, although the large majority of patients’ support organisations use the term ME. The Working Group is conscious that some patients, especially those who are severely affected, consider the use of the name CFS to be unrepresentative of their illness experience.”<sup>1</sup> It recommended the composite term CFS/ME be used until a consensus on terminology is developed.

### 4.1 Epidemiology

Reported prevalence rates vary because of the use of different diagnostic criteria (due to the fact that diagnostic criteria are not standardised).

It has been estimated that the overall population prevalence is 0.2–0.4%<sup>1</sup>.

A review of CFS/ME in the *Lancet* in 2006 put the worldwide prevalence between 0.2% and 2.6%<sup>2</sup>. The NHS choices website reports it is estimated that around 250,000 people in the UK have CFS/ME.

The mean age of onset is 29-35. It affects women more than men (75% cases are female). It can affect all social classes and ethnic groups<sup>2</sup>.

### 4.2 Aetiology

There is no generally accepted theory of the aetiology of CFS/ME. To date there has been no single cause found and CFS/ME is probably best regarded as a multifactorial heterogeneous illness with physical, psychological and social factors all playing a part.

Many theories have been proposed for pathophysiology of CFS/ME but the mechanisms remain elusive. Multiple studies have shown abnormalities in brain structure/function (including neuroendocrine responses) and muscular function, sleep disturbance, infectious factors and immune function but these often remain isolated findings which require further study and verification in clinical trials.

The complex nature of the aetiology has led researchers to try to identify factors which predispose to developing CSF/ME, those which precipitate it and those which perpetuate the illness.

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<sup>1</sup> A report of the CFS/ME Working Group (Report to the Chief Medical Officer of an Independent Working Group) 2002

<sup>2</sup> Prins JB, van der Meer JW, Bleijenberg, G. Chronic Fatigue Syndrome. *Lancet* 2006; 367:346-55

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Predisposing factors identified include personality factors of neuroticism and introversion.<sup>3</sup> Inactivity in childhood has also been identified.<sup>4</sup> To date no genetic abnormalities have been found although twin studies have shown a familial predisposition.<sup>5</sup>

Precipitating factors include an infectious trigger in up to three quarters of patients<sup>6</sup>. Infectious agents reported include Epstein Barr virus, as well as non-specific infections like a cold or a 'flu like' illness. CFS/ME has also been reported after Q fever and Lyme disease. Serious life events (such as death of close family members or loss of a job) have been associated with precipitating CFS/ME<sup>7</sup>.

Psychological and social factors appear to be involved in perpetuating the symptoms of the illness. Factors associated with increased fatigue and severity of the condition include: a strong belief in the physical cause of the illness, a focus on bodily sensations and a poor sense of control over the complaints<sup>8,9</sup>. Evidence suggests that patients with CFS/ME use more avoidance strategies to cope with the debilitating effects of fatigue. However avoidance strategies have been associated with more fatigue and more functional impairment, including greater psychosocial disturbance in CFS/ME<sup>10,11</sup>.

### 4.3 Differential Diagnosis

When considering a diagnosis of CFS/ME, the list of conditions that could be included in a list of differential diagnoses is large, because of the wide variety of possible symptoms. Any chronic condition that has fatigue as a symptom can be included, however fatigue may not be the main presenting symptom.

Conditions that may be considered as a differential diagnosis of CFS/ME include:

- Infectious: Epstein-Barr virus, influenza, HIV infection, other viral infections (retroviruses, enteroviruses) tuberculosis and Lyme disease

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<sup>3</sup> Hoogveld s, Prins JB, de Jong I, et al. Personality characteristics and the chronic fatigue syndrome: a review of the literature. *Gedragstherapie* 2001; 34: 275-305

<sup>4</sup> Viner R, Hotopf M. Childhood predictors of self reported chronic fatigue syndrome/myalgic encephalomyelitis in adults: national birth cohort study. *BMJ* 2004; 329: 941.

<sup>5</sup> Buchwald D, Herrell R, Ashton S, Belcourt M, Schmalting K, Goldberg J. A twin study of chronic fatigue. *Psychosom Med* 2001; 63: 936-43

<sup>6</sup> de Becker P, McGregor N, de Mierleir K. Possible triggers and mode of onset of chronic fatigue syndrome. *J Chronic Fatigue Syndr* 2002; 10: 3-18

<sup>7</sup> Hatcher S, House A. Life events, difficulties and dilemmas in the onset of chronic fatigue syndrome: a case-control study. *Psychol Med* 2003; 33: 1185-92

<sup>8</sup> Joyce J, Hotopf M, Wessely S. The prognosis of chronic fatigue and chronic fatigue syndrome: a systematic review. *QJM* 1997; 90: 223-233

<sup>9</sup> Heijmans JWM. Coping and adaptive outcome in chronic fatigue syndrome: importance of illness cognitions. *J Psychosom Res* 1998; 45: 39-51

<sup>10</sup> Ray C, Jeffries S, Weir WR. Coping and other predictors of outcome in chronic fatigue syndrome. *J Psychosom Med* 1997; 43:405-415;

<sup>11</sup> Antoni MH, Brickman A, Lutgendorf S, Klimas A, Imia-Fins A, Ironson G, Quillian R, Miguez MJ, van Riel F, Morgan R, Patarca R, Fletcher MA: Psychosocial correlates of illness burden in chronic fatigue syndrome, *Clin Infect Dis* 1994; 18:S73-S78

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- Endocrine: diabetes, hyper- and hypothyroidism, Cushing's disease, Addison's disease and adrenal insufficiency
- Psychiatric: depressive disorders, anxiety disorder and eating disorders
- Neurological: multiple sclerosis and Parkinson's disease
- Haematologic: anaemia, lymphoma
- Rheumatologic: rheumatoid arthritis, systemic lupus erythematosus (SLE), fibromyalgia, Sjögren's syndrome, polymyalgia rheumatica, giant cell arteritis, polymyositis, dermatomyositis
- Other: obstructive sleep syndromes (sleep apnea, narcolepsy), sleep disorders, occult malignancy, chronic illness (including renal, hepatic or pulmonary disease, autoimmune conditions and congestive heart failure), body weight fluctuation (severe obesity or marked weight loss), drug side effects (e.g., beta blockers, antihistamines), alcohol or substance abuse and heavy metal toxicity (e.g., lead)

NICE guidance recommends that when considering a diagnosis of CFS/ME, signs and symptoms that can be caused by other serious conditions ('red flags') should not be attributed to CFS/ME without consideration of alternative diagnoses or comorbidities, such as:

- Localising/focal neurological signs
- Signs and symptoms of inflammatory arthritis or connective tissue disease
- Signs and symptoms of cardiorespiratory disease
- Significant weight loss
- Sleep apnoea
- Clinically significant lymphadenopathy

### 4.4 Diagnosis

There is no international consensus around the diagnostic features of CFS/ME. As yet no specific biological marker or specific factor has been consistently identified in cases of CFS/ME and the diagnosis is made from the history of the symptoms and resulting disability while ruling out other specific causes of fatigue.

A number of definitions have been proposed including the CDC/Fukuda criteria, the Oxford case definition and the Canadian case definition. In the UK the Fukuda criteria is the one most commonly used, in almost all CFS services (information about the Oxford and Canadian criteria can be found in Appendix A).

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### 4.4.1 CDC / Fukuda criteria

In 1988 the United States Centers for Disease Control and Prevention (CDC) developed a case definition primarily to standardise the patient populations for research.

The case definition was revised in 1994 and is also known as the Fukuda Criteria<sup>12</sup>. This definition is now the most widely used internationally. Although these guidelines were primarily developed for use in research studies they are also used clinically.

#### **International Centre for Disease Control 1994 definition**

Clinically evaluated, unexplained, persistent or relapsing chronic fatigue lasting more than six months

- of new or definite onset
- not the result of ongoing exertion
- not substantially alleviated by rest
- including substantial reduction in previous levels of occupational, social or personal activities

Four of the following symptoms concurrently present for at least six months

- sore throat
- tender cervical or axillary lymph nodes
- muscle pain
- multi-joint pain
- new headaches
- unrefreshing sleep
- post-exertion malaise.

Exclusion criteria:

- active, unresolved, or suspected disease likely to cause fatigue
- psychotic, melancholic or bipolar depression
- psychotic disorders
- dementia
- anorexia or bulimia nervosa
- alcohol or other substance misuse
- severe obesity.

### 4.4.2 Classification

The classification of CFS/ME is not used for diagnostic purposes. The current classification does illustrate the difficulty of the complex nature of aetiology and the presence of both physical and psychological elements of the condition.

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<sup>12</sup> Fukuda K, Straus SE, Hickie I et al. The chronic fatigue syndrome: a comprehensive approach to its definition and study. *Annals of Internal Medicine* 1994, 121:953–959

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### 4.4.2.1 ICD 10

There are two classifications in use in the ICD 10. CFS/ME can be classified under neurological disorders as G93.3 (Benign myalgic encephalomyelitis), or under neurotic, stress-related and somatoform disorders as F48.0 (neurasthenia).

From the ICD 10:

G93.3 Benign myalgic encephalomyelitis – to be used where specific trigger such as a viral disease and/or where the symptoms do not fulfil the criteria for F48.0 (World Health Organization - UK Collaborating Centre, 2004).

F48.0 Neurasthenia – which has the following diagnostic features:

a. Either persistent and distressing complaints of increased fatigue after mental effort, or persistent and distressing complaints of bodily weakness and exhaustion after minimal effort;

b. At least two of the following:

- feelings of muscular aches and pains
- dizziness
- tension headaches
- sleep disturbance
- inability to relax
- irritability
- dyspepsia;

c. Any autonomic or depressive symptoms present are not sufficiently persistent and severe to fulfil the criteria for any of the more specific disorders in this classification.

In reality neither classification is satisfactory. When asked, 84% of respondents to a survey of members of the Association of British Neurologists did not view CFS as a neurological condition<sup>13</sup>. The difficulty lies in the fact that CFS/ME straddles both physical and mental health spectrums and cannot be classified as wholly physical or wholly mental in origin.

### 4.4.2.2 Diagnostic and Statistical Manual of Mental Disorders

The DSM-IV did not include the diagnosis of CFS/ME. However Neuroasthenia was classified as Undifferentiated Somatoform Disorder if the symptoms persisted for longer than 6 months. In the updated DSM-V (released in 2013) there has been a change with a new category named 'Somatic Symptoms and Related Disorders' replacing Somatoform Disorders. Undifferentiated Somatoform disorder has been removed and a new disorder of Somatic Symptom Disorder included.

Diagnostic criteria for Somatic Symptom Disorder are

A. One or more somatic symptoms that are distressing or result in significant disruption of daily life

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<sup>13</sup> Wojcik W, Armstrong D, Kanaan R. Is Chronic Fatigue Syndrome a neurological condition? A survey of UK neurologists. *J Psychosom Res* 2011; 70

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- B. Excessive thoughts, feelings or behaviours related to the somatic symptoms or associated health concerns as manifested by at least one of the following:
1. Disproportionate and persistent thoughts about seriousness of one's symptoms.
  2. Persistently high level of anxiety about health or symptoms
  3. Excessive time and energy devoted to these symptoms or health concerns
- C. Although any one somatic symptom may not be continuously present the state of being symptomatic is persistent (typically more than 6 months)

The DSM-V emphasizes that the diagnosis of Somatic Symptom Disorder depends on the distressing somatic symptoms PLUS the abnormal thoughts or behaviours in response to the symptoms (i.e. maladaptive thoughts) rather than an absence of medical explanation for somatic symptoms. It clearly states that it is not appropriate to give a mental disorder diagnosis solely because a medical (physical) cause cannot be found.

### 4.4.3 NICE Guidance

NICE guidance for the management of CFS/ME<sup>14</sup> was issued in 2007, with the overall goal of improving care for people with CFS/ME.

The NICE guidance advises healthcare professionals should consider the possibility of CFS/ME if a person has:

fatigue with all of the following features:

- new or had a specific onset (that is, it is not lifelong)
- persistent and/or recurrent
- unexplained by other conditions
- has resulted in a substantial reduction in activity level
- characterised by post-exertional malaise and/or fatigue (typically delayed, for example by at least 24 hours, with slow recovery over several days)

and one or more of the following symptoms:

- difficulty with sleeping, such as insomnia, hypersomnia, unrefreshing sleep, a disturbed sleep-wake cycle
- muscle and/or joint pain that is multi-site and without evidence of inflammation
- headaches
- painful lymph nodes without pathological enlargement
- sore throat
- impairment of short-term memory, and difficulties with word-finding, planning/organising thoughts and information processing

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<sup>14</sup> Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children

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- cognitive dysfunction, such as difficulty thinking, inability to concentrate,
- physical or mental exertion makes symptoms worse
- general malaise or 'flu-like' symptoms dizziness and/or nausea palpitations in the absence of identified cardiac pathology.

A diagnosis should be made after other possible diagnoses have been excluded and the symptoms have persisted for:

- 4 months in an adult
- 3 months in a child or young person; the diagnosis should be made or confirmed by a paediatrician

In summary, the fact that there are multiple different classifications with no universal agreement on diagnostic guidelines reflects the complex nature of the disease and the lack of a clear aetiology. There is little evidence that any of the case definitions or diagnostic criteria in use demonstrate accuracy in the diagnosis of CFS.

CFS/ME involves a complex range of symptoms that includes fatigue, malaise (in particular post exertional malaise), headaches, sleep disturbance, poor concentration / poor short term memory ('Brain Fog'), muscle and/or joint pain, sore throat, tender lymph nodes, stomach pain/bloating/constipation/diarrhoea/nausea, sensitivity or intolerance to light/loud noise/alcohol, dizziness, excessive sweating and difficulty controlling body temperature. Anhedonia, panic attacks, depression, irritability, and emotional lability are also commonly present.

A person's symptoms may fluctuate in intensity and severity, and there is also great variability in the symptoms different people experience. There is significant clinical overlap between CFS/ME and fibromyalgia syndrome (FMS).<sup>15</sup>

### 4.5 Functional Impairment and Levels of Severity

CFS/ME can be associated with profound levels of functional impairment.

Many cases of CFS/ME are mild or moderate, but up to one in four people with CFS/ME may have severe or very severe symptoms at some point in their illness. NICE guidance defines the following levels of severity according to the degree to which CFS/ME affects a person's functioning and daily life:

- People with **mild** CFS/ME are mobile, can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off, or use the weekend to cope with the rest of the week.
- People with **moderate** CFS/ME have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work, school or college and need rest periods, often sleeping in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.

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<sup>15</sup>White K Speechley M Harth M Ostbye T. Co-existence of chronic fatigue syndrome with fibromyalgia syndrome in the general population. *Scandinavian Journal of Rheumatology* 2000;29(1):44

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- People with **severe** CFS/ME are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. They are often unable to leave the house, or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed, and are often extremely sensitive to light and noise.

### 4.6 Management

The NICE guidance gives the following advice to healthcare professionals about the management of a patient with CFS/ME:

Healthcare professionals should recognise that the person with CFS/ME is in charge of the aims and goals of the overall management plan. The pace of progression throughout the course of any intervention should be mutually agreed.

An individualised management plan should be developed with the person with CFS/ME, and their carers if appropriate. The plan should be reviewed and changes documented at each contact. It should include:

- relevant symptoms and history
- plans for care and treatment, including managing setbacks/relapses
- information and support needs
- any education, training or employment support needs
- details of the healthcare professionals involved in care and their contact details.

Any decision to refer a person to specialist CFS/ME care should be based on their needs, the type, duration, complexity and severity of their symptoms, and the presence of co morbidities. The decision should be made jointly by the person with CFS/ME and the healthcare professional.

#### Symptom management

- Manage symptoms of CFS/ME as in usual clinical practice. Advice on symptom management should not be delayed until a diagnosis is established. This advice should be tailored to the specific symptoms the person has and be aimed at minimising their impact on daily life and activities.
- Share decision making with the person with CFS/ME during diagnosis and all phases of care. Acknowledge the reality and impact of the condition and the symptoms. Provide information on the range of interventions and management strategies covered in this guideline, including their risks and benefits. Take into account the person's age, the severity of their symptoms and the outcome of previous treatments.
- Complementary therapies are not usually recommended but may help symptom control.

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- Supplements such as vitamin B12, vitamin C, co-enzyme Q10, magnesium, NADH (nicotinamide adenine dinucleotide) or multivitamins and minerals are also not usually recommended but may help symptom control.

People with CFS/ME are, in general, sensitive to medications and therefore can develop side effects easily to many medications, which needs to be taken into account when prescribing.

### Function and quality-of-life management

- Sleep management – provide tailored sleep management advice, do not encourage daytime sleeping/naps
- Rest periods – advise people on how to introduce ‘rest periods’ into their routine
- Relaxation – various relaxation techniques can be advised for managing pain, sleep problems, co morbid stress or anxiety
- Diet – emphasize importance of well balanced diet, eating regularly, develop strategies to minimise problems due to nausea, sore throat or problems with buying and preparing food
- Aids and Adaptations - For people with moderate or severe CFS/ME, consider providing or recommending equipment and adaptations (such as a wheelchair, blue badge or stair lift). This should be as part of an overall management plan, taking into account the risks and benefits for the individual patient, to help them to maintain their independence and improve their quality of life

### Education and Employment

- Having to stop work or education is generally detrimental to people’s health and well-being. Address each person’s ability to continue in education or work early, and review it regularly.
- Proactively advise about fitness for work and education, and recommend flexible adjustments or adaptations to help people to return to them when they are ready and fit enough.

Liaise, with the person’s informed consent, with

- Employers and occupational health services
- Disability services through Jobcentre Plus
- Social care and Education services

### Treatment plans

- Offer an individualised, person-centred program that aims to sustain and gradually extend, if possible, the person’s physical, emotional and cognitive capacity and manage the physical and emotional impact of their symptoms.
- Explain the rationale and content of the different programmes, including their potential benefits and risks, and that no single strategy will be successful for all people with CFS/ME, or at all stages

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Recognise that the person is in charge of the aims of the programme. Agree together the choice of programme, its components, and progression through it, based on:

- the person's age, preferences and needs
  - the person's skills and abilities in managing their condition, and their goals
  - the severity and complexity of symptoms
  - physical and cognitive functioning
- 
- Offer cognitive behavioural therapy (CBT) and/or graded exercise therapy (GET) to people with mild or moderate CFS/ME, and provide them for those who choose them, because these are the interventions for which there is the clearest research evidence of benefit. Components of CBT or GET may be offered together with activity management strategies, sleep management and relaxation techniques, where the full CBT or GET program is not appropriate.
  - Offer people with severe CFS/ME an individually tailored activity management program as the core therapeutic strategy.
  - Consider referral to Pain Management clinic if pain is a predominant feature.
  - Consider low dose tricyclic antidepressant for poor sleep or pain.

NICE guidance provides the following definitions for CBT, GET and specialist care:

### **Cognitive Behavioural Therapy (CBT)**

An evidence-based psychological therapy that is used in many health settings, including cardiac rehabilitation and diabetes management. It is a collaborative treatment approach. When it is used for CFS/ME, the aim is to reduce the levels of symptoms, disability and distress associated with the condition. A course of CBT is usually 12–16 sessions. The use of CBT does not assume or imply that symptoms are psychological or 'made up'.

### **Graded Exercise Therapy (GET)**

An evidence-based approach to CFS/ME that involves physical assessment, mutually negotiated goal-setting and education. The first step is to set a sustainable baseline of physical activity, then the duration of the activity is gradually increased in a planned way that is tailored to the person. This is followed by an increase in intensity, when the person is able, taking into account their preferences and objectives, current activity and sleep patterns, setbacks/relapses and emotional factors. The objective is to improve the person's CFS/ME symptoms and functioning, aiming towards recovery.

### **Specialist Care**

A service providing expertise in assessing, diagnosing and advising on the clinical management of CFS/ME, including symptom control and specific interventions. Ideally this is provided by a multidisciplinary team, which may include GPs with a special interest in the condition, neurologists, immunologists, specialists in infectious disease, paediatricians, nurses, clinical psychologists, liaison psychiatrists, dieticians, physiotherapists and occupational therapists.

# Medical Services

## Avoid

- Specialist management programs which are delivered by practitioners with no experience in the condition
- Giving advice to person to undertake unsupervised or unstructured vigorous exercise
- Various drugs such as monoamine oxidase inhibitors, glucocorticoids, mineralocorticoids, thyroxine, antiviral agents, methylphenidate, dexamphetamine

## Preparing for a setback/relapse

Advise people with CFS/ME that setbacks/relapses are to be expected.

Develop a plan with each person with CFS/ME for managing setbacks/relapses, so that skills, strategies, resources and support are available when needed. This plan may be shared with the person's carers, if they agree.

## Review and ongoing management

Perform regular structured review of management, assessing improvement or deterioration in symptoms, assessing any side effects of medication, reviewing the diagnosis if signs and symptoms change, consider need for further investigation, consider referral to specialist, reviewing any equipment needs, assessing need for additional support.

(The NICE guidelines were reviewed in 2010 – 2011 to determine whether any amendments needed to be made to the 2007 guidelines in view of more recent medical evidence, however no new evidence was available to suggest that a change was required.)

### 4.6.1 Ongoing debate

Following release of the NICE guidance some patient organisations within the UK (ME association and Action for ME) released survey results which indicated that people with CFS/ME found pacing to be more beneficial and also reported that CBT and GET are sometimes harmful.

The report of the Chief Medical Officer's working group<sup>16</sup> defined the principles of pacing as "an energy management strategy in which patients are encouraged to achieve an appropriate balance between rest and activity. This usually involves living within physical and mental limitations imposed by the illness, and avoiding activities to a degree that exacerbates symptoms or interspersing activity with periods of rest. The aim is to prevent patients entering a vicious circle of overactivity and setbacks, while assisting them to set realistic goals for increasing activity when appropriate."

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<sup>16</sup> A report of the CFS/ME Working Group (Report to the Chief Medical Officer of an Independent Working Group) 2002

## Medical Services

An article published in *The Lancet* in March 2011 gave details of results from a randomised trial - PACE study - which looked at Adaptive Pacing Therapy (APT), Cognitive Behaviour Therapy (CBT), Graded Exercise Therapy (GET) and Specialist Medical Care (SMC) in the treatment for Chronic Fatigue Syndrome (CFS). The results suggested that CBT and GET could safely be added to SMC to moderately improve outcomes for CFS but APT was not an effective addition<sup>17</sup>. There were no differences between the groups of reported serious deterioration or serious adverse reactions.

The ME Association issued a press statement on the results of the PACE trial on the 18th of February 2011, which stated that ‘the results are at serious variance to patient evidence on both cognitive therapy and exercise therapy’. This was based on results from a survey performed by the ME Association in 2008<sup>18</sup>, during which a comprehensive questionnaire was sent to people with Chronic Fatigue Syndrome and their carers, which suggested that pacing was found to be more beneficial than Graded Exercise therapy.

Recent research reviewed treatment outcomes for patients attending NHS CFS/ME specialist services<sup>19</sup>. One of the aims of the research was to see whether the outcomes were similar to those of the PACE trial. Patients attending NHS specialist CFS/ME services were treated with CBT, GET, a combination of both or activity management, in group and/ or individual treatment sessions of varying numbers and lengths. The evidence showed that although improvements in fatigue similar to the PACE trial were present, there was far less improvement in levels of physical function in a clinical setting. One of the factors postulated for the difference was the amount of treatment patients underwent. In NHS it appeared that patients were offered 5-6 sessions, whereas in the PACE trial it was 12-14 sessions. There may also be differences in the content of the treatment offered between the trial and clinical settings. However it is clear that further research is required for further clarification of treatment outcomes.

At times it appears that the arguments and controversies around the aetiology of CFS/ME detract from the management of the condition itself. Following a biopsychosocial model of illness reinforces the idea of an illness having both physical and mental components with social influences. Understanding and treating CFS/ME should be less about the dichotomy of whether it is a physical illness or a mental illness and more about recognising the complex nature of the condition. The management regime offered should be effective in helping the patient and improving their condition no matter what the aetiology of the condition.

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<sup>17</sup> White PD, Goldsmith KA, Johnson AL, Potts L, Walwyn R, DeCesare JC, et al. Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. *Lancet* 2011; 377: 823-836

<sup>18</sup> Managing my M.E. What people with ME/CFS and their carers want from the UK's health and social services. The results of the me association's major survey of illness management requirements. ME Association 2010.

<sup>19</sup> Crawley E, Collin SM, White PD, Rimes K, Sterne JAC, May MT, and CFS/ME National Outcomes Database. Treatment outcomes in adults with chronic fatigue syndrome: a prospective study in England based on the CFS/ME National Outcomes Database. *Q J Med* 2013; 106: 555-565

### 4.7 Prognosis

CFS/ME is not associated with increased mortality. Studies have shown that whilst some patients do improve (figures vary from 17 to 64%), between 10-20% worsen over time and less than 10% recover fully to a pre-morbid level of functioning.

CFS/ME often follows a variable fluctuating course with periods of remission interspersed with relapses.

Factors that have been associated with a poorer prognosis include<sup>20</sup>:

- Older age
- Longer illness duration
- Fatigue severity
- Co-morbid psychiatric illness
- Physical attribution of symptoms

However a recent study looking at treatment outcomes did not find that depression, anxiety or duration of illness predicted outcome.<sup>21</sup>

CFS/ME in children and adolescents is associated with a better prognosis.

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<sup>20</sup> Joyce J, Hotopf J, Wessely S. The prognosis of chronic fatigue and chronic fatigue syndrome: a systematic review. *QJM* 1997; 90: 223-233

<sup>21</sup> Crawley E, Collin SM, White PD, Rimes K, Sterne JAC, May MT, and CFS/ME National Outcomes Database. Treatment outcomes in adults with chronic fatigue syndrome: a prospective study in England based on the CFS/ME National Outcomes Database. *Q L Med* 2013; 106: 555-565

## 5. Face-to-Face Assessment in the Disability Analysis Setting

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Questions which need to be considered when completing assessments in the disability analysis setting include:

- To what extent is the person functionally impaired (taking into account any variability)?
- Consistency - Is the claimed degree of disability in keeping with the history, clinical findings and natural history of the disorder?
- What is the prognosis?

In order to provide advice on these matters, a clear, focused and personalised assessment must be performed.

### 5.1 Before the Assessment

As with any face-to-face assessment, review carefully the information available on MSRS (for Revised WCA cases) or in the file. This may consist of claim forms completed by the claimant (or their carer), letters from their GP or hospital specialists, factual reports as well as previous reports (such as an ESA 85 or and IB 85).

In Revised WCA cases particular attention must be paid to the current claimant questionnaire (ESA50) and all areas where the claimant indicates that there may be a problem must be fully explored. At times the claimant may also bring additional evidence to the assessment. Any evidence brought by the claimant must be read and the report should make reference to the evidence that has been considered and justification provided if there is a conflict between the opinion of the HCP and the other medical evidence.

In DLA claims the HCP will need to read the information provided by the DM on the DLA request form (DBD313A) and ensure the report addresses all the queries raised by the DM.

### 5.2 Setting the Scene at the Beginning of the Assessment

In order to ensure that the assessment yields the maximum amount of information, HCPs should invest time in creating a good rapport with the claimant. Because of the nature of the condition and the differing perceptions surrounding it, some individuals may adopt a defensive attitude, assuming that the HCP will approach the proceedings with in-built disbelief. HCPs should make it clear that their mind is open, that they are prepared to listen, and that their report will be fair and objective.

# Medical Services

## 5.3 History

### 5.3.1 Condition History

Symptoms should be carefully elicited. Fatigue, post-exertional malaise, muscle pain, poor concentration and disturbed sleep are commonly reported, but be sure to enquire about any other related symptoms.

Any concomitant condition must be identified and individually recorded, as it may be contributing to any functional impairment present.

Information about any treatment received, including medication or specialist treatment, must be recorded along with its impact on the symptoms/function.

### 5.3.2 Typical Day History

An account of the activities of a typical day should be taken, in keeping with the general guidelines (see Revised WCA Handbook or Guidance for Health Care Professionals undertaking Disability Living Allowance/Attendance Allowance Assessments Handbook). The HCP should explore all of life's key activities in the process, such as feeding, cooking, keeping the house clean, shopping, gardening, social life and so on. This should include clarifying details such as how often the task is performed, is it repeatable and is there any after effects? Evidence of consistency should be sought in how each of these activities is managed. This in turn should be confirmed by informal observation where possible.

It should be noted in interpreting this evidence that one of the common complaints of claimants with CFS/ME is that although tasks can often be accomplished they cannot be sustained; or reliably performed again without significant detriment (e.g. exhaustion, to the extent of being unable to continue with any other activities for the rest of the day/ next few days). Ensure this is probed and explored within the typical day history.

### 5.3.3 Variability

In addition, careful account must be taken of variability; since CFS/ME, like most other chronic conditions, encompasses a *spectrum* of capabilities. Information on variability, indicating to the DM 'where' the claimant sits on the severity spectrum, is an important contributor to the HCP's advice. It is not sufficient to simply make the general comment that the symptoms "vary from day to day", or between one part of the day and the next. The DM requires information on the actual duration of disabling problems; the frequency of days when severe fatigue or pain is experienced; the average proportion of "bad" days to "good", and a description of what the person says he/she can and cannot do on the "good" days and the "bad" days.

In Revised Work Capability assessments remember to look for added clues about the extent of variability, and other ways CFS/ME impacts on a claimant's life, by scrutinising information which may be contained under the section headed 'About your illnesses or disabilities' (page 3, of ESA 50 version 01/13).

## Medical Services

Here, claimants have an added opportunity to describe in their own words the way in which they feel their condition(s) affects them; to expand on their personal experiences of living with CFS/ME – especially important if they feel that subsequent parts of the form (detailing the functional 'Activity' areas) are not applicable/ "don't fit" their view of the difficulties they have.

### 5.4 Examination

#### 5.4.1 Physical Examination

It goes without saying that any physical examination performed must be carried out with particular care and consideration. HCPs should seek and document the claimant's express permission to carry out any physical examination. Consent must be requested verbally and then formally documented within the report. HCPs should also ensure the claimant is happy to proceed at each stage of the physical examination. HCPs should be mindful of the basic principles of examination etiquette, which was addressed in their initial training when joining the company (and which is dealt with further in the Learning Set, "General Principles of Examination (MED-CMEP~115)" which is available on sharepoint). The range of joint movements must be assessed through active movements and the use of passive movements to assess these movements would not be considered appropriate. If the claimant indicates a movement is causing discomfort or pain then the examination of that movement should stop. Insensitive or inappropriately 'rough' examination can cause exacerbation of CFS/ME symptoms.

In essence, there should be a *functional* need for any physical examination and HCPs should be able to justify this. HCPs may be criticised for 'over-examining' if it results in unnecessarily tiring the claimant, when there was little justification to do so (in a similar vein, they should be able to defend their reasoning for *not* undertaking a particular examination if it would have yielded useful evidence: e.g. checking for signs of muscle-wasting). Whilst HCPs may feel that a physical examination is important in order to provide the DM with the most comprehensive evidence on which to base their decision, they should respect the wishes of claimants who are reluctant to participate in / attempt an activity. Claimants should certainly never be pushed to complete an activity in the face of obvious pain. HCPs are reminded that if they are unable to perform a formal examination due to pain or fatigue, they can still record formal observations for the exam (as opposed to general observations) such as any obvious joint deformities in the hands, any generalised muscle wasting or intrinsic muscle wasting in the hands etc

It is important to remember that the person may well be examined by another disability analyst at some time in the future in order to determine progress, and the methods and style of recording clinical findings must be in accord with Atos Healthcare's standards and recommendations.

HCPs are reminded when carrying out an MSO, it should be able to be completed with the claimant wearing loose indoor clothing. If an abnormality is suspected, and therefore a regional inspection and examination required, it would be usual to ask the claimant to remove the relevant items of outer clothing in order to complete this task. Further explanations and consent to proceed are essential at this stage.

## Medical Services

HCPs are also reminded to consider whether the presence of an attendant, or a relative or friend should be offered. If an attendant, relative or friend is present, the HCP should record the fact on the report form, making a note of the person's identity. If the claimant does not want an attendant, the HCP should record that the offer was made and declined.

Characteristically the physical examination rarely reveals definitive positive clinical findings, but particular features, such as muscle-wasting, should be positively sought; recorded; and explained to the DM.

When a particular functional deficit is claimed, for example mobilising or manual handling, the associated muscle groups and joints should receive particular attention and muscle power carefully assessed and recorded – again, bearing in mind the general principles of examination as discussed above.

### 5.4.2 Mental State Examination

Because of the possible effects on mental functioning of CFS/ME, it will almost always be appropriate to assess the claimant's mental state in the form of a mental state examination.

CFS/ME can affect concentration, memory and cognition and mood. Therefore a mental state examination should clearly document associated findings including cognitive function. Like the physical examination findings, the mental state examination findings contribution to the advice given must be clearly explained to the DM.

In Revised WCA cases if the claimant indicates any problems with mood, concentration or 'brain fog' then a MSE must always be documented. If a mental health/function assessment is not carried out, then the reasons for not doing so should be fully justified. In DLA reports, a MSE should always be documented.

## 5.5 Observed Behaviour

This should be carefully noted, assessed and recorded. As usual, observations recorded must be focused, relevant and in accordance with Atos Healthcare's guidance in relation to personal descriptions. Remember however that the claimant will almost certainly complain of variability and fatiguability and a "snapshot" account may be challenged on this basis. In addition it is a frequent complaint that a high level of activity on one day may well be achieved but will not result in incapacitating malaise until the next day.

## 5.6 Logical Reasoning and Justification of Advice

An important step in disability analysis is to logically reason all the available evidence in order to formulate the advice. Remember evidence is not just that available from the face-to-face assessment. Sources such as the ESA 50 (in Revised WCA cases), hospital/specialist letters as well as information from carers if available must be considered.

## Medical Services

In CFS/ME, where there are few if any overt clinical findings, it is particularly important to carefully evaluate whether the person's description of their disability is consistent with their daily activities and lifestyle.

Take careful account of the effects of fatigue, of variability of symptoms, and of the ability to reasonably sustain any given activity, not just the ability to perform it once. Ensure the advice given is not formed from a "snapshot" of the claimant on the day of assessment, but reflects their functional ability over a period of time. Taking all of this into account, if a claimant cannot repeat an activity with a reasonable degree of regularity, and certainly if they can perform the activity only once, then they should be considered unable to perform that activity.

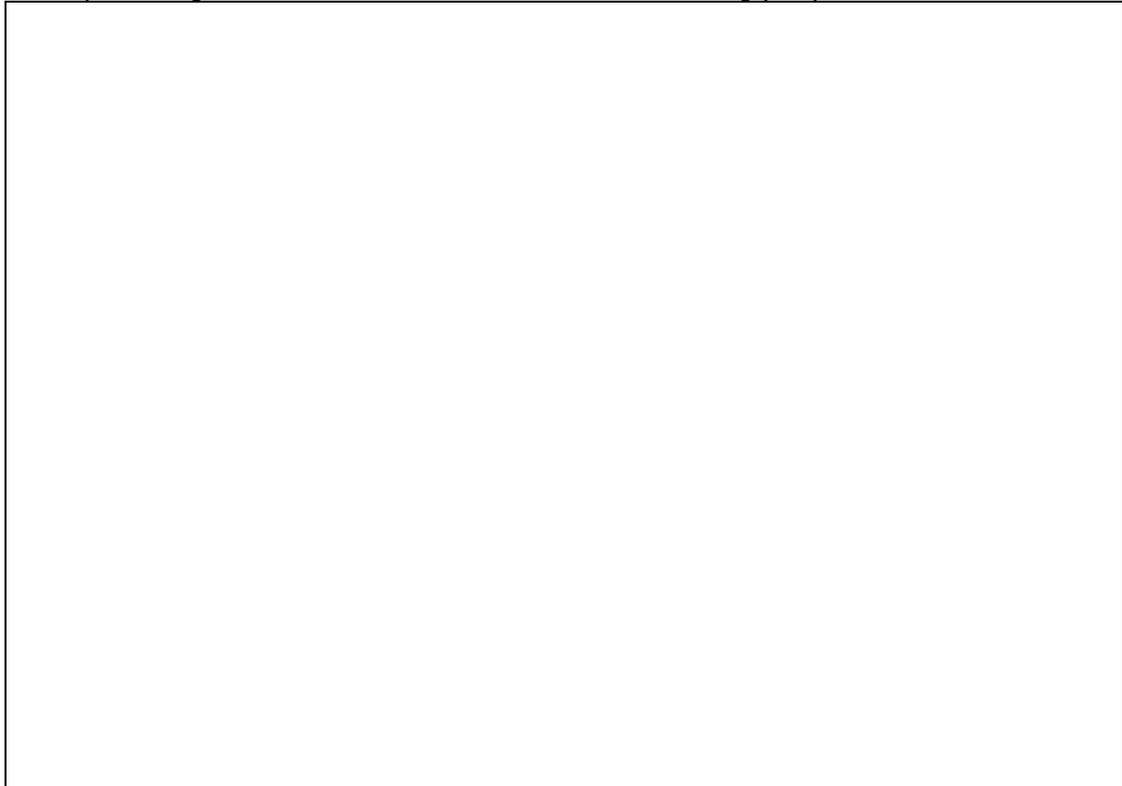
## 6. CFS/ME and the Revised Work Capability Assessment

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HCPs will recall the main aims of the ESA Work Capability Assessment are to provide a fairer, more accurate and more robust assessment of the level of a person's functional ability in relation to capability for work in the modern workplace, as well as to ensure that those who currently have limited capability for work and work related activity are identified.

The Work Capability Assessment has been reviewed regularly since its inception to ensure the aims are fulfilled. These reviews have resulted in revision of the regulations on two occasions (2011 and 2012) so that the process is now known as the Revised Work Capability Assessment.

Thinking about the current Revised WCA activity groups along with the LCW and LCWRA descriptors (HCPs may wish to refer to the Revised WCA Handbook), what descriptors might be relevant to consider when assessing people with CFS/ME?



A review of symptoms associated with CFS/ME reveals great heterogeneity and therefore it is likely that multiple activity areas and descriptors may need to be considered.

Symptoms such as fatigue, post-exertional malaise, muscle and joint pain may affect lower limb and upper limb activities; mobilising, sitting and standing, reaching, picking up and moving and manual dexterity.

## Medical Services

CFS/ME is not usually associated with sensory loss (affecting vision, hearing or speech). It is also not usually associated with loss of consciousness or incontinence. Therefore sensory, consciousness and continence functional impairment is unlikely unless other conditions affecting these modalities are present.

Symptoms of CFS/ME such as fatigue, post-exertional malaise, poor sleep, poor concentration and cognitive difficulties may all impact on mental functioning, especially within the understanding and focus group of activities. If the symptoms are significant they may affect the ability to complete personal action and if severe hazard awareness may be affected. Unless there are other co-morbid mental illness conditions (such as depression or anxiety) present, it is unlikely there will be functional impairment of the adapting to change or social interaction activities. The scope of these activity groups shows the focus of these activities is intended for conditions such as psychosis, autism, severe anxiety and depression.

For the purposes of Revised WCA, skill is required to assess the degree to which stated difficulties in persisting with tasks is due to the physical component of the illness, and which is due to psychological factors – and there may be a risk of double application of physical and mental function descriptors. The ability to perform activities reliably and repeatedly is integral to the activity descriptors in Revised Work Capability Assessment (Amended 2012 Regulations) and to the advice given to the DM in any of the benefit assessments.

HCPs may wish to reinforce their knowledge by re-reading the scope of each of the Revised WCA descriptors in the Revised WCA handbook.

### 6.1 Revised Work Capability Assessment Case Study

Review the information in the following case scenario, think about which descriptors may be appropriate and write a justification of the advice.

Mr GD

52 years old

Med 3: ME

Referral type: IBR (no previous reports available)

ESA 50 information: He indicates he has severe CFS with ongoing significant fatigue and indicates he has problems with mobilising, sitting and standing and initiating personal action.

#### History

He became unwell about 10 years ago. There was no preceding illness; he just developed severe fatigue over the course of a few weeks. The doctors didn't know what was wrong with him. He underwent multiple investigations but he was told everything was 'normal'. After 18 months of ongoing unremitting fatigue and post-exertional malaise his GP diagnosed him with CFS. He was told there was no specific treatment. He has never been referred to a specialist CFS unit.

## Medical Services

He has read a lot around the topic. He has learnt to manage his condition himself by pacing his activities. He describes symptoms of muscle and joint pains, poor sleep and headaches. He also describes poor concentration culminating in a 'brain fog' of things become too overwhelming.

He takes paracetamol and ibuprofen as required to help with the muscle/joint pain, with some effect.

Lives with his wife and two teenage children in a bungalow (moved from a house 8 years ago because of his condition). Last worked 10 years ago as an accountant, stopped work because of his illness. Wife brought him to the MEC, she dropped him outside the front door and went to park the car 100m away. He could not have managed to walk that distance.

Sleeps poorly, has difficulty getting to sleep and wakes several times during the night. Normally is awake by 6am. Does not feel refreshed in the morning. Wife brings him a cup of tea and toast in bed before she goes to work. He normally stays in bed for a couple of hours, getting up around 8 or 9am. Some days, he will stay in bed longer if he needs to. This occurs a few times a week. After having the illness so long now he knows his limits and mostly avoids doing anything which will make his condition worse. His condition has varied in severity over the years. About 3 years into his illness he was very severe and he was bed bound for an extended period. He has improved slightly since that time and would describe his condition as moderately severe now. He still is rarely able to leave the house.

He manages to get washed and dressed unaided. He takes his time and has a break between washing and dressing, resting for 15 minutes. He has constant muscle and joint pains and it makes any movement difficult. He sits while shaving and cleaning his teeth. They have a modified wet room to make it easier for him. He was not able to get in and out of the bath. He sits to have a shower.

After washing and dressing he spends a short amount of time on the computer. No more than 15 minutes. He has found that if he limits it to 15 minutes then he is able to use the computer a couple of times a day. If he spent longer on the computer in one go, it tires him out. He finds it difficult to concentrate and he will have to rest for a few hours afterwards. He rests regularly during the day for at least 15-30 minutes.

He is unable to do any of the housework or cooking because of fatigue and muscle/joint pains. His wife does most of it but as the children are getting older, they are helping out more as well. His wife does the grocery shopping online and it is delivered every couple of weeks. His children put the groceries away when they get home after school. Sometimes she will go to the supermarket as well, but she goes alone as he finds it too exhausting to cope with. The last time he went to the supermarket was 2 years ago and he was bedbound for 3 days afterwards. There is a local shop at the end of their street (about 60m away) but he has not been there for years. He might be able to walk there and back slowly (with a rest) but he knows that he would feel very tired afterwards and would require an extended period of rest (days) to recover.

He reads small amounts at a time. His wife gets him library books regularly although it normally takes him several weeks to finish a book. He is able to extend the loans online.

## Medical Services

He does not tend to watch TV, he finds concentrating for an hour or so to watch a programme quite tiring.

He very rarely leaves the house, normally only for GP appointments or occasionally he will go for a drive on the weekend with his family. His wife always parks right outside the GP surgery to reduce the amount of walking he has to do. Also he always stays in the car whenever they go out for a drive. His children and wife will get out and walk about their destination but he could not manage this. His wife always drives. He stopped driving at the beginning of his illness because he felt his concentration was poor. Occasionally his wife takes him to visit his elderly father who is in a local rest home. He finds trips out of the house very tiring and normally he will have to rest for a day or two afterwards.

### Examination

Lower Limb: Hip, knee and ankles full range of movement bilaterally (movements performed slowly), normal power. Able to bend forward to reach knees, Declined to squat (as he was concerned it would cause pain). Evidence of generalised muscle wasting present. Calluses were not present on soles of feet.

Upper Limb: Shoulder, elbow and wrists full range of movements bilaterally (movements performed slowly), normal power, normal finger movements, normal grip and pinch power bilaterally

Mental State Examination: well kempt, normal build, appears tired, normal rapport, normal eye contact, normal behaviour, speech normal, concentration adequate, cognition normal, normal insight

### Observed behaviour

Rose slowly from sitting 3 times without assistance, walked slowly 10m to assessment room, antalgic gait. Slowly got on and off couch but did not need assistance, slowly able to remove/put on coat unaided, able to handle glasses and manage buttons without assistance.

### Advice

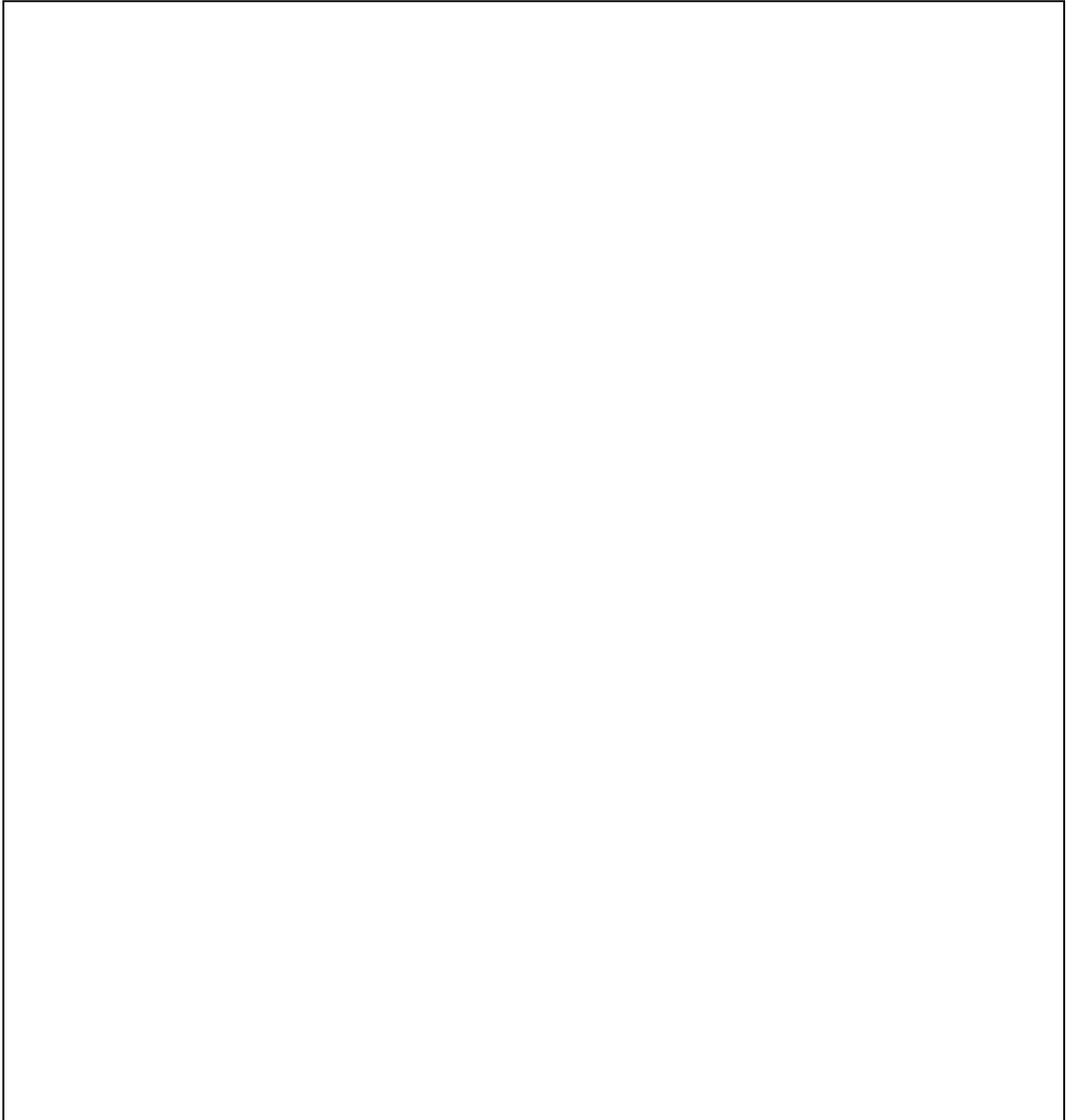
Thinking about the information above, what advice would you give the DM?

## Medical Services

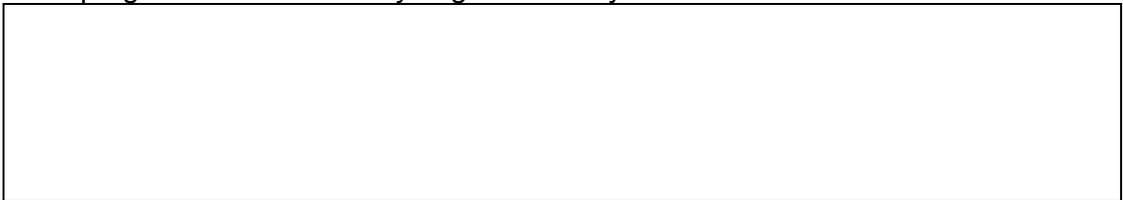
What pieces of evidence are you using to support your advice?

Write a comprehensive justification for your advice. Remember to address any variability or inconsistency within the evidence.

## Medical Services



What prognosis advice would you give and why?



## 7. CFS/ME and Disability Living Allowance

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Disability Living Allowance consists of 2 components:

**Care** - payable to those who need help with personal care or who have difficulty planning and preparing a main meal.

**Mobility** - payable to those with mobility problems due to a physical difficulty with walking, or with a need for guidance or supervision when walking in unfamiliar places out of doors due to physical or mental health problems.

### 7.1 Higher Rate Mobility Component

This is payable to claimants who are:

- Unable to walk due to physical disability
- Virtually unable to walk without severe discomfort due to physical disability (and some other deemed conditions including prescribed categories of severely sight impaired people)

#### 7.1.1 Forming a Mobility Opinion

DLA legislation requires the claimant to have a physical disability in order to be entitled to the higher rate mobility component. Where a person has a condition with both physical and mental elements (such as CFS/ME), providing the physical problem is contributing to walking difficulties, Upper Tribunal Judges have ruled that all the walking problems should be considered 'physical' in this context.

##### 7.1.1.1 The Limb Function Table

An area of evidence within the DLA report is the limb function table. HCP's opinions here need to be consistent with their mobility opinion. There are four levels of function referred to in this table. It allows the conversion of medical findings in the limbs into levels of function for the DM.

These levels of function broadly correlate with the levels of disability:

- Full function and slight impairment (1 & 2) correlate with significant disability unlikely
- Substantial impairment (3) correlates broadly with significant disability likely
- Nil function (4) correlates broadly with severe disability likely

Some HCPs struggle when completing this table for claimants with CFS/ME. Remember it is reflecting the HCP's opinion on limb **function**, not just clinical examination findings.

## Medical Services

Therefore ensure the effects of symptoms such as fatigue, post-exertional malaise, muscle and joint pain are reflected when completing this table. For example if a claimant has significant lower limb functional impairment due to fatigue this should be reflected with '3' being documented in the appropriate boxes. If the claimant's condition is very severe (such that they are bedbound) then it is likely '4' would be appropriate. Remember any inconsistencies in the evidence must clearly be explained for the DM in the justification of the advice given.

The DM needs to understand all aspects of a claimant's mobility, not just the likely walking distance or speed and stability of gait but also if any halts are necessary or there is any variability in function.

### 7.2 Care Component

To qualify for the lowest rate of the care component of DLA, a person will have to be so severely disabled physically or mentally that they need attention from another person for a significant portion of the day in connection with bodily functions and/or they cannot plan and prepare a cooked meal for themselves if they have the ingredients.

To qualify for the middle rate of the care component in DLA they need frequent attention from another person throughout the day in connection with their bodily functions and/or continual supervision throughout the day by another person to avoid substantial danger to themselves or others.

To qualify for the highest rate of the care component in DLA they need frequent attention from another person throughout the day in connection with their bodily function and/or continual supervision throughout the day by another person to avoid substantial danger to themselves or others. They also need prolonged, or repeated, attention from another person during the night in connection with their bodily functions and/or need another person to be awake for a prolonged period or at frequent intervals during the night to watch over them, to avoid substantial danger to themselves or others.

Remember attention is defined as helping someone in connection with his or her bodily functions. Examples of bodily functions include: breathing, hearing, seeing, communicating, eating and drinking, walking, sitting, sleeping, cleanliness and skin protection (including being turned in bed), getting into or out of bed, dressing/undressing, going to the toilet (including undressing, wiping and re-dressing). Bodily functions do not include shopping or other domestic tasks, many of which would normally be undertaken by a home carer.

The symptoms of CFS/ME can certainly affect bodily functions, such as walking, getting in and out of bed, sleeping, going to the toilet etc, especially if severe. Remember to take a detailed typical day history that also addresses any variability present. People with significant CFS/ME symptoms may also have difficulty planning and preparing a cooked meal for themselves.

## Medical Services

### 7.3 Disability Living Allowance Case Study

Review the information in the following case scenario, think about the mobility opinion and care opinion you would give with the available evidence.

Miss KL

20 year old woman

Information from the DM indicates diagnosed with CFS 1 year ago. GP advises that she has been referred to specialist CFS clinic. No information received from hospital specialist. GP unaware of current functioning.

History provided by the claimant:

Problems began just over a year ago. She was diagnosed with glandular fever after an illness lasting a few weeks, which really knocked her about. She initially seemed to be getting better but the tiredness didn't improve. She was at university and had taken time (a few weeks) off sick when she was diagnosed with glandular fever. She attempted to return to her studies but after a couple of weeks, she was feeling so unwell she had to stop. To date she has not been able to return. She describes the main symptoms as overwhelming fatigue, poor concentration and poor sleep.

She was living in a flat with friend at university but has had to return to live with her parents.

Her GP made the diagnosis and referred her to the CFS clinic at the local hospital, which she has found beneficial. She has seen the consultant a few times, but mainly sees the specialist CFS nurse regularly. She has been commenced on a graded exercise therapy programme, which is monitored closely by the CFS nurse. She has seen some improvements since beginning but realises she has a long way to go before she can consider herself recovered. Any progress is slow and she has had a number of setbacks along the way when her condition has worsened, which has been very frustrating.

It has made her feel very low and 6 months ago she was diagnosed with depression. She was commenced on an antidepressant at that time, but does not think there has been much improvement since. She feels low and tearful every day. She feels a sense of hopelessness because progress is so slow. She worries that she might never get well. She struggles with a lack of motivation and apathy with is doubly hard on top of the feeling of exhaustion. She has lost interest in seeing her friends. She admits to occasional thoughts of self harm, but would never act on them because of her family.

She sleeps poorly; she gets to sleep ok but wakes several times during the night. Once awake, she finds it difficult to get back to sleep. She wakes in the morning at different times but always feels un-refreshed. She rests during the day, but tries not to sleep, as this disrupts her sleep even more overnight. When she wakes at night, if she can't get back to sleep then she will listen to podcasts. She finds this relaxing, otherwise she finds herself getting stressed that she is not sleeping.

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Her parents, especially her mum, have been very supportive and helpful for which she is thankful. At the beginning of her illness her symptoms were much worse and her mum was helping her get out of bed and get washed and dressed. She has improved since then and now is able to manage these things for herself at her own pace. She tries to get up and washed and dressed everyday. Occasionally (once or twice a month) her condition is worse and on those days she will stay in bed or rest on the sofa all day.

She finds the thought of cooking exhausting. Her mother is preparing all her meals at the moment. She hopes as she continues to improve that she will progress to making her breakfast and lunch and then onto cooking evening meals again. She used to really enjoy cooking and finds it so hard to accept that she can no longer manage it currently. She is unable to help with the housework. She is following her GET plan and anything more than the basic self care tasks and the planned exercise at this stage she would not cope with (such as the cooking and housework).

She finds that using a computer or watching TV can worsen her fatigue, so she limits those activities to a few times a week for short periods (15 mins). During the day she will spend time listening to the radio (normally via podcasts). She will also often read magazines, because she can pick them up and read for short periods. She does small amounts of exercise according to her GET plan. Currently she has 2 exercise sessions per day, where she walks for 10 mins at a slow pace around the block. This has gradually been increased from just doing stretches to the current level of activity over the last 6 months. She has found that now moving around within the house no longer brings on the fatigue like it used to. She keeps in close contact with the physiotherapist, as she does not want to do too much and end up having a relapse. The physiotherapist and CFS nurse also help with maintaining the motivation to complete the exercises. She is happy with her progress but feels that any additional activity such as cooking is beyond her at the moment, both from the fatigue and lack of motivation).

She is able to get to the local shops a couple of times a week as well. This is about 150m away, in the next street. She will go to buy some sweets or a magazine.

Sees a couple of close friends occasionally. They are making an effort to keep in touch with her, as she does not feel up to socialising currently. They come to the house to pick her up and mostly go to a local café for coffee. They are mindful that she cannot walk far and always try to park within 100m of the café. She does keep in touch with them via mobile, sending the occasional text, but texts far less than before she became unwell.

She does not need any help using the toilet during the day. She does not usually need the toilet at night. She does not report any incontinence.

No night wandering. No behavioural problems.

### **Examination findings**

Lower Limb: Hip, knee and ankles full range of movement bilaterally, normal power. Able to bend forward to reach knees, declined to squat. No evidence of muscle wasting. Soft calluses present on soles of feet.

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Upper Limb: Shoulder, elbow and wrists full range of movements bilaterally, normal power, normal finger movements, normal grip and pinch power bilaterally

Mental State Examination: well kempt, normal build, appears tired, poor rapport, poor eye contact, flat affect, did not smile during assessment, tearful at times, spoke very little (mother provided a lot of the history), voice quiet, concentration adequate, cognition normal, normal insight

### **Observed behaviour**

Assessment completed in claimant's home (lives with her parents). Mother answered the door and claimant was sitting in an armchair in the sitting room. She was able to get out of the chair unaided. She was able to get on and off the bed (for the examination). She walked 10m slowly with a normal gait.

What mobility opinion would you give?

What pieces of evidence support your mobility opinion?

What care opinion would you give?

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What pieces of evidence support your care opinion?

What prognosis advice would you give and why?

## 8. Self Assessment and Case Study Guidance

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### 8.1 Knowledge Self Assessment Quiz

Having had some time to consider the information within this document, review the questions from self assessment exercise in section 2 again. Have any of your answers changed?

	Yes	No	Don't Know
CFS/ME is entirely psychological in origin			
CFS/ME is wholly physical in origin			
CFS/ME symptoms are usually associated with mild levels of functional impairment			
Most people with CFS/ME will recover to pre-morbid functional levels although it may take a long time			
Depression is part of the CFS/ME condition			
There is often overlap in the symptoms experienced in CFS/ME with the condition of fibromyalgia			
Muscle pain is not a symptom found in CFS/ME			
CFS/ME can be diagnosed with a biochemical marker			
CFS/ME has clear diagnostic guidelines			
The aetiology of CFS/ME has been clearly elucidated			
CSF/ME is always triggered by a viral infection			
Antidepressant medication is effective in the treatment of CFS/ME			
There is consensus about the management of CFS/ME			
NICE guidelines recommend offering cognitive behavioural therapy and graded exercise therapy but not adaptive pacing therapy in the management of CFS/ME			
Patient groups in the UK prefer adaptive pacing rather than cognitive behavioural therapy and graded exercise therapy in the management of CFS/ME			

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## 8.2 Revised WCA Case Study Suggested Guidance

### What advice would you give the DM?

Support Group for mobilising, unable to reliably and repeatedly mobilise 50m

### What pieces of evidence are you using to support your advice?

- History of ongoing severe fatigue and muscle/joint pains
- Moved to a bungalow to help cope with disability and has modified wet room
- Rarely leaves the house
- Unable to walk to corner shop or go grocery shopping
- Dropped outside MEC as unable to walk 100m from carpark
- Unable to do housework
- Does not leave the car during family drives
- When attends GP, wife always parks car outside to minimise walking distance.
- Although examination findings mostly normal (which is consistent with the condition), there is evidence of generalised muscle wasting and a lack of callus formation on the soles of the feet.

### Suggested example of justification of advice: Support Group Mobilising

Mr D has longstanding severe Chronic Fatigue Syndrome (CFS) with ongoing symptoms including significant fatigue, muscle and joint pains.

His daily activities are severely restricted due to pain and fatigue. He does manage personal care activities at a slow pace but is unable to undertake activities such as housework and shopping. He rarely leaves the house. He is not able to walk to the local shop 60m away. This is consistent with observed behaviour of a slow antalgic gait. The clinical examination findings of generalised muscle wasting and a lack of callus formation on the soles of the feet are also consistent with moderately severe CFS.

Functional impairment (from fatigue/pain) is unlikely to be improved by the use of aids. Overall he is likely to have severe restriction of his ability to mobilise short distances reliably and repeatedly.

### What prognosis advice would you give and why?

Given the older age, long duration of the illness and ongoing severity of fatigue a longer term prognosis would be appropriate.

### 8.3 Disability Living Allowance Suggested Case Example Guidance

#### What mobility opinion would you give?

Able to walk at least 150-200m

#### What pieces of evidence support your mobility opinion?

- Following Graded Exercise Therapy programme, currently walking for 10 mins at a slow pace (likely to be at least 500m) twice a day
- Able to mobilise around the house without significant difficulty
- Able to walk to the local shops 150m away for small items a couple of times a week
- Able to walk short distances (up to 100m when out with friends)
- Clinical Examination findings normal

#### What care opinion would you give?

Likely to have some attention needs (coping with hot pans, using a traditional cooker) because of problems with significant fatigue. From the evidence (history and observations) it appears that she would not be able to reliably and repeatedly prepare a main meal for herself (equivalent to low rate care).

With regards to the 'mental health, learning disabilities and cognitive impairment' section of the report the evidence indicates she is not neglecting her hygiene/nutrition, she is aware of common dangers, she does not wander and is not destructive to property.

#### What pieces of evidence support your care opinion?

- Despite following GET (with improved walking ability) still has ongoing symptoms of significant fatigue in other aspects of daily living
- Unable to prepare meals for herself, mother does this currently
- Unable to help with housework
- Is managing GET plan at the moment but any additional activities such as cooking would not be possible

#### What prognosis advice would you give and why?

The younger age, shorter duration of the illness and improvement of fatigue with treatment would be consistent with a short to medium term prognosis.

## 9. Further Reading

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- DWP's published medical guidance for DLA/ AA, available on sharepoint or on the internet <http://www.dwp.gov.uk/publications/specialist-guides/medical-conditions/a-z-of-medical-conditions/>
- Occupational aspects of the Management of Chronic Fatigue Syndrome: A National Guideline (2006)-  
[http://www.anhops.com/docs/92\\_8\\_273539\\_CFSyndrome\\_full\\_review.pdf](http://www.anhops.com/docs/92_8_273539_CFSyndrome_full_review.pdf)
- Treatments for chronic fatigue syndrome (Occupational Medicine review – K A Rimes & T Chalder 2005) - <http://www.ncbi.nlm.nih.gov/pubmed/15699088>
- Diagnosis and Management of Chronic Fatigue Syndrome/Myalgic encephalomyelitis in adults or children - NICE Guidelines (National Collaborating Centre for Primary Care & Royal College of GPs) –  
<http://www.nice.org.uk/nicemedia/live/11824/36191/36191.pdf>
- A systematic review describing the prognosis of chronic fatigue syndrome (R. Cairns & Hotopf 2005) - <http://www.ncbi.nlm.nih.gov/pubmed/15699087>
- Chronic Fatigue Syndrome: A Review (Afari N & Buchwald, D) -  
<http://www.ncbi.nlm.nih.gov/pubmed/12562565>
- CDC information on Chronic Fatigue Syndrome <http://www.cdc.gov/CFS/>
- Carruthers BM, Jain AK, De Meirleir KL, Peterson DL, Klimas NG, Lerner AM et al. (2003) Myalgic encephalomyelitis/chronic fatigue syndrome: clinical working case definition, diagnostic and treatment protocols. Journal of Chronic Fatigue Syndrome 2003; 11(1):7- 115  
[http://www.aqem.org/includes/documents/consensus\\_canadian\(full\).pdf - page=18](http://www.aqem.org/includes/documents/consensus_canadian(full).pdf_page=18)
- Crawley E et al. Treatment outcome in adults with chronic fatigue syndrome: a prospective study in England based on the CFS/ME National Outcomes Database. Quarterly Journal of Medicine, 2013, 6, 555- 565  
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3665909/pdf/hct061.pdf>
- CMO Working Group Report –  
[http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalassets/dh\\_4064945.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalassets/dh_4064945.pdf)
- NHS - <http://www.nhs.uk/conditions/chronic-fatigue-syndrome/pages/introduction.aspx>
- Holgate ST et al. Chronic fatigue syndrome: Understanding a complex illness. Nature Reviews Neuroscience, 2011, 12, 539 – 544  
<http://www.ncbi.nlm.nih.gov/pubmed/21792218>

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- Various documents available on sharepoint including:
  - Revised WCA Handbook
  - Guidance for Health Care Professionals undertaking Disability Living Allowance/Attendance Allowance Assessments Handbook
  - Mobility Questions in DLA
  - General Principles of Examination Learning Set
  - EBM – Chronic Fatigue Syndrome / Myalgic Encephalomyelitis
  - Variability
- ME Association (2010) Managing my ME – What people with ME/CFS and their carers want from the UK's health and social services <http://www.meassociation.org.uk/wp-content/uploads/2010/09/2010-survey-report-lo-res4.pdf>
- Action for ME. ME 2008: what progress? Action for ME 2008 [http://www.actionforme.org.uk/Resources/Action\\_for\\_ME/Documents/get-informed/ME 2008 What progress.pdf](http://www.actionforme.org.uk/Resources/Action_for_ME/Documents/get-informed/ME_2008_What_progress.pdf)
- ME/CFS/PVFS An exploration of the key clinical issues (written by Medical Adviser to ME association) [http://www.leger.me.uk/health\\_professional\\_information/key\\_clinic\\_issue.pdf](http://www.leger.me.uk/health_professional_information/key_clinic_issue.pdf)

## 10. Conclusion

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The objectives of this module were to enable HCPs to:-

- Have an overview of CFS/ME including aetiology, diagnosis, management and prognosis
- Consider the assessment of CFS/ME in disability analysis, developing a consistent and focused approach
- Consider the assessment of CFS/ME in Revised WCA and DLA cases

In order to evaluate your understanding of this module, please answer the following questions, referring to the reference material when required.

## **11. Chronic Fatigue Syndrome MCQ**

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**On completion please return to the Clinical Manager or Training Support Manager at your Medical Services Centre**

## **Appendix A - Oxford and Canadian Case Definitions**

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### **11.1.2 Oxford Case Definition**

The Oxford Criteria were developed at a consensus meeting in Oxford in 1991<sup>1</sup>. They retained some of the features of the initial CDC case definition but included physical and mental fatigability. Psychiatric illness was no longer excluded.

Severe, disabling fatigue lasting at least six months that:

- affects both physical and mental functioning
- is present more than 50% of the time

Other symptoms possibly present:

- myalgia
- sleep disturbances
- mood disturbance.

Exclusion criteria:

- active, unresolved or suspected disease likely to cause fatigue
- psychotic or bipolar depression (but not uncomplicated major depression)
- psychotic disorder
- dementia
- anorexia or bulimia nervosa.

### **11.1.3 Canadian Case Definition (Canadian Expert Consensus Panel)**

This new case definition<sup>2</sup>, developed and published in 2003, provided a more clinical focus. It considered post-exertional malaise essential to the diagnosis as well as the presence of neurological/cognitive, autonomic, neuroendocrine and immune manifestations.

#### **Clinical Working Case Definition of ME/CFS**

A patient with ME/CFS will meet the criteria for fatigue, post-exertional malaise and/or fatigue, sleep dysfunction and pain (items 1–4); have two or more neurological/cognitive manifestations (item 5) and one or more symptoms from two of the categories of autonomic, neuroendocrine and immune manifestations (item 6); and adhere to item 7.

1. Fatigue: The patient has a significant degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level.

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<sup>1</sup> Sharpe MK, Archard LC, Banatvala JE, et al. A report – chronic fatigue syndrome: Guidelines for research. *Journal of the Royal Society of Medicine* 1991, 84:(2)118–121

<sup>2</sup> Carruthers BM, et al. Myalgic encephalomyelitis/chronic fatigue syndrome: clinical working case definition, diagnostic and treatment protocols. *J Chronic Fatigue Syndr* 2003; 11: 7-116

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2. Post-exertional malaise and/or fatigue: There is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post-exertional malaise and/or fatigue and/or pain and a tendency for other associated symptoms within the patient's cluster of symptoms to worsen. There is a pathologically slow recovery period—usually 24 hours or longer.

3. Sleep dysfunction:\* There is unrefreshed sleep or sleep quantity or rhythm disturbances such as reversed or chaotic diurnal sleep rhythms.

4. Pain:\* There is a significant degree of myalgia. Pain can be experienced in the muscles and/or joints, and is often widespread and migratory in nature. Often there are significant headaches of new type, pattern or severity.

5. Neurological/cognitive manifestations: Two or more of the following difficulties should be present: confusion, impairment of concentration and short-term memory consolidation, disorientation, difficulty with information processing, categorising and word retrieval, and perceptual and sensory disturbances – e.g. spatial instability and disorientation and inability to focus vision. Ataxia, muscle weakness and fasciculations are common. There may be overload phenomena: cognitive, sensory – e.g. photophobia and hypersensitivity to noise – and/or emotional overload, which may lead to “crash” periods and/or anxiety.

\* There are a small number of patients who have no pain or sleep dysfunction, but no other diagnosis fits except ME/CFS. A diagnosis of ME/CFS can be entertained when this group has an infectious illness type onset.

6. At least one symptom from two of the following categories:

a. Autonomic manifestations: orthostatic intolerance – neurally mediated hypotension, postural orthostatic tachycardia syndrome, delayed postural hypotension; light-headedness; extreme pallor; nausea and irritable bowel syndrome; urinary frequency and bladder dysfunction; palpitations with or without cardiac arrhythmias; exertional dyspnoea.

b. Neuroendocrine manifestations: loss of thermostatic stability – subnormal body temperature and marked diurnal fluctuation, sweating episodes, recurrent feelings of feverishness and cold extremities; intolerance of extremes of heat and cold; marked weight change – anorexia or abnormal appetite; loss of adaptability and worsening of symptoms with stress.

c. Immune manifestation: tender lymph nodes, recurrent sore throat, recurrent flu-like symptoms, general malaise, new sensitivities to food, medications and/or chemicals.

7. The illness persists for at least six months. It usually has a distinct onset, although it maybe gradual. Preliminary diagnosis may be possible earlier, three months is appropriate for children.

To be included, the symptoms must have begun or have been significantly altered after the onset of this illness. It is unlikely that a patient will suffer from all symptoms in 5 and 6. The disturbances tend to form symptom clusters that may fluctuate and change over time.

Exclusions: Exclude active disease processes that explain most of the major symptoms of fatigue, sleep disturbance, pain and cognitive dysfunction. If a potentially confounding medical condition is under control, then the diagnosis of ME/CFS can be entertained if the patients meet the criteria otherwise.

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### Observation Form

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