

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

(Module 6)

MED-CMEP~0017

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Foreword

This training has been produced as part of a training programme for Healthcare Professionals (HCPs) who conduct assessments for The Centre for Health and Disability Assessments on behalf of the DWP.

All HCPs 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 HCPs 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 HCP 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 HCPs.

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1. Introduction

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.

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.

3. CFS/ME Case Study



Thinking about the information provided:

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4. Overview of CFS/ME

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.”¹ 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%¹.

A review of CFS/ME in the *Lancet* in 2006 put the worldwide prevalence between 0.2% and 2.6%². 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 groups².

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 physiological, psychological and social factors all playing a part.

Many theories have been proposed for pathophysiology of CFS/ME but precise mechanisms remain elusive. Multiple studies have shown abnormalities in brain structure/function (including neuroendocrine responses) and muscular function. There have also been numerous studies that have demonstrated abnormalities of sleep and abnormalities within the immune system (including abnormal cytokine function). Other studies have suggested an association with previous exposure to infectious agents. However, there is no consistent abnormality that has been demonstrated across all people with CFS/ME. There is no laboratory abnormality (or biomarker) that allows one to make a confident diagnosis of CFS/ME and the

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

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

diagnosis remains a clinical one based on identifying the very characteristic pattern of symptoms. It is likely that the term CFS/ME represents several different conditions and much research currently concentrates on describing and classifying these different conditions (usually referred to as “phenotypes” of CFS/ME). This will allow more carefully targeted intervention 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.

To date no genetic abnormalities have been found although twin studies have shown a familial predisposition.³

Precipitating factors include an infectious trigger in up to three quarters of patients⁴. 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/ME⁵.

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^{6,7}. 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^{8,9}.

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.

³ Buchwald D, Herrell R, Ashton S, Belcourt M, Schmaling K, Goldberg J. A twin study of chronic fatigue. *Psychosom Med* 2001; 63: 936-43

⁴ 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

⁵ 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

⁶ Joyce J, Hotopf M, Wessely S. The prognosis of chronic fatigue and chronic fatigue syndrome: a systematic review. *QJM* 1997; 90: 223-233

⁷ Heijmans JWM. Coping and adaptive outcome in chronic fatigue syndrome: importance of illness cognitions. *J Psychosom Res* 1998; 45: 39-51

⁸ Ray C, Jeffries S, Weir WR: Coping and other predictors of outcome in chronic fatigue syndrome. *J Psychosom Med* 1997; 43:405-415;

⁹ 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

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

- Infectious: Epstein-Barr virus, influenza, HIV infection, other viral infections and tuberculosis
- 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 considerable controversy over the diagnostic definition of CFS/ME and numerous different criteria have been proposed. As noted above no specific biological marker or abnormality on physical examination 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).

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 Criteria¹⁰. 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.
- cognitive dysfunction

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.

¹⁰ 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

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.

4.4.3 NICE Guidance

NICE guidance for the management of CFS/ME¹¹ 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
- cognitive dysfunction - including impairment of short-term memory, and difficulties with word-finding, planning/organising thoughts and information processing, inability to concentrate (patients will often refer to these symptoms as “brain fog”)
- physical or mental exertion makes symptoms worse (patients will often refer to this phenomenon as “payback”)
- 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

¹¹ Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) in adults and children

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).¹²

4.5 Functional Impairment and Levels of Severity



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.

¹²White 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

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

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. A graded return to work is often helpful

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

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.

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 group¹³ 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."

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 addition¹⁴. 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 2008¹⁵, 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 services¹⁶. One of the aims of the research was to see whether the

¹³ A report of the CFS/ME Working Group (Report to the Chief Medical Officer of an Independent Working Group) 2002

¹⁴ 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

¹⁵ 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.

¹⁶ 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

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.

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 include¹⁷:

- Older age
- Longer illness duration
- Fatigue severity
- Comorbidities (psychiatric or physical)
- Physical attribution of symptoms

However a recent study looking at treatment outcomes did not find that depression, anxiety or duration of illness predicted outcome.¹⁸

¹⁷ Joyce J, Hotopf , Wessely S. The prognosis of chronic fatigue and chronic fatigue syndrome: a systematic review. *QJM* 1997; 90: 223-233

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

¹⁸ 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



5.1 Before the Assessment



5.2 Setting the Scene at the Beginning of the Assessment



5.3 History

5.3.1 Condition History

Symptoms should be carefully elicited. Fatigue, post-exertional malaise, muscle pain, disturbed sleep, poor concentration and other features of cognitive dysfunction and 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 simply to 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).

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



5.4.2 Mental State Examination



5.5 Observed Behaviour



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.

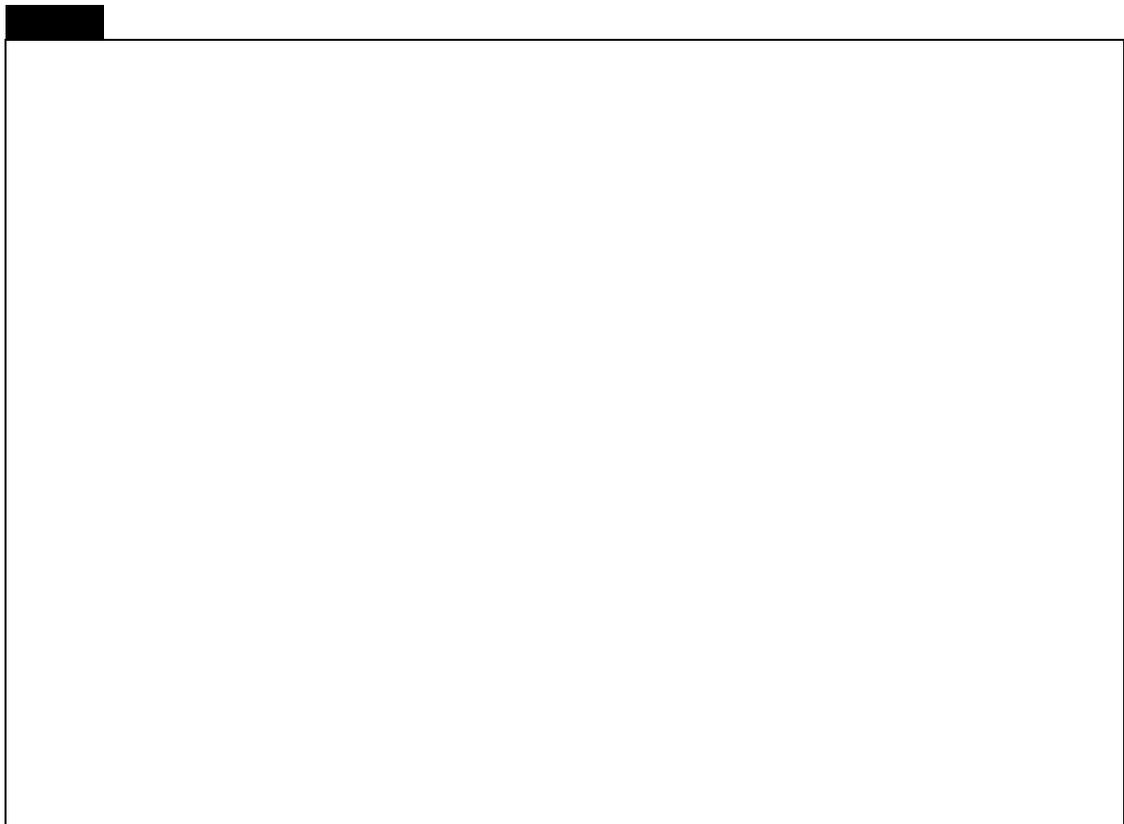
In CFS/ME, where there are few if any overt clinical findings, it is particularly important to carefully evaluate whether the person's description of their disability is consistent with their daily activities and lifestyle.

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

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.



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.

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.

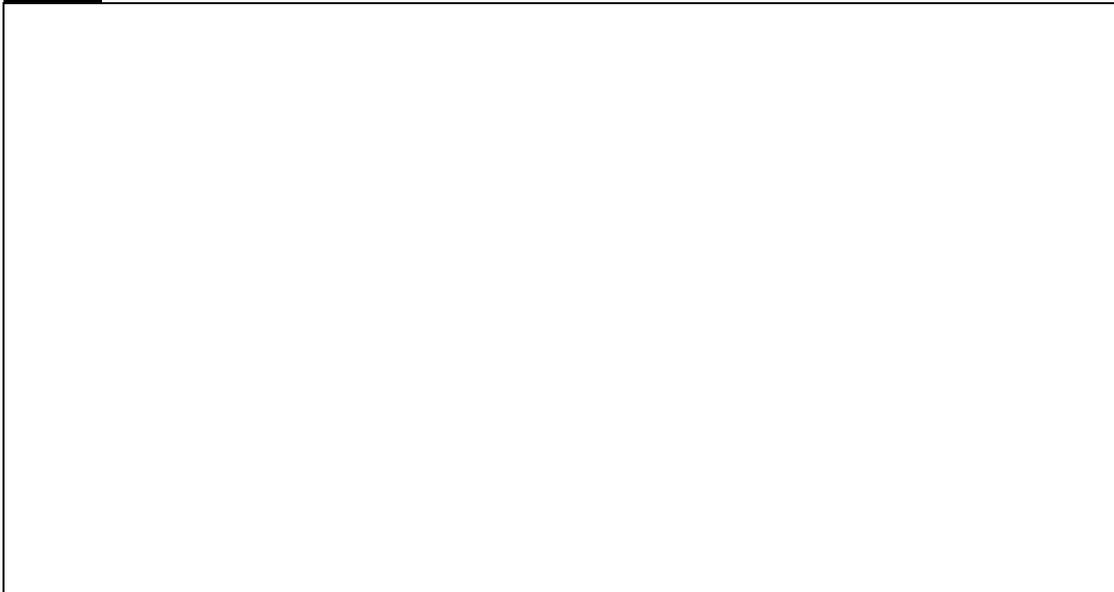
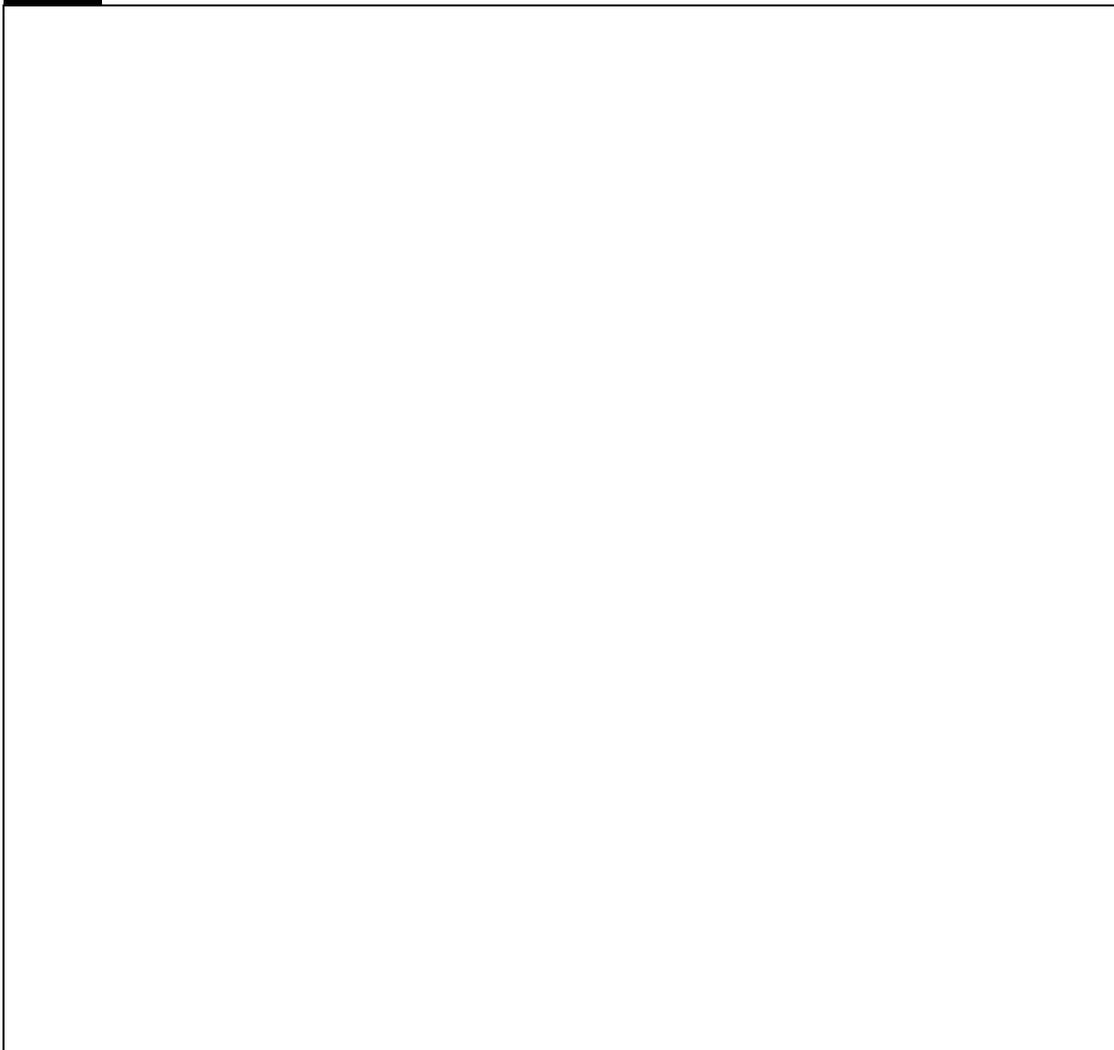
HCPs may wish to reinforce their knowledge by re-reading the scope of each of the Revised WCA descriptors in the Revised WCA handbook.

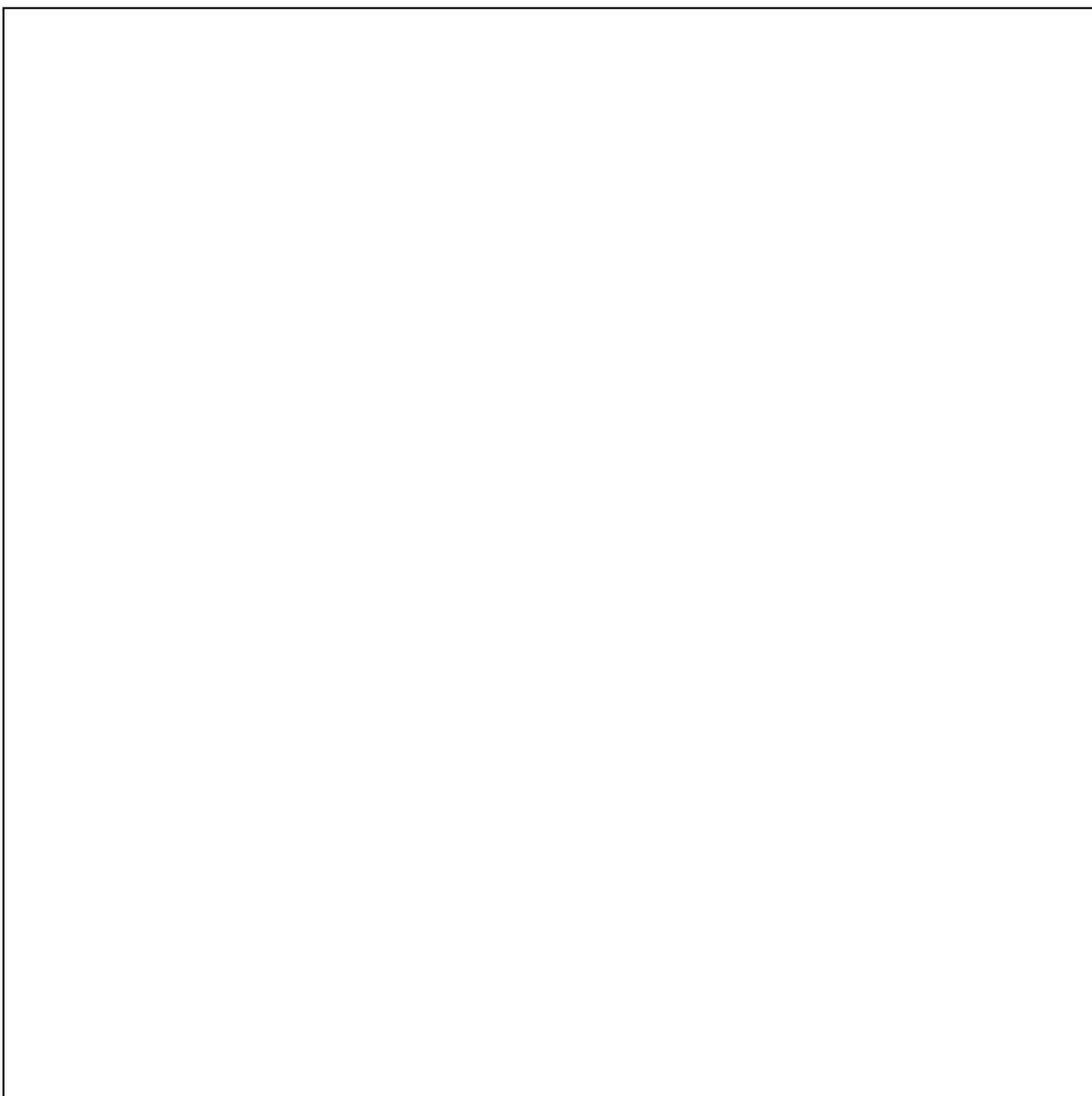
6.1 Revised Work Capability Assessment Case Study









7. CFS/ME and Disability Living Allowance

Disability Living Allowance consists of 2 components:

Care – [REDACTED]

Mobility – [REDACTED]

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

[REDACTED]

7.2 Care Component

[REDACTED]

[REDACTED]

7.3 Disability Living Allowance Case Study

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

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[REDACTED]

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8.2 Revised WCA Case Study Suggested Guidance



8.3 Disability Living Allowance Suggested Case Example Guidance



9. Further Reading

- 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
- 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](http://www.aqem.org/includes/documents/consensus_canadian(full).pdf) -
[page=18](http://www.aqem.org/includes/documents/consensus_canadian(full).pdf)
- 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
- 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>

- 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

10. Conclusion

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

Name:	Registration Number:
Signature:	Date:

		Correct	Incorrect
1.	████████		
2.	████████		
3.	████████		
4.	████████		
5.	████████		
6.	████████		
7.	████████		

On completion please return to the Clinical Manager or Training Support Manager at your Assessment Service Centre (ASC)

Appendix A - Oxford and Canadian Case Definitions

11.1.2 Oxford Case Definition

The Oxford Criteria were developed at a consensus meeting in Oxford in 1991¹. 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 definition², 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.

¹ 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

² 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

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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