

MEDICAL SERVICES

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

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Module: 6

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Foreword

This training has been produced as part of a Continuing Medical Education programme for Health Care Professionals (HCPs) approved by the Department for Work and Pensions Chief Medical Adviser to carry out assessments.

All HCPs undertaking medical assessments must be registered practitioners who in addition, have undergone training in disability assessment medicine. 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 and disability analysts, 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 HCPs receive. 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. Guidelines

These guidelines form part of the Medical Services programme for continuing medical education for HCPs. They are part of a series, 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.

1.1 Introduction

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.

Our particular focus in CFS / ME is in the assessment and measurement of overall functional disablement. It is hoped that this training module will encourage you to approach these cases in a way which is objective, thoughtful and structured.

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

1.2 Objectives

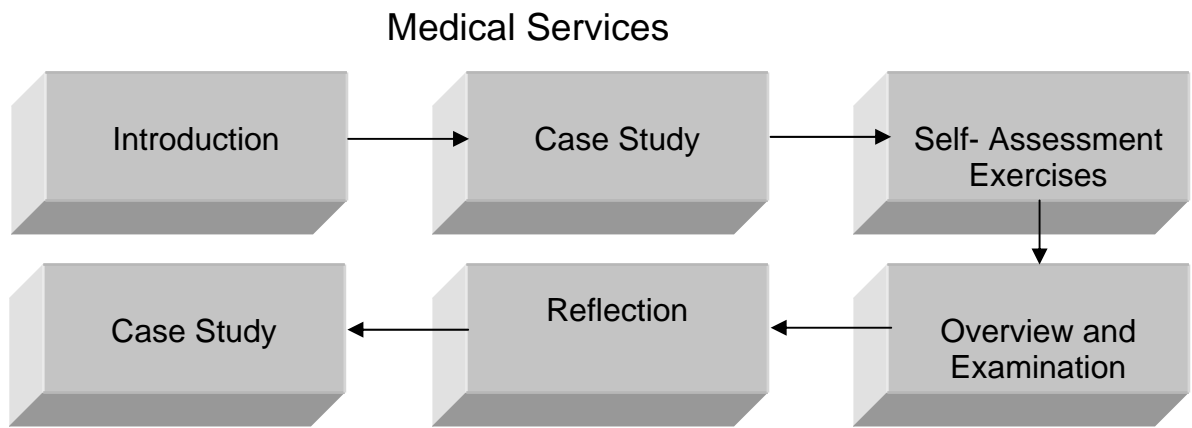
By the end of this module you should be able to:-

- Describe the key diagnostic features of chronic fatigue syndrome
- Describe a consistent and focused approach to the assessment of these claimants
- Identify the critical prognostic features
- Understand and fulfil the DM's specific requirements

1.3 How to use the Guidelines

After the introduction, there is a short case study which you should consider. The data has been obtained from a small number of live cases, and modified to protect claimant confidentiality. Once you have considered the case, read and respond to the self-assessment exercises which follow it.

You should then read the overview and the suggested examination protocols. Having completed this, you should reflect on what you have done and you may usefully reconsider the case study in light of what you read.



1.4 Self-assessment exercise 1

What are your perceptions of CFS? Before proceeding with the module, it would be helpful for you to complete the following short exercise. First read the question, and then tick the most appropriate box.

	Yes	No	Don't Know
CFS is entirely psychological in origin			
CFS is wholly physical in origin			
CFS is partly physical, and partly psychological in origin			
There is usually some evidence of a precipitating viral infection			
Most cases of chronic fatigue are attributable to abnormal illness behaviour			
There is no consensus view on treatment of the condition			
As regards the outlook, each case is different: there are no clear prognostic indicators			

1.5 Case Study

Now read the following case summary. Try to decide how you will approach the examination and the task of providing the DM with advice.

Mrs D is a 42-year old woman. You have been asked to assess her and provide a report for a non-medical decision maker. She has completed a claim form herself, amplifying it with several additional pages of hand-written text and a pamphlet describing the features of "ME". She describes her main symptoms as fatigue, muscle pains, sleeplessness and poor concentration.

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1.5.1 Self-assessment exercise 2

Mrs D gives the following history:

Her symptoms began three years previously after a flu-like illness which affected her but not the other members of her family. She was employed at the time as manager of a caravan suppliers business and had to go off work due to this attack, which she described as “severe flu, with limb pains, headache, sweating and malaise. She consulted her doctor, who advised bed rest and simple analgesics and after ten days she returned to work, although still feeling unwell.

After a few days back at work she felt so unwell that she went off sick again, and has not returned since. She says that her employer has been very unsympathetic, and in fact even before her illness there had been difficulties in the business due to staff problems and she was having to do the work of two junior staff who had left, as well as her own. She says that this additional burden was not acknowledged by her employer.

Her past medical history included a number of episodes of absence from work due to “nerves” and on questioning she says that she has always been subject to episodes of depression and anxiety. She attributes these to family problems, including her mother’s chronic illness and her son’s involvement with drugs. There is no history of significant physical problems, apart from repeated urinary infections when she was in her 30’s.

She lives in a two-storey end-terrace house with her husband, who is unable to work due to a back problem. Her son lives in the next town, and rarely visits. He is unemployed. Her daughter lives on the next street, and is very attentive and helpful, and visits daily with her two-year old daughter.

Mrs D gets up between 09:30 and 11:00 on most days if she feels well enough, having been brought her breakfast by her husband. She sleeps poorly, often wakening several times during the night. After breakfast she showers and dresses and then spends the day sitting watching television or videos. Some days she does not dress in day clothes at all if she is feeling particularly fatigued and about two days per week she either does not get up at all or returns to bed. She has been trying to do some cooking lately, but finds it very tiring and mostly her husband attends to all the routine household tasks. However her daughter does all the ironing, and accompanies her husband in the car to do the weekly shopping.

She attended her General Practitioner at the start of her illness, and he eventually referred her for a psychiatric opinion last year. Mrs D says that this was wholly inappropriate as she does not feel that she is suffering from a mental illness. She did not like the psychiatrist and she has no intention of returning to his clinic. She accepts her GP’s advice that the condition will “take time” to resolve and no longer sees him on a regular basis.

A report from her GP states “ME 3 years after flu-like illness. Past history of anxiety related to family problems. Antidepressants (1 year ago) - no improvement: ?compliance.”

- *Are there special considerations guiding your initial approach to these claimants?*

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- *Take a little time to draw up an idealised structure for the examination of a person with the condition.*
- *What areas of the history would you concentrate on, and why?*
- *If you were performing a physical examination, what areas of the physical examination would you concentrate on, and why?*
- *The information provided has been deliberately left incomplete: make a note of the additional data you would require in order to assess the case as a disability analyst, including advice on prognosis.*

1.5.2 Overview

The term CFS / ME encompasses a range of disorders which share the common features of unexplained fatigue, or post-exertional malaise, and the absence of any objective sign of illness. It is characterised further by the complaint of muscle pain, poor concentration and sleep disturbance. Anhedonia, irritability, and emotional lability are also commonly present and it is important to note that the fatigue is not confined to physical tiredness, but sufferers may complain also of mental fatigue, lack of concentration and often, some degree of short-term memory impairment.

Fatigue is central rather than peripheral in origin and neurophysiological studies are usually normal. As in multiple sclerosis and depression the fatigue is subjective, in comparison to the objectively measurable fatigue of myasthenia gravis.

Muscle pain is variable in nature and severity and it may or may not be provoked by activity. There is significant clinical overlap between CFS / ME and fibromyalgia syndrome (FMS).¹

Diagnosis is made by a process of exclusion and in addition relies heavily on the person's self-report. Patients often complain that their disability goes unrecognised because there are no visible or objective signs of illness. The Fukuda criteria (Annex B of the appended report of the Chief Medical Adviser's expert group) are helpful, but are viewed by some workers as unduly restrictive in the context of case definition.

CFS / ME is one of a group of conditions called 'Medically Unexplained Syndromes' and is probably best regarded as a heterogeneous spectrum of disorders, multifactorial in origin and sharing a similar symptom complex. In CFS / ME

¹ 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

²Wessely S. Chronic fatigue syndrome. *Medicine* 2000;28(5):72

³Wessely S, Chalder T, Hirsch S, Wallace P, Wright D. Psychological symptoms, somatic symptoms, and psychiatric disorder in chronic fatigue and chronic fatigue syndrome. *Am J Psychiatry* 1996;153(8):105

⁴B Van Houdenhove. Psychiatric comorbidity and chronic fatigue syndrome. *BJPsych* 2006;188:395

⁵UM Nater, JM Lin, EM Maloney, et al. Psychiatric comorbidity in persons with chronic fatigue syndrome identified from the Georgia population. *Psychosom Med* 2009; 71(5):557-65

⁶RR Taylor, LA Jason. Comparing the dis with the scid: Chronic fatigue syndrome and psychiatric comorbidity. *Psychology & Health* 1998; 13(6):1087-1104

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physical, psychological and social factors all play a part.

At one end of the scale are the (uncommon) cases where there is a very clear history of the sudden onset of fatigue after a proven infection, such as Epstein Barr virus; at the other, cases strongly associated with current or pre-existing psychiatric disorder. There is conflicting evidence on the rates of psychiatric co-morbidity in individuals with CFS/ ME²⁻⁴; with some studies suggesting that rates are influenced by *referral bias*⁵ and yet others suggesting that the *type* of psychiatric instrument used in research influences the outcome⁶.

Regardless, of primary importance to the disability analyst is whether or not there are concurrent mental health symptoms in the case they are assessing. Evidence from the ESA50 may not readily reveal this information; some claimants may feel that the functional 'Activity' areas of the form don't reflect their experiences of living with CFS/ ME. Clues may only be found under the section headed 'About your illnesses or disabilities' (page 3, of ESA50 version 03/11) - where claimants have an opportunity to describe *in their own words* the way in which they feel their condition affects them. It is important to expand upon any clues given in the ESA50 by taking an appropriately detailed and focussed typical day history during the examination.

None of the various groups of diagnostic criteria for CFS/ ME can be taken as definitive, either in the clinical or disability analysis environment; and it is important to remember that they have been developed for research rather than for therapeutic purposes.

1.6 Self-assessment exercise 3

What is the focus of the disability analysis examination in CFS / ME? Write down the questions to be addressed when assessing people with this illness.

1.6.1 Questions to be addressed during the disability analysis assessment

1.	To what extent is the person functionally impaired?
2.	Do mental or physical features predominate?
3.	Is there a co-morbid condition present?
4.	If so, is it mental or physical?
5.	To what extent does the co-morbid condition contribute to the overall disablement?
6.	Is the claimed degree of disability in keeping with the history, clinical findings and natural history of the disorder?
7.	What is the prognosis: <ul style="list-style-type: none">• For CFS / ME?• For any complicating co-morbid condition?

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

1.6.2 The assessment

It goes without saying that any examination performed must be carried out with particular care and consideration. Many sufferers complain that insensitive or

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inappropriately 'rough' examination has caused significant exacerbation of their condition.

Claimants should be encouraged to indicate when a manoeuvre is giving rise to undue discomfort or causing unacceptable fatigue. 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)"].

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.

1.6.3 Setting the scene

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

1.6.4 History

Present complaints should be carefully elicited. Post-exertional malaise, muscle pain, poor concentration and disturbed sleep are of course commonly volunteered. Hyposomnia rather than hypersomnia is more common in non-post-viral cases. It is important to record the person's understanding of their illness⁷.

The mode of onset of the disorder is important. There is some evidence that cases arising after a proven viral infection have a greater chance of complete recovery, and run a shorter course.

Any concomitant physical or mental condition must be identified and individually assessed, as it may independently influence the course of the illness and may indeed be amenable to treatment. If treatment is already underway for the co-morbid condition, what is the nature of the treatment (e.g. antidepressants) and for how long has it been in place? The presence of a co-morbid psychiatric disorder has a negative influence on the prognosis⁸.

1.6.5 Past medical history

A history of previous episodes of fatigue has a bearing upon the prognosis.

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1.6.6 Occupational history

It has been found that work-related stress may be a triggering factor, and many patients go on to take less stressful jobs.

⁷Sharpe M, Chalder T, Palmer I, Wessely S. Chronic fatigue syndrome. *General Hospital Psychiatry* 1997; 19(3):185

⁸Joyce J, Hotopf M, Wessely S. The prognosis of chronic fatigue and chronic fatigue syndrome; a systematic review. *QJM* 1997; 90(3):223

1.6.7 Analysis of activities of daily living

An account of the activities of a typical day should be taken, in keeping with the general guidelines (see Employment and Support Allowance, ESA, Handbook). You 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. 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 these patients 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).

However, you should be alert to lifestyle patterns which may maintain disability; for example it is common for individuals with CFS to complain that they feel very unwell in the mornings, and yet this is clearly exacerbated by a routine where they stay in bed until lunch time.

1.6.8 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' on the severity spectrum the claimant sits, 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 to know 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 "bad" days. Remember to look for added clues about the extent of variability, and other ways CFS 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 ESA50 version 03/11). 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 – especially important if they feel that subsequent parts of the form (detailing the functional 'Activity' areas) aren't applicable/ "don't fit" their view of the difficulties they have.

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1.6.9 Physical Examination

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 your methods and style of recording clinical findings must be in accord with Medical Services standards and recommendations.

Characteristically the physical examination rarely reveals definitive positive clinical findings, but particular features, such as muscle-wasting, should be positively sought (bearing in mind the principles discussed above, in section 1.6.2); 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.

1.6.10 Psychological assessment

It is rarely possible to perform a full psychological assessment. However it is generally accepted that since CFS encompasses both physical and psychological components it would be wrong to neglect either.

Because of the possible effects on mental functioning of CFS, it will almost always be appropriate to assess the claimant's mental state and, in the case of ESA, to complete a mental health/function assessment.

If the claimant states that "There's nothing *mentally* wrong with me ..." it should be explained that CFS is a condition which can affect concentration, memory and mood. The assessment is to demonstrate to the decision maker any difficulties the claimant may have in these areas. If a mental health/function assessment is not carried out in ESA, then the reasons for not doing so should be fully justified.

For the purposes of ESA, considerable 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 scoring. Of course our professional experience often suggests that both play a part. The ability to perform activities reliably and repeatedly is integral to the activity descriptors in Revised WCA (ESA, under 2011 regulations).

1.7 Self-assessment exercise 4

A man claiming ESA suffers from CFS. He also has osteoarthritis of his lumbar spine, hips, knees (confirmed by recent x-ray), shoulders and elbows (also confirmed by recent x-ray). His mobility is limited by sore joints and tiredness – he can walk 100m maximum on the flat when using crutches; but finds it impossible to propel a wheelchair more than a few metres, due to stiffness and pain in his upper limb joints. He often avoids carrying out routine activities like vacuuming because it is too fatiguing. He lives alone, and manages to get himself up, washed and dressed daily. He washes the pots after every meal, and uses the washing machine once a week. He finds it too tiring to cook proper meals, and mainly uses the microwave to heat up ready-meals or soup; or he makes sandwiches. The decision

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maker requires to know whether mental or physical factors are the cause of his mobility problems. How do you decide what advice to give?

The preferred approach to the above problem is to decide which component contributes most to the disablement. As always, you should remember that the responsibility for deciding entitlement to benefit ultimately lies with the DM, and as long as you explain your advice adequately and in keeping with the balance of probability you will have fulfilled your task. For example, a global justification summary for the above case, might read:

“On the basis of evidence acquired from the clinical history, typical day history, and physical and mental health examination, it seems reasonable that *physical* factors contribute most to his difficulties with mobilising. Although his ability to complete tasks is impaired due to reduced drive, it is preserved to a reasonable degree, as suggested by his ability to do other housework and perform routine self-care activities. In contrast, he does have moderately severe degenerative changes in both knees and elbows (as confirmed by the recent x-ray reports; copies of which are attached to the ESA50), suggesting that physical factors play a significant part and probably are the predominant reason for his difficulties with mobilising.”

1.7.1 Observed behaviour

This should be carefully noted, assessed and recorded. As usual your observations must be focused, relevant and in accordance with Medical Services 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.

1.7.2 Disability Living Allowance

DLA legislation requires the claimant to have a physical disability in order to be entitled to the higher rate mobility. Where a person has a mixed physical/mental problem, providing the physical problem is contributing to walking difficulties, Commissioners have ruled that all the walking problems should be considered ‘physical’ in this context.

The reader is referred to the distance learning ‘Mobility Questions in DLA’; however the following should be noted when giving advice to the DM on a claimant’s mobility:

- Where there is an underlying physical problem, even when much of the disability relates to factors outside that physical diagnosis, the cause should be considered as PHYSICAL (e.g. CFS / ME)
- Where there is no physical diagnosis the examining Health Care Professional will need to decide whether - it is more likely than not – the claimant has a physical illness. Where there is no evidence of mental illness within the presentation then in most such cases the examining Health Care Professional should accept a PHYSICAL component.

Having accepted that CFS / ME is a medically unexplained syndrome which

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sometimes has a physical component and sometimes has a mental health component, examining HCPs should of course assess any physical problems (e.g. walking) and any mental health problems (e.g. concentration).

1.7.3 Disability analysis in the context of treatment

The combination of cognitive behavioural therapy⁹ and graduated exercise¹⁰

⁹Deale A, Chalder T, Marks I, Wessely S. Cognitive behaviour therapy for chronic fatigue syndrome: a randomised control trial. *Am J Psychiatry* 1977; 154:408

¹⁰ Fulcher K, White P. Randomised controlled trial of graded exercise in patients with the chronic fatigue syndrome. *BMJ* 1997; 314:1647

is at present the mainstay of treatment, but several writers stress the importance of the concept of *collaboration* in any treatment regime. In order to obtain such collaboration it is necessary to obtain the patient's trust. It is essential therefore that the disability analyst does not jeopardise such trust built up between patient and medical carer by allowing any preconceived opinion of CFS to intrude upon what should be a thoughtful, caring and above all, objective assessment.

1.8 Self-assessment exercise 5

What factors do you take into consideration at present when advising the decision maker on prognosis?

1.8.1 Prognosis

When advising the decision maker about prognosis it is helpful to note that factors suggesting a good prognosis include:

- a definite history of an acute viral illness at the outset, and occurring against an uncomplicated psychological background
- clinical features showing a pattern of evolution towards functional recovery
- early diagnosis aimed at eliminating associated physical disorders and identifying psychiatric illness along with other complicating psychological or social factors
- a management regime which encompasses physical, psychological and social elements.

The risk factors for poor prognosis include;

- an older age;
- the onset of symptoms without any clear precipitating factor;
- a background of adverse psychological and social factors;
- severe and unremitting symptoms, especially of more than four years' duration;
- delayed diagnosis and especially self diagnosis where the patient becomes convinced of a single cause to the exclusion of all others;

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- a management regime which either over-emphasises the importance of complete rest or which advocates a rapid return to pre-illness levels of physical activity¹¹.

Although outdated, the report of the Chief Medical Adviser's Expert Group gives a useful overview of the condition from the point of view of the disability analyst (Appendix A).

HCPs should also refer to the DWP's published medical guidance for DLA/AA, available on Livelink or on the internet (<http://www.dwp.gov.uk/publications/specialist-guides/medical-conditions/a-z-of-medical-conditions/>).

¹¹Chief Medical Adviser's Expert Group; Chronic fatigue syndrome. *Department of Social Security* 1996

You should now read this, and the interested reader is further invited to review the following:

- Occupational aspects of the Management of Chronic Fatigue Syndrome: A National Guideline (2006)
- Treatments for chronic fatigue syndrome (Occupational Medicine review – K A Rimes & T Chalder 2005)
- Diagnosis and Management of Chronic Fatigue Syndrome/Myalgic encephalomyelitis in adults or children (National Collaborating Centre for Primary Care & Royal College of GPs)
- A systematic review describing the prognosis of chronic fatigue syndrome (R. Cairns & Hotopf 2005)
- Disability and Chronic Fatigue Syndrome – A Focus on Function (Ross et al 2004)
- Chronic Fatigue Syndrome: A Review (Afari N & Buchwald, D)

Once you have read the papers:

1) *Return to Self-assessment exercise 1 and see whether your views have altered.*

2) *Look again at the case example and address the following questions again:*

- *Are there special considerations guiding your initial approach to these claimants?
How would you prepare for the assessment of Mrs D?*
- *Draw up an idealised structure for the examination of a person with the condition.*
- *What areas of the history would you concentrate on, and why?*

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- *What areas of the physical examination would you concentrate on, and why?*
- *The information provided has been deliberately left incomplete: make a note of the additional data you would require in order to assess the case as a disability analyst, including advice on prognosis.*

1.9 Objectives

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

- describe the key diagnostic features of chronic fatigue syndrome / myalgic encephalomyelitis
- describe a consistent and focused approach to the assessment of these claimants
- identify the critical prognostic features
- understand and fulfil the DM's specific requirements

You should ensure that you are satisfied that these have now been met.

Appendix A - Chief Medical Adviser's Expert Group

CHRONIC FATIGUE SYNDROME - PROGNOSIS & CHRONICITY

REPORT OF THE FIRST MEETING

Introduction

1. Chronic fatigue syndrome (CFS) is a controversial area of medicine which over the years has attracted extremes of opinion on various issues such as causation, diagnosis, management and prognosis. This has often precluded there being constructive debate on the subject. This in turn has led to a sense of confusion in the medical profession generally which has often been interpreted by sufferers and their advocates (sometimes with justification) as a lack of interest or a denial that the condition exists at all.
2. It is against such a background that doctors from Benefits Agency Medical Services (now Medical Services) have had to try to give consistent and meaningful advice on individual claims to social security benefits and also on cases relating to various schemes administered by other government departments and agencies (e.g. N.H.S. and Teachers superannuation schemes). The Chief Medical Adviser (CMA) is very anxious to ensure consistency of medical advice which is based upon the prevailing consensus of informed expert opinion on the subject. This is in keeping with the Government's desire to ensure that all people receive those benefits to which they are entitled. Clearly knowledge of prognosis and of those factors which lead to chronicity is very important for Benefits Agency (now Medical Services) doctors to be able to give informed, consistent and appropriate advice. Indeed in some areas, e.g. NHS pensions, a knowledge of the prognosis is a crucial part of the decision making process. Prognosis and chronicity cannot, of course, be looked at in isolation.
3. The Chief Medical Adviser's Expert Group was therefore set up to give him personal advice specifically on those factors which affect the prognosis and chronicity of the chronic fatigue syndrome. It should be noted that the remit of the group was more narrowly focused than the Joint Royal College's Working Party on Chronic Fatigue which has been requested by the Chief Medical Officer and which is due to report shortly. The first meeting of the group took place on 6 March 1996.

Membership of the Group and Conduct of the Meeting

4. Individuals representing a wide variety of disciplines and interests were identified and personally invited to join the group by the CMA. The aim was to have input from as broad a base as possible.

The following interests and disciplines were represented: academic research into CFS, clinical interest in the field (from psychiatry, neurology, infectious diseases and general practice), occupational medicine, the insurance industry, CFS support groups and the Disability Living Allowance Advisory Board (DLAAB).

Members were supported by officials from the Departments of Social Security and Health. (A full list of members and officials is at Annex A).

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5. The CMA and Officials opened the discussion by highlighting the important issues arising from the published literature from the past 10 years. These were taken from a database of around 350 papers. The findings of the National Task Force on CFS/PVFS/ME, whose report was published in September 1994, were highlighted, particularly where they pointed to controversies relating to prognosis and chronicity.
6. Individual members were then each asked to give a five minute presentation summarising their views on prognosis and chronicity and how these were affected by factors such as diagnostic criteria and management strategies. This was then followed by a structured discussion led by officials designed to identify areas of consensus and disagreement.

Summary of Structured Discussion

7. In order to try and bring together a wide-ranging discussion, the main areas covered, conclusions reached and disagreements identified are considered under three main headings: diagnosis, management and prognosis.

(i) Diagnosis

- The present definitions are inadequate and it may well be that the prevalence of the condition is currently being underestimated.
- The Fukuda criteria were generally thought to be the best available (Annex B). However, it was thought that the minor criteria needed modification, and that this may deal with the apparent underestimate mentioned above.
- There is not just one clinical picture of CFS. As time goes by, it is likely that more and more definite sub-groups will be identified and the numbers with chronic fatigue of unknown cause will fall.
- The prevalence of fatigue in the general population is high, but using the presence of fatigue alone is likely to be an over-estimate of the prevalence of CFS.
- Some members felt that delayed fatigue (e.g. occurring the day after excess activity) was pathognomic. However, others did not agree, believing that fatigue unrelated to the level of rest or exercise was more typical.
- It was generally thought that early diagnosis (and hence appropriate management) was essential in order to minimise the chances of a poor prognosis. However, on whether the duration per se was a good prognostic indicator, there was no general consensus.
- Clinicians from different disciplines tended to see different patterns of clinical manifestations and there was a danger of drawing general conclusions from specific experiences.
- Clinicians recognised certain diagnostic groups as having different prognoses. For example, those who develop chronic fatigue after a clearly defined episode of glandular fever do well.

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However, those who develop chronic fatigue against a background of complex interacting psychological and social circumstances are likely to do badly. There was also an impression that those developing the condition after a severe infection e.g. meningitis, do badly.

- It was agreed that a common language was required e.g. for outcome, fatigue etc.
- It was pointed out that many criteria employed were meant to be used for research rather than clinical purposes.
- Similarly the definition of chronic as meaning 6 months or longer, whilst useful for research purposes, should not be an absolute requirement clinically.

(ii) Management

- The sooner appropriate management was started, the better the prognosis.
- There was general agreement that a holistic approach was required with physical, psychological, social and employment factors all needing to be addressed.
- There was a need to establish a baseline of physical ability. There was a tendency for patients to overestimate their capacities and help was required in establishing baseline performance.
- Activity should be increased in a managed, stepwise manner.
- Although it was agreed that patients should be prevented from over-exerting on good days, there was recognition of that fact that too much rest could lead to the problems of deconditioning.
- It was recognised that lifestyle modification was important and that many patients need to accept lower levels of activity than they had previously regarded as being normal. Within this it was noted that many patients had previously led lives which were extremely physically active.
- It was important to exclude and treat co-existing physical diseases and maintaining factors.
- Sleep problems needed to be specifically identified and managed.
- There was discussion as to whether the condition should be managed by specialists or GPs. There was general agreement, however, that an overall understanding of and interest in the condition was more important than a particular specialist background.

Specialist support should, however, be used appropriately e.g. in the investigation of underlying physical disease or the assessment of specific psychological or psychiatric factors.

- It was important that GPs did not uncritically accept a self-made diagnosis.

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- There was discussion of the role of self help groups in the management and the suggestion that such involvement may be a bad prognostic indicator. It was suggested that such groups are more active where the general standard of management is poor and consequently that they attract people whose poor prognosis has been contributed to by inappropriate treatment.
- There was general agreement that randomised controlled trials were required for the evaluation of clinical management techniques.

(iii) Prognosis

- Proper medical, occupational, social and financial support is essential to achieve maximum benefit.
- The presence of stress worsens the prognosis.
- Lifestyle modification may enable the patient to cope and return to relative normality, even though the condition is still present.
- Five factors were important and all had an effect on the overall prognosis - demographic, clinical, psychological, social and management.
- Despite the discussion above, it was generally agreed that no generalisations could be made about the involvement of support groups on the prognosis.
- Symptoms of alcohol intolerance were not thought to be useful prognostic indicators.
- Some patients do not recover despite optimum conditions of management.
- Although it has been suggested that younger patients (under 25) have a better prognosis, the evidence for this is conflicting.
- There was a clinical impression that variability of symptoms and especially where they appear to be evolving was a good sign that the patient was getting back to normal.
- Although duration of symptoms per se was not thought to be helpful in determining prognosis, where these had been severe and unrelenting, the prognosis appeared to be poor, particularly after four years.
- Recovery should not necessarily be equated as getting back to the same condition as before the illness. Similarly it was important to note that prognosis and functionality were different concepts.
- It was generally agreed that somatisation disorders had a poor prognosis and that the more symptoms, the more likely somatisation was to be present.
- There was a need for future research to be directed towards answering questions on prognosis.
- In the current environment clinicians, researchers and support workers must be prepared to say that they do not know.

Conclusions

8. It should be recognised that these conclusions are based on the personal views of the members and not all will necessarily be based on the results of controlled clinical studies. Chronic fatigue syndrome is a complex condition which is not fully understood. Consequently it is not possible to draw up universally accepted diagnostic criteria. It is generally accepted, however, that the Fukuda criteria are the best available, but that

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these will need to be modified in the light of developing experience. Because of this, it is not possible to define concrete sets of favourable or unfavourable prognoses. It is also important to note that generalisations on prognostic factors will not necessarily apply to each individual patient. In addition, in each case, there will often be conflicting favourable and adverse factors interacting to determine the overall outcome. Despite this it is possible to describe two scenarios representing the extremes of good and bad prognosis:-

(i) Good prognosis:-

- A definite history of some acute viral illness (particularly glandular fever) at the onset and occurring on an uncomplicated psychological background.
- Clinical features showing a pattern of evolution towards functional recovery.
- Early diagnosis aimed at eliminating associated physical disorders and identifying psychiatric illness along with any other complicating psychological or social factors.
- A management regime which encompasses physical, psychological and social elements. One which concentrates on lifestyle modification and strikes a balance between overactivity and the risks of deconditioning, and which takes a stepwise approach to achieving functional improvement. One which also deals with maintaining factors such as sleep disturbance.

(ii) Poor prognosis

- The onset of symptoms without any clear precipitating factor but set against a complex background of adverse psychological and social factors, or with an onset following a severe infective illness.
- Clinical features characterised by severe and unremitting symptoms, particularly if lasting over four years. The presence of multiple symptoms especially those suggesting somatisation.
- Delayed diagnosis and especially self diagnosis where the patient becomes convinced of a single cause to the exclusion of all others.
- A management regime which overemphasises the importance of either complete rest or which advocates a rapid return to pre-illness levels of physical activity. One which does not recognise the need to treat such features as depressive illness or sleep disturbance.

Recommendations

9. - The Group recommends that guidance to Benefits Agency doctors on chronic fatigue in all areas of work is reviewed to ensure that it accurately reflects this emerging consensus and also that it should have the opportunity to comment on any revised guidelines.

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- Although the Group's purpose is specifically to give advice to Chief Medical Adviser, it is recommended that this report and any subsequent reports be made widely available to all those with an interest in Chronic Fatigue Syndrome.
- The Group recommends that it should continue to meet on a three monthly basis in order to refine its advice in the light of any newly published research.
- The Group endorses the view previously expressed, notably by the National Task Force, on the need for further controlled studies on the causation and management of CFS, and that prognostic factors need to be addressed specifically in these.
- The Group recommends that officials explore the feasibility of conducting casework studies in social security and related areas to see whether the process of identifying prognostic factors can be refined.

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Annex A

Chronic Fatigue Syndrome

CMA's Expert Group - List of Members and Officials

[Chair: Chief Medical Adviser DSS]

Dr Robin Cox	- Consultant Occupational Physician. Previously: Chief Medical Officer, CEEB and National Power
Professor R Grahame	- Chairman Disability Living Allowance Advisory Board, and Professor of Clinical Rheumatology Guy's Hospital
Dr John LoCascio	- Medical Director, UNUM UK
Professor A J Pinching	- Professor of Immunology, St Bartholomew's Hospital
Dr Charles Shepherd	- Medical Adviser, The ME Association
Dr D Pheby	- Cancer Epidemiology Unit, Dept. Epidemiology and Public Health Medicine, University of Bristol
Dr P White	- Senior Lecturer and Honorary Consultant Psychiatrist St Bartholomew's Hospital
Dr Anne Macintyre	- Medical Adviser to Action for M.E. and CHROME (Case History Research on ME)
Dr Meirion B Llewellyn	- Senior Registrar in Infectious Diseases, University Hospital of Wales
Dr L S Illis	- Consultant Neurologist, Lymington, Hampshire
Dr D Miller	- Faculty of Occupational Medicine

Medical Policy Managers/Advisers, Department of Social Security

Representative from Department of Health

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Annex B

Summary of Fukuda Criteria

Fukuda K et al: Annals of Internal Medicine 1994; 121, 12, 953-959

- (1) Fatigue lasting for six months or longer where other known causes have been excluded from history, physical examination, mental state assessment and appropriate tests.
- (2) Four or more of the following present concurrently for six months or longer:-
 - (i) Impaired memory or concentration
 - (ii) Sore throat
 - (iii) Tender cervical or axillary lymph nodes
 - (iv) Muscle pain
 - (v) Multi-joint pain
 - (vi) New headaches
 - (vii) Unrefreshing sleep
 - (viii) Post-exertion malaise.

Evaluation

Chronic fatigue syndrome / myalgic encephalomyelitis: Guidelines for the Disability Analyst

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

If the objectives have been achieved you should have no difficulty in responding correctly.

		Correct	Incorrect
1.	Cases in which there is a clear history of an acute precipitating viral infection occurring in an uncomplicated psychological background have a better prognosis.		
2.	The combination of cognitive behavioural therapy and antidepressants should be the mainstay of treatment.		
3.	A patient's belief that a physical, (e.g. viral) rather than a psychological cause underlies CFS is to be encouraged as it will improve the prognosis		
4.	Reported prevalence in primary care is in the region of 1 – 2%.		
5.	Some degree of short-term memory impairment is invariably present in CFS when neuro-psychological tests are performed.		
6.	Hyposomnia rather than hypersomnia is more common in non-post-viral cases.		
7.	The onset of symptoms without any clear precipitating cause is a positive prognostic factor even in situations where there is an adverse social background.		

Name:

GMC/NMC
Number:

SIGNATURE:	
DATE:	

On completion please return to the Medical Manager at your Medical Services Centre.

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