



Training & Development

Chronic fatigue syndrome /Myalgic Encephalomyelitis (or encephalopathy) and PIP Assessments CPD Module

(HP CPD Workbook)

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Foreword

This Workbook has been produced as part of an ongoing training program for Health Professionals approved or appointed by the Department for Work and Pensions Chief Medical Adviser to carry out benefit assessment work.

All Health Professionals undertaking medical assessments must be registered medical practitioners nursing practitioners, occupational therapists, paramedics or physiotherapists who, in addition, have undergone training in disability assessment medicine and specific training in PIP Assessment. The training includes distance learning modules, 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 Assessors, the Health Professionals will have detailed knowledge of the principles and practice of relevant diagnostic techniques and therefore such information is not contained in this training module.

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

Thus, although the training module may be of interest to non-medical readers, it must be remembered that some of the information may not be readily understood without background medical knowledge and an awareness of the other training given to Health Care Professionals. Some HPs from these professional groups may find it a useful revision and are welcome to participate if they wish

PIP Clinical Director

October 2016

Introduction

This workbook is part of the ongoing training programme for Health Professionals (HPs) working as Disability Analysts. It is designed as a learning tool to consolidate HPs understanding of CFS/ME and it's relation to PIP. It is a stand-alone document which can be used by HPs who wish to do extra study or for their Line Managers to distribute where they feel further information and support is required. The HP should already be familiar with all sections of the PIP Assessment Guide.

What's in the Module?

This self contained workbook which can be completed either electronically or in paper format. It is designed so that an HP can work through the tasks independently.

The focus for this training is CFS/ME and PIP Assessments to ensure understanding of the condition; appropriate information gathering; appropriate descriptor choice and the reasons for those choices.

The module is split into 3 parts:

Part 1 will guide the HP through clinical information on CFS/ME, before looking at the likely functional impact of the condition in PIP Assessments. There is a mid-module MCQ which the HP will send to their CSL for marking. This will act as a progress and knowledge check.

Part 2 is comprised of 10 short case examples which the HP will send to their CSL for marking and are used to encourage the HP to think about how to provide descriptor advice to claimants with CFS/ME. This will consolidate the HP's knowledge and understanding

Part 3 has two full practice case examples of claimants with CFS/ME for the HP to read and select the most appropriate descriptors. Answers should be sent to the CSL for marking

How long does the module take?

It should be completed at a pace suitable to the HP

Is there a test?

Yes – a mid-module MCQ's and 2 case studies to be completed, which will demonstrate competency.

What does the HP need to do?

- Work through the module independently completing the mid –module MCQ, 10 case examples and the 2 fictional case studies either electronically or as a hard copy and send to CSL
- Complete a reflective log of the learning activity (useful for revalidation purposes)

Overall Aim

To enhance knowledge and understanding of CFS/ME in relation to PIP.

1. Part 1

Activity 1 - Pre-module reflection

This module contains case examples and further guidance on all aspects of CFS/ME assessment. Before you start, take a few minutes to reflect on any aspects of assessing CFS/ME that you find challenging. These could be history taking, descriptor choice (perhaps just one or two that you struggle with), justification or something else. You may wish to discuss these issues with a colleague or clinical lead after you have completed the module, and use them for reflection on any further learning you personally require.

I find CFS/ME assessment challenging because....

What is CFS/ME?

CFS/ ME is a chronic illness with a wide range of symptoms reported by sufferers including headaches, sleep problems muscle pain and problems with concentration. The predominant symptom reported by the majority of people, is extreme fatigue and feeling generally unwell after minimal exertion.

There is no set pattern for how CFS/ME symptoms can occur, and there may be a wide range of variability, from month to month, week to week, day to day, or even in the same day. The severity of symptoms can range from mild through to severe, where the severe symptoms can have a huge impact on that person's functional ability and also on their families and loved ones.

How common is CFS/ME in the UK?

Surprisingly there is a lack of data to show the prevalence of CFS/ ME in the UK, so figures are only estimates. It is possible that in a GP practice with 10,000 patients, up to 40 people are likely to have CFS/ ME and of those, half will need input from specialist services

What causes CFS/ME?

As yet, the definitive causes for CFS/ ME are not yet fully understood.

Certain viral infections can trigger CFS/ME, however it is also known that people with CFS/ME have no problems with continuing infection with the virus. The belief is that other factors called 'maintaining factors' may be what keeps the CFS/ME going and can delay recovery. Maintaining factors could be conditions such as depression, anxiety and difficulty sleeping (RCPSYC 2016).

Lack of understanding of this and the disease processes associated with this chronic condition can lead to people experiencing profound illness and disability which in turn, impacts on their families and carers.

How is CFS/ME diagnosed?

- In children and young people – A diagnosis is made after 3 months of persistent symptoms where other possible diagnoses have been excluded. The diagnosis is made or confirmed by a Paediatrician
- In Adults – A diagnosis is made after 4 months of persistent symptoms where other possible diagnoses have been excluded

What tests are used to diagnose CFS/ME?

There are no specific tests for this condition. The diagnosis is made on the basis of excluding other disease processes which could account for the symptoms reported.

Nice (2007) advises that healthcare professionals should consider the possibility of CFS/ME if a person has:

- Fatigue with all of the following features:
 - » New or specific onset (not lifelong)
 - » Not relieved by rest
 - » Not associated with continuing effort
 - » Persistent and/ or recurrent
 - » Unexplained by other conditions
 - » Has resulted in a substantial reduction in activity level characterised by post exertional malaise (delayed fatigue for at least 24 hours with delayed recovery period of several days, for example)

and

- Sore throat
- Cognitive dysfunction (includes difficulty word-finding, problems concentrating, problems with short term memory, difficulty thinking, difficulty processing information, difficulty organizing thoughts)
- Tender lymph nodes without pathological enlargement
- Dizziness
- Nausea
- Palpitations where cardiac pathology has been excluded
- Headaches
- Muscle and/ or joint pain where multiple sites are affected and for which there is no evidence of inflammation
- Sleep problems – hypersomnia, insomnia, disturbed sleep, unrefreshed sleep

The presence of 'red flags' may indicate another serious condition. In particular, the following features should be investigated:

- Localizing/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

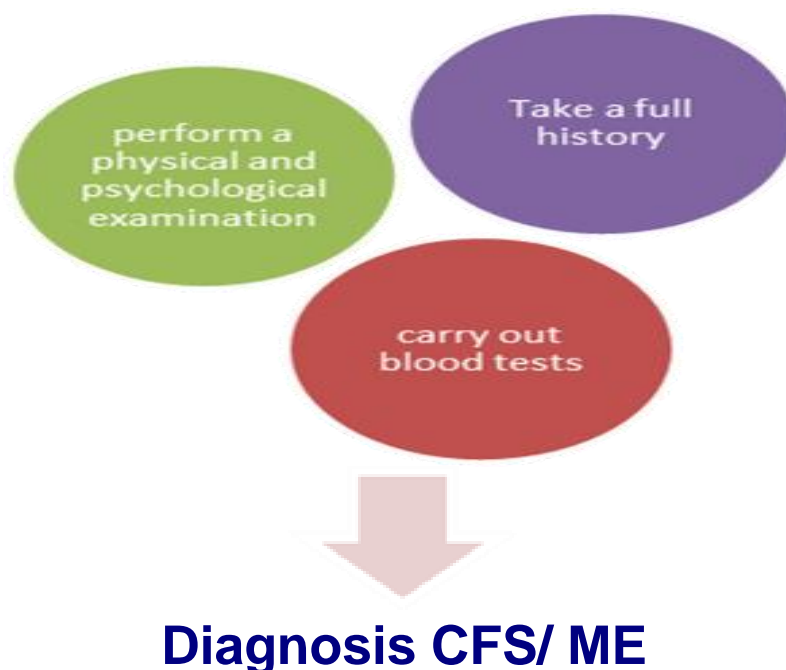


Figure 1 shows how the Healthcare Practitioner in the clinical setting may reach the diagnosis of CFS/ME

Blood tests can include; full blood count, urea and electrolytes, liver function, thyroid function, creatinine kinase (CK), serum calcium, serum creatinine, serum ferritin (in children and young people only), c-reactive protein (if inflammation is present) and erythrocyte sedimentation rate (ESR) or plasma viscosity.

If the person is a child or young person, referral to a Paediatrician for assessment to exclude other diagnosis; this should occur within 6 weeks

It is left to the clinical judgement of the clinician to decide whether further tests are needed to exclude any other diagnoses

The following tests are NOT recommended to be done routinely to aid diagnosis:

- The head-up tilt test (records blood pressure and heart rate on a minute by minute basis, while the table is tilted in a head-up position at different levels. It is usually used to find the cause of fainting spells)
- Auditory brainstem responses (gives information on the inner ear (cochlea) and brain pathways for hearing. It is a neurological test of auditory brainstem function in response to click (auditory) stimuli)
- Electrodermal conductivity (the skin's electrical resistance varies with the state of the sweat glands. If the sweat gland activity increases, then so does skin conductance)

Expected prognosis

Due to the high degree of variability, the chronic nature of the condition, prognosis advice is difficult, but in general it is suggested that:

- Most people will improve over time
- Some people will recover and be able to resume work/ study and normal activities
- Some people will continue to experience symptoms or relapse
- Some people with severe CFS/ ME may remain housebound
- For those children and young people who have a diagnosis of CFS/ME, the prognosis is optimistic

Are any treatments available for people with CFS/ME

There are some treatments which have been shown to be beneficial in helping CFS/ME sufferers. They may not work for every person but the treatment can be tailored to meet the needs of the individual.

Treatment may include

- Supervised graded exercise therapy (GET) – This provides a framework for the individual to gradually increase the amount of physical activity and develop stamina, without over-tiring. Approximately 2/3 of people find this helpful
- Cognitive Behavioural Therapy (CBT) – This is a talking therapy which identifies and addresses unhelpful beliefs about the illness and aims to improve coping skills
- Pacing – Works to adjust a person's daily activities so that they can manage them without becoming overtired, and without triggering a relapse

(RCPSYCH, 2016).

- Medications may be prescribed to improve and manage the symptoms. Specific drug treatment for children and young people is usually started by a Paediatrician

- Anti-emetic drugs are usually only prescribed in severe cases of nausea. Dietary advice would be the likely first step
- Psychological therapies may be recommended for mental health symptoms
- Dietician input may be necessary for those people undertaking an exclusion diet or dietary manipulation, due to the risks of malnutrition
- Aids and adaptations such as a stair lift or wheelchair, may be recommended to aid independent living

When is someone likely to be referred for CFS/ME care?

Referral to specialist services for people with CFS/ ME is suggested as follows:

- Mild CFS/ME – referral within 6 months of presentation
- Moderate CFS/ME – within 3-4 months
- Severe CFS/ME – immediate referral

The PIP HP needs to bear in mind, that these are suggested timescales. Some claimants may have been waiting longer than these timescales due to the demand for the service in their area. **The HP must not make any assumptions that the longer the person has waited for the referral, the lesser the likely severity of their CFS/ME symptoms.**

CFS/ME and PIP Activities 1 – 12

So, in which of the activity areas may someone with CFS/ME report functional restriction?

Firstly, claimants with multiple conditions causing functional impact may struggle in a number or all activity areas and advice should be given accordingly.

Remember that variability in symptoms and functional level is one of the key features of this group of conditions. It is essential the functional history considers variability and the impact of good/bad periods on the claimant's needs in all relevant areas. Probing questions and actively asking about what is different between good and bad days will be necessary. Simply commenting in the "variability" section on numbers of good and bad days is unlikely to be sufficient.

For each activity area consider:

- The severity of CFS/ ME
- Are there co-morbidities which are adding to the claimant's functional difficulty?
- Are they affected for the majority of the time?
- Can they do the task reliably, repeatedly, safely and in a timely manner?
- Is the level of severity claimed consistent with their input, medication, and knowledge of the condition?
- Do they use/ need aids to improve functional ability?

xxx

Activity 1 - Preparing food:

xxxxxx

Activity 2 – Taking nutrition:

XXXXX

Activity 3 – Managing therapy or monitoring a health condition:

XXXXX

Activity 4 – Washing and bathing:

XXXXX

Activity 5 - Managing toilet needs or incontinence:

XXXXX

Activity 6 – Dressing and undressing

XXXXX

Activity 7 – Communicating verbally:

XXXXX

Activity 8 – Reading and understanding signs, symbols and words:

XXXXX

Activity 9 – Engaging with other people face to face:

XXXXX

Activity 10 – Making budgeting decisions:

XXXXX

Activity 11 – Planning and following journeys:

XXXXX

Activity 12 – Moving around:

XXXXX

The importance of probing activity 12



Mid-module Assessment

You will now check your baseline understanding of what you have studied in Part 1 of this module, by answering 10 True or False questions.

REMEMBER TO READ THE QUESTIONS CAREFULLY BEFORE ANSWERING.

Name:		Das ID:	Date:	
			True	False
1	XXXXXX			
2	XXXXXX			
3	XXXXXX			
4	XXXXXX			
5	XXXXXX			
6	XXXXXX			
7	XXXXXX			
8	XXXXXX			
9	XXXXXX			
10	XXXXXX			

2. Part 2

The HP should read through each fictional case example and choose follow the instructions for each activity. In some cases the HP will be asked to consider what information is missing, and in others, the appropriate descriptor choice will be requested.

Case Example 1

XXXXXX

What information is missing, that would enable you to advise on which descriptor applies in Activity 8?

Case Example 2

XXXXXX

Which descriptor applies for Activity 1? Circle one: A B C D E F

Case Example 3

XXXXX

Which descriptor applies for Activity 12? Circle one: A B C D E F

Case Example 4

XXXXX

What information is missing, that would enable you to advise which descriptor applies in Activity 5?

Case Example 5

XXXXX

Which descriptor applies for Activity 4? Circle one: A B C D E F G

Case Example 6

XXXXX

Which descriptor applies for Activity 2? Circle one: A B C D E F

Case Example 7

XXXXX

Which descriptor applies for Activity 3? Circle one: A B C D E F

Now consider the following in addition to the case information above:

XXXXXX

Which descriptor applies for Activity 6? Circle one: A B C D E F

Case example 8

XXXXXX

Which descriptor applies for Activity 7? Circle one: A B C D E

Case example 9

XXXXXX

Which descriptor applies for Activity 9? Circle one: A B C D

Case example 10

XXXXXX

What information would you discuss with the GP to enable you to choose descriptors for Activities 10 and 11?

XXXXX

Which descriptor applies for Activity 10? Circle one: A B C D

Which descriptor applies for Activity 11? Circle one: A B C D

3. Part 3

Case example 1

XXXXX

*Is this enough information to address the principle of variability?
Think about what else you could ask, to get more information.*

XXXXX

Now choose descriptors for activities 1 - 12 considering all the evidence you have. Remember to consider the principles of variability and reliability when making your choices.

Activity 1:

Activity 2:

Activity 3:

Activity 4:

Activity 5:

Activity 6:

Activity 7:

Activity 8:

Activity 9:

Activity 10:

Activity 11:

Activity 12:

Case example 2

Choosing descriptors

Now choose descriptors for activities 1 - 12 considering all the evidence you have. Remember to consider the principles of variability and reliability when making your choices.

Activity 1:

Activity 7:

Activity 2:

Activity 8:

Activity 3:

Activity 9:

Activity 4:

Activity 10:

Activity 5:

Activity 11:

Activity 6:

Activity 12:

4. References

NICE (2007) *Chronic fatigue Syndrome / myalgic encephalomyelitis (or encephalopathy): diagnosis and management. Clinical Guideline.* www.nice.org.uk/guidance/cg53

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