

The Assessment of Fluctuating Conditions (Facilitator Notes)

MED-CMEP~176

13th September 2021

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 Department for Work and Pensions.

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.

Document control

Superseded documents

Version history

Version	Date	Comments
4 Final	13 th September 2021	Signed off by DWP
4b Draft	31 st August 2021	Update following external review
4a Draft	5 th July 2021	Review and update
3 Final	20 th November 2019	Signed off by DWP
3b Draft	14 th November 2019	Update following external review
3a Draft	18 th July 2019	Review and update
2 Final	9 th July 2018	Signed off by SH&S
2b Draft	1 st May 2018	Update after external review
2a Draft	5 th February 2018	Review and updated
1 Final	17 th February 2017	Signed off by SH&S

Changes since last version

General formatting with amendment of any typographical or spelling errors

Author updated

Clinical findings changed to examination findings where relevant

Section 2 – information on Dysautonomia and Long COVID included, and on bipolar disorder updated

Section 5 – information on case scenarios updated to reflect changes made in pre-course reading document

Section 6 – additional clarification points included in facilitation notes

Section 7 – note added for clerical completion of evaluation form only in exceptional circumstances

Appendix B - minor amendments made to Case Scenarios for correction of any typographical errors and clarification of some activities

Appendix C – LEARN form included

Appendix D – Level 1 and 2 Evaluation Form included

Address on Observation Form updated

Outstanding issues and omissions

Updates to Standards incorporated

Issue control

Author: Clinical Content Specialist Team

Owner and approver: Department for Work and Pensions

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Introduction

This learning event, **The Assessment of Fluctuating Conditions**, has been designed for all HCPs who provide advice on Work Capability Assessments (WCA).

This document provides a framework for the event; it gives details of the key messages and activities, and includes master copies of all materials.

The Training Day

The training course is a 3.5 hour facilitated learning event including a 15 minute tea break.¹

A total of 5 Continuing Professional Development Points (CPD) will be awarded on completion of this learning event including the pre-course reading (1.5 CPD points).

In addition, facilitators will be awarded 5 CPD points for successful completion of the Train the Trainer (TTT) event.

The overall aim of the learning event is:

- To enhance HCP expertise in the exploration of variability in fluctuating conditions.

Objectives of the learning event

By the end of this learning event, participants will have:

- Considered enhanced questioning techniques to ensure variability is adequately addressed
- Considered symptoms that are likely to be associated with variability
- Considered clinical examination findings in the context of variability and their use as part of the overall evidence
- Considered fictitious case scenarios that reflect both good and poor practice in addressing variability

¹ Times given in the facilitation notes are based on a 09:00 hrs start and a 12:30 finish or 13:15 hrs start and a 16:45 finish. Actual session durations are the same for the morning or afternoon start time.)

Responsibilities

Facilitators will issue link to an on-line evaluation form. The clerical version (available in Appendix D) is only for use in exceptional circumstances.

Facilitation Notes

General guidance notes are provided on the following pages for each of the sessions included in the event.

The facilitation notes do not provide a script; they outline:



Session Aims



An overview of how the session should be delivered (the actual dialogue and process is determined by the facilitator)



Advises you of the materials that are provided and/or needed



Suggests the approximate time needed to complete any particular learning activity

Facilitators are advised to have a copy of the pre-course reading for reference throughout the facilitated learning event. Participants must bring their own copy of the pre-course reading with them. All participants must complete the pre-course reading and exercises, prior to attending as this is an integral part of the learning event activity. Participants will build and establish further understanding on the concepts raised in the pre-course activities. Any participant who has not completed the pre-course reading and exercises will not be allowed to continue with the facilitated learning event.

Facilitator / Trainer Criteria

- At least 12 months approval in WCA
- Facilitation skills trained, *preferably with experience of training delivery*
- No quality issues
- No complaints issues

1. Welcome and Introduction



Objectives

- To ensure participants are aware of and understand the objectives and agenda of the event
- To introduce the facilitator



Materials

Pre-course reading

White board/Flip Chart



Duration

10 minutes (09:00 - 09:10 hrs or 13:15 – 13:25 hrs)



Facilitation Notes

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
Welcome Domestics & Introductions	5 min	<p>Welcome participants and introduce self.</p> <p>Explain facilities:</p> <p>Room(s)</p> <p>Toilets</p> <p>Fire evacuation procedure</p> <p>Lunch / Breaks</p> <p>Messages / mobile phones</p> <p>Advise participants about the timings of the learning event.</p> <p>Ask participants to briefly introduce themselves.</p>	
Event Aims & Objectives	3 min	Share the learning aims and objectives of the event with the participants.	Talk

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>(Copy in participants pack - Introduction.)</p> <p>The overall aim of the learning event is:</p> <ul style="list-style-type: none"> To enhance HCP expertise in the exploration of variability in fluctuating conditions. <p>Objectives of the learning event</p> <p>By the end of this learning event participants will have:</p> <ul style="list-style-type: none"> Considered enhanced questioning techniques to ensure variability is adequately addressed Considered symptoms that are likely to be associated with variability Considered clinical examination findings in the context of variability and their use as part of the overall evidence Considered fictitious case scenarios that reflect both good and poor practice in addressing variability 	Flip chart
Pre-course reading check	2 min	<p>Conduct a brief check on pre-course reading completion (including the 4 preparatory reflective exercises and 4 case scenario exercises).</p> <p>All participants must have completed the pre-course reading and exercises, prior to attending as this is an integral part of the learning</p>	Ask

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>event activity. Participants will build and establish further understanding on the concepts raised in the pre-course activities.</p> <p>Any participant who has not completed the pre-course reading and exercises will not be allowed to continue with the facilitated learning event.</p> <p>Questions may arise at this stage – wherever possible, acknowledge and redirect to the relevant section of the learning event.</p>	

2. Symptoms and Variability



Objectives

- To consider symptoms that are likely to be associated with variability



Materials

White board/Flip Chart



Duration

30 minutes (09:10 - 09:40 hrs or 13:25 – 13:55 hrs)



Facilitation Notes

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
Objective	1 min	<ul style="list-style-type: none"> To consider symptoms that are likely to be associated with variability <p>Remind participants that when considering conditions / symptoms subject to variability, all advice given must remain medically reasonable and be based on the balance of probability.</p>	Tell
Definition	2 min	<p>Ask for a quick definition of a fluctuating condition.</p> <p><i>A fluctuating condition can be defined as - Any chronic condition - physical or mental (or a combination of the two) - where a characteristic clinical feature is significant variation in the overall pattern of ill health and/or disability, which may be combined with variations in the type and severity of the symptoms being experienced.</i></p>	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		Participants were provided with a useful definition in the pre-course reading. This was produced by a group of stakeholder charities following the Independent Review of the Work Capability Assessment published in 2010.	
Conditions associated with variability	5 min	<p>Ask for examples of conditions participants feel are not associated with variability. (This was also part of the pre-course reading exercise.)</p> <p>Invite brief discussion.</p> <p>Emphasise the vast majority of conditions will have variability and indeed it is difficult to think of any condition with no variability at all.</p> <p>Link to pre-course reading and the cycle of variability. Briefly mention the 3 broad types (Type A, Type B, Type C) in the cycle of variability.</p>	Ask List – capture on flip chart
Variability – Common symptoms	22 min	<p>In this segment the focus is to briefly discuss an overview on some of the common symptoms likely to be associated with variability including:</p> <ul style="list-style-type: none"> • Fatigue • Pain • Joint swelling • Mobility 	List on flip chart

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<ul style="list-style-type: none"> Breathlessness Mood, anxiety, distress, motivation Cognition Dysautonomia <p>Again link to the pre-course reading.</p> <p>Briefly discuss each of these in turn and emphasise symptom variability:</p> <p>Fatigue Emphasise - may be physical and/or mental fatigue. Debilitating activity induced fatigue which results in a persisting and substantial functional impairment is a key diagnostic feature of ME/CFS and is required to make a diagnosis. However fatigue occurs in a range of other conditions such as rheumatoid arthritis (chronic fatigue affects about 89% of people living with rheumatoid arthritis), Long COVID, HIV, multiple sclerosis, Parkinson's, Inflammatory Bowel Disease, etc.</p> <p>Remind participants: It might be useful to use some of the internal learning resources and external resources listed in pre-course reading to refresh and expand knowledge symptoms, variability, and the impact of the specific conditions.</p>	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>When assessing fatigue it is extremely important to ask the person:</p> <ul style="list-style-type: none"> • What does fatigue mean to them • To describe what fatigue means • What doing an activity does to their level of fatigue <p>Also remember:</p> <ul style="list-style-type: none"> • Highlight the importance of ascertaining what happens if someone attempts to push through fatigue (and the knock on impact on other activities) • Address post exertion symptom exacerbation <p>Briefly discuss fatigue in general and possible contributory factors (some mentioned in pre-course reading).</p> <p>Discuss interaction – mood /fatigue; pain /fatigue; cognition/fatigue.</p> <p>Highlight the importance of exploring the symptom(s) and ascertaining the effect on starting and finishing a task safely, reliably and repeatedly.</p> <p>Also highlight effect of post exertion fatigue.</p> <p>Note: pacing is the most widely known and used form of activity and energy management for people with MF/CFS, although people may be familiar with the Spoon Theory which is mentioned in the pre-course reading.</p>	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>If asked - emphasise spoon theory is a metaphor used to explain the reduced amount of energy available for activities of daily living and productive tasks that may result from disability or chronic illness.</p> <p>A person who runs out of spoons has no choice but to rest until their spoons are replenished.</p> <p>Pain Briefly mention the types of pain:</p> <ul style="list-style-type: none"> • Musculoskeletal • Visceral • Neuropathic • Central <p>Focus on pain and variability rather than specific theories about pain mechanisms.</p> <p>Emphasise the need for a good clear description of how the pain affects activities of daily living.</p> <ul style="list-style-type: none"> • How the pain varies over time • How the intensity of pain varies • How it varies with activity • Emphasise need to consider the ability to reliably repeat the activity and how this would allow for a better representation of the likely level of disability • Discuss “incident pain” – 	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>exacerbation with a particular action or activity</p> <p>Remind participants of the additional resources in the pre-course reading including the internal learning module on Chronic Pain.</p> <p>Joint swelling Briefly mention and discuss that this may be associated with particular conditions such as any arthritic condition/connective tissue disorder.</p> <p>Remember to emphasise variability may occur with swollen joints and the severity of restricted joint movement.</p> <p>Mobility Briefly mention and discuss that this may be associated with various conditions such as rheumatoid arthritis, connective tissue disorders, cardiorespiratory conditions, ME/CFS, Parkinson's disease, multiple sclerosis, Long COVID, etc.</p> <p>Remember to emphasise variability may occur due to pain, fatigue, joint swelling, breathlessness, etc.</p> <p>Breathlessness Participants should be experienced in addressing this symptom.</p> <p>Discuss variability – e.g. COPD baseline vs. acute exacerbations. Asthma – reversible airway disease</p>	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>– acute exacerbations, frequency of these, use and effect of treatment, reliever and prevention medication. Briefly mention cardiac conditions such as angina and cardiac failure. Remind about effort tolerance. (Re-direct to specific suggested reading if necessary.)</p> <p>Mood, Anxiety and Motivation These can fluctuate during the day and can also vary depending on response to medication e.g. worsening symptoms as effects of medication wear off. Discuss diurnal variation:</p> <ul style="list-style-type: none"> • General trend for low mood in morning for depression • Higher levels of anxiety in the afternoon / evening for anxiety disorder • Emphasise that multiple patterns of variability may occur concurrently for example: good week (week to week variability) - with bad mornings (within day variability) <p>Mention bipolar disorder. Discuss particular patterns of variability including:</p> <ul style="list-style-type: none"> • Rapid cycling bipolar disorder (4 or more episodes of mania, hypomania or depressive episodes per year) 	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<ul style="list-style-type: none"> Bipolar II disorder where at least one hypomanic episode is experienced but they also have severe depressive episode (s) with very prolonged depressive type symptoms <p>Mention psychotic illnesses such as schizophrenia – emphasise negative symptoms in schizophrenia with disturbance of mood and poor motivation.</p> <p>Discuss low motivation in general – may occur in depressive episodes.</p> <p>Mention anxiety type symptoms and how these may be a constant background symptom but also have worsening precipitated by particular situations / activities or just arising for no particular cause.</p> <p>Link the particular symptom(s) – mood, anxiety and motivation - with possible functional effects and emphasise how fluctuation likely to affect ability to initiate, reliably and safely complete and repeat particular tasks / activities.</p> <p>Cognition</p> <p>Mention cognitive impairment is a common symptom of many fluctuating conditions.</p> <p>Discuss cognitive impairment including mention of key components of cognitive function:</p>	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<ul style="list-style-type: none"> • Learning and memory • Problem solving • Word finding • Attention, concentration and mental speed <p>Dysautonomia This is a disorder of the autonomic nervous system, with failure or excessive/overactive actions of the sympathetic or parasympathetic nervous systems. May occur in various conditions such as diabetes, Parkinson's, ME/CFS, Long COVID, etc. Dysautonomia may lead to orthostatic intolerance, postural hypotension, postural tachycardia syndrome, etc.</p> <p>Interaction Remember to discuss how conditions and symptoms may interact and cause a greater than anticipated disability from an isolated symptom / condition.</p> <p>In particular mention:</p> <ul style="list-style-type: none"> • Pain and fatigue • Pain and low mood • Cognitive impairment and pain • Cognitive impairment and fatigue <p>Other symptoms Acknowledge other symptoms are associated with variability. For example, gastrointestinal</p>	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>symptoms, including continence (inflammatory bowel disease, HIV etc.).</p> <p>Remind about medication / treatment side effects and impact on variability. Emphasise similar principle to explore intensity, frequency, and effect on ability to complete and repeat task / action in a safe reliable manner.</p> <p>Remind participants that when considering conditions / symptoms subject to variability, all advice given must remain medically reasonable and be based on the balance of probability.</p>	

3. History Taking and the Variability Semi-Structured Interview



Objectives

- To consider enhanced questioning techniques to ensure variability is adequately addressed



Materials

White board/Flip Chart

Participant Pack – Appendix A (Semi-Structured Interview Desk Aid)

Laminated Semi-Structured Interview Desk Aid



Duration

40 minutes (09:40 – 10:20 hrs or 13:55 – 14:35 hrs)



Facilitation Notes

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
Objective	1 min	<ul style="list-style-type: none"> To consider enhanced questioning techniques to ensure variability is adequately addressed 	Tell
General recap of good interview skills	4 min	<p>Review best practice in history taking.</p> <p>Ask participants to share good general points on history taking / interview skills.</p> <p>Expected answers should include:</p> <ul style="list-style-type: none"> Empathetic approach Putting the claimant at ease Clear explanations Active listening 	Ask

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<ul style="list-style-type: none"> • Taking breaks from writing/typing to maintain eye contact with the claimant • Exploring the How? When? Where? Why? Who? What? By using open questions mainly and closed questions judiciously to clarify as necessary • Need for empathy and good soft skills as claimant may be anxious about the process 	
Variability – clinical and typical history	20	<p>Recap points from pre-course reading about history taking.</p> <p>Invite participants to share reasons why it is important to address variability.</p> <p>Expected answer to include:</p> <ul style="list-style-type: none"> • The disabling aspects of fluctuating conditions are not usually visible during observations and physical examination at assessment • Markers for disease often do not correlate with the degree of disability experienced from invisible pain or fatigue • Mental fatigue, anxiety and any cognitive difficulties may hamper the ability of the claimant to provide adequate information • Comorbidities and interaction of factors are likely to have a greater impact than the simple sum of the individual components 	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<ul style="list-style-type: none"> • Variability of health condition is cited by claimants in the work-related activity group as a top factor making it difficult for them to work (based on stakeholder charity survey information) <p>Revisit cycle of variability and 3 types. Remind participants that certain conditions may present with variability in any of the 3 types.</p> <p>Pre-course reading – 3 main patterns:</p> <ul style="list-style-type: none"> • Type A • Type B • Type C <p>Make sure discussion points include coverage of:</p> <p>Good / Average / Bad time periods for:</p> <ul style="list-style-type: none"> • Hour to hour variability • Day to day variability • Per Week variability • Within the day variability • Over longer periods – several months or within the year • Predictable variability (illness, stress, etc) <p>Briefly mention the 4 reflective exercises completed in the pre-course reading.</p> <p>Note to facilitator: These reflective exercises were included to act as a platform for the next activity –</p>	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>introducing the Variability Semi-Structured Interview Desk Aid.</p> <p>The pre-course document has additional responses to the reflective exercise.</p> <p>In summary:</p> <ul style="list-style-type: none"> • Reflective exercise 1 - concerns about addressing payback / post exertion fatigue • Reflective exercise 2 – concerns about having to break up tasks and pace activities • Reflective exercise 3 – concerns about variable pain and fatigue; need for some balancing of activities • Reflective exercise 4 – concern about recognition of effect of variable intensity of anxiety type symptoms and need for support 	
The Variability Semi-Structured Interview Desk Aid	15	<p>Introduce Variability Semi-Structured Interview Desk Aid.</p> <p>Tell participants it is not mandatory to ask each question. It is designed as a prompt to help HCPs better explore variability.</p> <p>Remind participants when addressing variability - reliably, repeatedly, safely and in a timely manner, must be considered as all factors must be achievable to conclude the action is manageable.</p>	<p>Participant Pack Appendix A (Semi-Structured Interview Desk Aid)</p> <p>Handout Semi-Structured Interview Laminated Desk Aid</p>

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>Remind participants that when considering conditions / symptoms subject to variability, all advice given must remain medically reasonable and be based on the balance of probability.</p> <p>Discuss points in turn under the main headings:</p> <ul style="list-style-type: none"> • Ask yourself • Consider Exploring with the Customer • Further prompts for Activity Areas <p>Reiterate the importance of addressing variability in the condition history and the typical day.</p> <p>Discuss each of the activity areas and the questions in the Semi-Structured Interview:</p> <ul style="list-style-type: none"> • Behaving Appropriately • Social Engagement • Personal Action • Sensory • Continence • Sitting and Standing • Mobilising <p>Highlight how the specific questions help inform about the salient aspects of variability.</p> <p>In particular - highlight the questions that explore how the claimant “feels after” and reiterate the effect this may have on the ability to repeat the task in a safe and timely manner.</p>	Talk & Discuss

4. Role Play using the Variability Semi-Structured Interview Desk Aid



Objectives

- To practice enhanced questioning techniques to ensure variability is adequately addressed



Materials

White board/Flip Chart

Participant Pack – Appendix A (Semi- Structured Interview Desk Aid)

Participant Pack – Appendix B – Case Scenarios 1 and 2 (role plays)



Duration

25 minutes (10:20 – 10:45 hrs followed by a 15 minute break; or 14:35 – 15:00 hrs followed by a 15 minute break)



Facilitation Notes

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
Objective	1 min	<ul style="list-style-type: none"> To practice enhanced questioning techniques to ensure variability is adequately addressed 	Tell
Role Play Scenarios	24 min	<p>Emphasise to group these are fictitious scenarios designed for learning purposes.</p> <p>In this activity, the expectation is to practice using the Variability Semi-Structured Interview Desk Aid to help inform the history.</p> <p>There are no awards for acting skills.</p>	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>Refer the participants to Appendix B in their Participants Packs. These 2 fictitious role play scenarios contain information for the ‘interviewing HCP’ and for the ‘claimant’.</p> <p>The participant who is role playing the “claimant” will have a script containing some key points.</p> <p><i>There is no expectation to memorise and deliver this verbatim.</i></p> <p>Note to facilitator: This activity should allow the participants to get a feel for the Semi-Structured Interview Desk Aid in the learning environment. A full history may not be possible for each scenario, but perhaps a condition history for one and more focus on the typical day for the other.</p> <p>Divide the group into pairs: For each pair, one participant acts as the “HCP” for the scenario and the other role plays the “claimant”. For scenario 2, the participants switch roles.</p> <p>Scenario 1 Participant 1 - reads <i>points for the interviewing HCP</i> and role plays the “HCP”.</p> <p>Participant 2 - reads <i>points for the claimant</i> and role plays the “claimant”.</p>	Participant Pack Appendix B – Case Scenarios

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>This claimant is living with chronic HIV/hepatitis B co-infection and depression.</p> <p>Fatigue is a prominent feature of daily living.</p> <p>There is some variability in the levels of fatigue within the day and also for longer intervals.</p> <p>There is associated low mood and anxiety; this also varies.</p> <p>The “interviewing HCP” has the opportunity to explore the variability in symptoms (anxiety, low mood, fatigue) and the effect on function.</p> <p>The particular functional areas identified in the questionnaire provide rich and fertile areas for exploration using the Semi-Structured Interview.</p> <p>Scenario 2 (Participants to switch roles from scenario 1 role play.)</p> <p>Participant 2 - reads <i>points for the interviewing HCP</i> and role plays the “HCP”</p> <p>Participant 1 - reads <i>points for the claimant</i> and role plays the “claimant”</p> <p>The claimant is living with systemic lupus erythematosus (SLE).</p>	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>The main functional areas affected are physical.</p> <p>There is significant variability in function with average days and bad days with more intense fatigue and pain.</p> <p>After completing both role plays – regroup and gather reaction / thoughts of participants.</p> <p>Invite questions on how the desk aid may have assisted the participants in terms of evidence gathering.</p> <p>Emphasise that the Semi-Structured Interview Desk Aid is a tool; it is an approach designed to help address variability.</p> <p>Ensure participants are clear that the desk aid should not be used as a list of questions that may impair communication. It should serve as a prompt to ensure variability is adequately addressed within the history.</p>	
Break	15 min		

5. Observations and Examination: Variability Considerations



Objectives

- To consider clinical examination findings in the context of variability and their use as part of the overall evidence



Materials

White board/Flip Chart

Pre-course Reading – Case Scenario A (History & Examination Findings)

Pre-course Reading – Case Scenario B (History & Examination Findings)



Duration

30 minutes (11:00 – 11:30 hrs; or 15:15 – 15:45 hrs)



Facilitation Notes

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
Objective	1 min	<ul style="list-style-type: none"> To consider clinical examination findings in the context of variability and their use as part of the overall evidence <p>Remind participants that while only a few conditions are addressed within the case scenarios, similar principles would apply to any fluctuating condition where variability is present.</p>	Tell
Case Scenario A & B - Discussion	29 min	Participants should have prepared for this discussion as part of the pre-course exercise and submitted the answers to the exercise prior to the facilitator led event.	Refer to Pre-course reading – Case Scenarios A and B

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>Mention that these cases represent extremely complex scenarios that we are unlikely to see on a regular basis and therefore the level of detail is greater than would be expected in most cases.</p> <p>Focus on general points about addressing variability and potential for history and examination findings to be at variance.</p> <p>Remind participants that advice must be medically reasonable.</p> <p>Acknowledge there may be other descriptors, but for discussion purposes, focus on the selected descriptors.</p> <p>Ask participants to review the information in Case Scenario A.</p> <p>This is a fictitious case scenario; the “claimant” is living with rheumatoid arthritis. The scenario script contains details of the history and examination.</p> <p>Follow this up with a group discussion.</p> <p>Some key points:</p> <ul style="list-style-type: none"> • Major point – the examination findings (in isolation) are not highly suggestive of significant disability but the history suggests otherwise • Has provided a description and some approximation of the average week • Acknowledges the day of 	Review and discuss

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>assessment is not like the average day/week</p> <ul style="list-style-type: none"> Multiple joints affected, worse in the average week Significant fatigue described during the average week (but also gets less intense fatigue in the good week) Describes functional restriction in multiple areas including gripping, walking/mobilising, picking up and moving, In addition, the level of care and fact awaiting medication review suggest significant disability likely Mobility – likely to have some disability – case may be made for advising Wd (200m) considering the multiple factors including the walking pace (slow – very slow), the distance covered, and the fluctuating nature of the pain and fatigue; effective use of walking aids unlikely due to upper limb restrictions and fatigue <p>The fact she walks 5 minutes to the park and the examination findings may sway some to select a lower descriptor (without considering reliability, discomfort and fatigue issues)</p> <ul style="list-style-type: none"> Sitting and standing – likely to have some disability – a case may be made for advising Sb (30 minutes sit/stand) ; although able to sit and stand, she still gets fatigued and needs to rest (even lie down between tasks); also at the park, she walks to stretch legs after sitting for about 30 minutes while she prefers to lie 	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>down if at home</p> <p>The fact that she sat for 40 minutes at assessment and stood up may sway some to suggest a less disabling descriptor</p> <ul style="list-style-type: none"> Picking up and moving – likely to have some disability – a case may be made for advising Pb (unable to manage 1 litre); the typical day describes lifting restrictions including now only using a small travel size kettle and 1 pint milk cartons <p>Repeat with case scenario B.</p> <p>Ask participants to review the information in Case Scenario B.</p> <p>This is a fictitious case scenario; the “claimant” is living with bipolar disorder. The scenario script contains details of the history and examination.</p> <p>Follow this up with a group discussion.</p> <p>Some key points:</p> <ul style="list-style-type: none"> Major point – the examination findings (in isolation) are not highly suggestive of significant disability but the history suggests otherwise Has provided a history with significant variation in mood The history also highlights episodes where mood gets even lower Describes function during each of 	<p>Review and discuss</p>

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>the main periods of low mood (note the significant input on the bad days)</p> <ul style="list-style-type: none"> • Describes anxiety and trigger for worsening (social interaction) • Note the encouragement and preparation for social interaction and going out • Note other indicators including the level of medication and input • Personal action - a case may be made for IAC; although appearing well kempt at assessment, there is good evidence in the history supporting prompting for personal action during the bad days • Coping with change – a case may be made for CCc; although the MSE features did not indicate very high anxiety levels, he had coaching and preparation to attend and was accompanied; he manages appointments to his GP but if unexpected things like the HMRC letter arrive he gets anxious • Getting about – a case may be made for GAc; the history is consistent with struggling to go to new places but managing locally • Coping with social engagement – a case may be made for CSb – the overall evidence suggests he is unable to reliably manage interaction with strangers; although the MSE features did not indicate very high anxiety levels, he had coaching and preparation to attend and had to 	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>be accompanied</p> <p>Ask for thoughts about both of the case histories and how using an approach such as the Semi-Structured Interview may allow the variability to be addressed.</p>	

6. Further Case Scenario Consideration



Objectives

- To consider fictitious case scenarios that reflect both good and poor practice in addressing variability



Materials

White board/Flip Chart

Appendix B – Case Scenario 3 (History)

Appendix B – Case Scenario 4 (History & Examination Findings)

Pre-course reading – Case Scenario C

Pre-course reading – Case Scenario D



Duration

50 minutes (11:30 – 12:20 hrs; or 15:45 – 16:35 hrs)



Facilitation Notes

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
Objective	1 min	<ul style="list-style-type: none"> To consider fictitious case scenarios that reflect both good and poor practice in addressing variability 	Tell
Further Case Scenario Discussion (pre-course Case Scenarios C & D)	24 min	<p>Participants should have prepared for this discussion as part of the pre-course exercise.</p> <p>These are fictitious case scenarios. The scenario script contains details of the history.</p>	Refer to Pre-course reading – Case Scenario C & D

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>Both scenarios asked the following questions:</p> <ul style="list-style-type: none"> Overall assessment – Was variability adequately addressed in the scenario? <p><i>Expected response: No</i></p> <ul style="list-style-type: none"> What issues have you identified? What are the areas of improvement? <p>Invite participants to quickly review the scenario in small sub –groups or individually and discuss their answers.</p> <p>Ask participants (or sub- groups) to share their answers and discuss.</p> <p>Some key points – Scenario C</p> <p>This is a fictitious scenario for a claimant living with ME/CFS</p> <ul style="list-style-type: none"> The questionnaire mentions multiple areas of restriction; these have not been addressed or adequately explored in the history The history mentions activities but does not explore variability, how the claimant manages the activities, the frequency activities are performed or impaired, or the ability to repeat activities Cycle of variability not really explored 	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<ul style="list-style-type: none"> Multiple references to some days , but not much indication of the actual frequency Unclear if the day of assessment is a good day, a bad day or otherwise Use of equipment and aids mentioned in questionnaire is not explored Variability in fatigue not explored Is the claimant too tired to start particular tasks? Effect of completing one activity not clear – in particular history does not explore post activity symptom exacerbation Post-exertional symptom exacerbation is a key diagnostic feature of ME/CFS Limitations due to pain not fully explored Pain itself is not explored, is it due to ME/CFS or another condition? Mobility not clarified – how long? Variation in times? Pace? Ability to repeat? Comments such as ‘brain just drifts’ and ‘brain fog’ mentioned in questionnaire are not explored in the condition history or the typical day – not sure how she really manages activities like the computer and what the cooking “sometimes” involves 	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>Some key points – Scenario D</p> <p>This is a fictitious scenario for a claimant living with relapsing remitting multiple sclerosis.</p> <ul style="list-style-type: none"> • The questionnaire mentions multiple areas of restriction; these have not been addressed or adequately explored in the history • Cycle of variability not explored • Dizziness (medication side effect) not explored • Memory problems not explored further in the typical day • Continence issues not addressed sufficiently in the condition history or impact explored further in the typical day • Other issues including - pain, fatigue, grip problems and not explored adequately • Bathroom – lack of exploration into what her sister helps her with and how often • Some description of how she manages coursework / online study – still unclear how often unable to manage hour or so of reading • Still unclear of reliability with housework activities mentioned • Hobby – what stops her from engaging in card making 	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>more often?</p> <ul style="list-style-type: none"> • Use of aids and appliances not properly explored • She walks / mobilises using a walking frame but unclear as to - How well? How often? What pace? Ability to repeat? Any stops? 	
Further Case Scenario Discussion – Case Scenario 3	25 min	<p>Ask participants to review the information in case scenario 3. This is a fictitious case scenario; the “claimant” is living with ulcerative colitis.</p> <p>The scenario script contains details of the history without any examination findings.</p> <p>This scenario is completed to a fairly reasonably good standard with details to cover variability in both the condition history and typical day.</p> <p>Some key points – Case Scenario 3</p> <ul style="list-style-type: none"> • Details to help give a picture of the cycle of variability • Range of symptoms described including bowel symptoms, fatigue and joint pain • Impact of flare up on timely completion of activities such as dressing detailed • Impact on studying detailed • Actions to help cope with bowel described including diet and restricting where going out to places with readily accessible toilets 	Refer to Participant Pack Appendix B – Case Scenario 3 (History)

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<ul style="list-style-type: none"> Information on why she avoids taking the bus Pattern of rest stops to help pace activities when out at the shopping centre <p>Facilitator note: The focus is to look at the scenario and identify how variability is covered in the history.</p> <p>Descriptor choice discussion may arise but try to focus on history:</p> <ul style="list-style-type: none"> For mobilising – a case may be made for Wd although she manages 5 -10 minutes she is not really able to repeat this without resting and even then she is only able to manage the walking closer to 5 minutes; She gets more fatigued with increasing activity For standing and sitting - a case may be made for Sc – based on the sitting time and fatigue on standing; about half the time she manages to sit for 30 minutes the other times she sits for 1 hr to study but has to rest; alternating this with standing is likely to add to the fatigue Upper limb – a case may be made for none apply (based on the history only) For continence – a case may be made for Cb - the risk is 	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<p>always there if she keeps close to the toilet to avoid getting caught short; she uses pads but still has accidents if caught short</p> <p>An additional scenario is available for participants to review post event, reflect on the history and examination findings with a view to selecting possible descriptors.</p> <p>Encourage participants to complete and discuss with their CSL if they have any particular concerns.</p> <p>This is a fictitious case scenario; the “claimant” is living with Psychosis. The scenario script contains details of the history and examination findings.</p> <p>This scenario is completed to a fairly reasonably good standard with details to cover variability in both the condition history and typical day.</p> <p>Some key points – Case Scenario 4</p> <ul style="list-style-type: none"> • Describes recent past and allows for an indication of cycle of variability • Mood described including variability within the day and over longer periods • Safety and precautionary actions with kitchen tasks described • Poor concentration explored and impact on activities 	<p>Refer to Participant Pack Appendix B – Case Scenario 4 (History & Examination Findings)</p>

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		<ul style="list-style-type: none"> • Issues with motivation explored in particular the impact on personal action • Anxiety and impact on activities such as social engagement, going out and coping with changes explored • Clarified ability to go out locally • There are features of anxiety in the MSE and indicators consistent with difficulty interacting • Descriptors – case may be made for some scoring descriptors due to the overall presentation including the variability • Hazard awareness – AHc - He does not require constant close observation, but struggles at times with sustained focus which has led to accidents • Personal action – IAc – noted the difficulties during the bad weeks • Coping with change – CCc - noted the history of distress with unexpected events and features of anxiety in MSE • Getting about – GAc – consistent history presented; also anxiety noted in MSE • Coping with social engagement – CSb – consistent history; MSE shows problems with rapport and features of anxiety 	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		In both of these scenarios, participants may be able to identify how aspects could reasonably be obtained using the Variability Semi Structure Interview Desk Aid as a tool.	

7. Closure and Key Points



Objectives

- To capture key learning points from participants
- To remind participants to complete online feedback
- Closure of event



Materials

White board/Flip Chart



Duration

10 minutes (12:20 – 12:30 hrs; or 16:35 – 16:45 hrs)



Facilitation Notes

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
Objectives	1 min	<ul style="list-style-type: none"> • To capture key learning points from participants • To remind participants to complete online feedback • Closure of event 	Tell
Key Points Capture	7 min	<p>Recap aims and objectives of the event.</p> <p>Invite participants to share one key learning point from the event.</p> <p>Remind participants to document learning activity using reflective learning forms such as the LEARN</p>	

TOPIC	Duration	KEY POINTS	Actions (Slide/Handout/ Syndicate groups/etc.)
		form (Learning Experience and Reflections Note), available in both Pre-course Reading and Facilitator Notes (Appendix C).	
Online feedback	2 min	Invite participants to provide feedback online. Provide link and send electronically. Clerical form available in Appendix D is to be used only in exceptional circumstances, when online form completion is not possible.	

Appendix A – Variability - Semi-Structured Interview Desk Aid

Reliably, Repeatedly and Safely Prompt Guide

**Centre for Health and
Disability Assessments**
Operated by MAXIMUS

Ask Yourself:

- What is the likely variation in this medical condition? Does treatment vary and does it have an effect on function?
- What is the likely "cycle of variability" in this condition? (Hourly, daily, weekly, monthly, long term or a combination.) Why may it be different for this individual?
- Consider ability to complete activities in a reasonable time and what a reasonable time for this activity may be.
- Is today's function representative?
- For all functional areas consider whether the individual suffers significant pain, distress or exhaustion

Consider Exploring with the Customer:

- Ask the customer if their condition varies
- Ask the customer to describe **both** their cycle of variability and what that means to them on their good/bad/average days.
- Is there anything the customer does to avoid or mitigate how their symptoms vary?
- How do they cope with changes to their symptoms?
- Can they complete actions safely? Do they feel unsafe at any point? Can they complete activities when required to do so?
- Do the symptoms resulting from the completion of a task mean other tasks could not be completed reliably and repeatedly and safely and in a reasonable time?

"If none of the descriptors can be completed reliably, repeatedly and safely, the individual is considered **unable** to complete the activity"

V1 2/2017

Reliably, Repeatedly and Safely Prompt Guide

**Centre for Health and
Disability Assessments**
Operated by MAXIMUS

<p>Behaving Appropriately</p> <ul style="list-style-type: none"> Does the individual always react in the same way? How does it vary? Can they do anything to manage/control their behaviour? 	<p>Social Engagement</p> <ul style="list-style-type: none"> When required can they talk to other people? (Consider cycle of variability) Do they do anything to get ready to talk to other people? Can they interact with familiar/unfamiliar people? 	<p>Personal Action</p> <ul style="list-style-type: none"> Is today representative of their usual function? Explore what support or preparation the individual needed to attend and the support they require on other days. Does anything affect ability to perform tasks reliably, repeatedly & safely?
<p>Sensory</p> <ul style="list-style-type: none"> Are there any environmental factors that impact their ability to understand communication or communicate with others? (Noise/ Lighting/Contrast sensitivity issues) How do they cope in unfamiliar locations in terms of navigation or communication? Can they manage communication or navigation reliably? 	<p>Continence</p> <ul style="list-style-type: none"> Does anything trigger incontinence or increase the frequency? (Consider the cycle of variability) Can they manage their behaviour to avoid incontinence? How do they cope if they are unsure of the location of toilets? Even if toilets are easily accessible, do they still have problems? 	<p>Sitting and Standing</p> <ul style="list-style-type: none"> When necessary can they always stand or sit as needed? Are some times of day/month/year better or worse than others? How do they feel after sitting or standing for a period?
<p>Mobilising</p> <ul style="list-style-type: none"> Consider where the individual goes. Can they go there whenever they need to? How long does this take them? Does the time taken vary? How does this compare to people of their age without health problems? Can they complete the journey at their pace, if not what makes them stop? Could they repeat the journey? How would they feel after completing it? 		

"If none of the descriptors can be completed reliably, repeatedly and safely, the individual is considered **unable to complete the activity"**

Appendix B – Case Scenarios

These are available within the Participants Pack.

Case Scenario 1 – Role Play

Case Scenario 2 – Role Play

Case Scenario 3 – History

Case Scenario 4 – History & Examination Findings

Scenario 1 – Role Play – Semi-Structured Interview Practice

The following case scenario is fictitious and has been solely designed to support learning activities.

Points for the interviewing HCP

- You have been asked to interview a claimant who is living with HIV/ hepatitis B co-infection and depression
- The questionnaire has indicated “it varies” for multiple functional areas and capabilities including: moving around and using steps; sitting/standing; picking up and moving things; coping with changes; going out and coping with social situations
- Take an appropriate history for this claimant

Scenario 1 – Role Play – Semi-Structured Interview Practice

The following case scenario is fictitious and has been solely designed to support learning activities.

Points for the “claimant”

(This is not an exact script but provides some points you may wish to provide during the interview if probed. *You are not expected to provide a verbatim response.*)

- You are living with HIV, Hepatitis B and depression
- Diagnosed with HIV and Hepatitis B 3 years ago but you think you may have had the condition for several years before as you previously had addiction problems with intravenous use of heroin. (You stopped misuse about 4 years ago)
- You have been seeing the specialist at the hospital over the last 3 years
- You have had lots of tests including scans of the liver; you know all is not right with the liver
- You have are having treatment with antiviral medication (you do not remember the names but you have to take them on time and regularly)
- You were told the blood tests show you are responding to treatment for both infections
- The main symptom you are having is fatigue; you put this down to the HIV and Hepatitis B condition and the medication, but also think the depression is not making things better
- You are tired all the time; but you also have periods of time you are so tired you barely move around
- Tiredness means you are so drained your limbs feel very heavy like lead and you cannot move; you also find it difficult to think
- Your energy levels vary within the day. You also have longer episodes where you feel more tired than normal; you noted this has been happening about every 3 - 4 months and lasts about 2 weeks before settling (these are your really bad weeks)
- The specialist is aware of the variation in your energy levels; you were referred to the mental health team and have commenced counselling due to low mood but more so the anxiety
- Regarding the Depression – you feel low most of the time; you tend to feel even lower on days when the fatigue is really bad; no self harm thoughts or actions; you are anxious every day as you are never sure how your energy levels will be for the day; you think the pattern with the mental health is similar to the fatigue as this just adds to the mental distress; your anxiety is made

worse if you have to go out or speak with people; you are on no medication for the mental health issues

- You do not have any good days, but have bad and really bad days
- The really bad days usually occur during the really bad weeks, but may also occur outside of this if you do push yourself too much
- During the really bad days you cannot do much: activities on a really bad day are - having a quick wash at the sink, back to bed /sofa, eating/drinking a little, going to bathroom as needed
- On really bad days, one of your relatives or your friend, spends more time at your house helping you as your energy levels are too low
- On the bad days you are able to do a bit more things but have to watch what you do as can never tell how much energy reserves you have left; you may be able to do a bit of paperwork such as look at correspondence for about 10 -15 minutes
- Today is a “normal” bad day so far but you are concerned this may worsen later and you may have a really bad one tomorrow as you feel you are pushing yourself by attending today
- No bad day is the same; but you feel more tired early in the morning so you try to adjust your activities
- (It is mid –morning now so you are able to make it to the assessment)
- By mid afternoon you feel very tired again and need to rest
- You avoid going out or having appointments in the afternoon as the fatigue can be very intense and if you attempt more than minimal activities (such as walking from the sofa to the kitchen to get a light snack), you may end up having to rest for the remainder of the day and the following day
- After your mid afternoon rest you try to get up and try to watch TV but never do anything to exert yourself (you no longer go out to socialise as you feel tired; you also feel too anxious)
- At home you are able to walk from room to room on the level, but limit going up and down the stairs as you find the stairs make you tired and if you do the stairs more than once or twice you feel more exhausted
- You have a quick wash in the bathroom and dress yourself in the mid-morning; This does not make you feel exhausted but you know if you pushed yourself to do more, immediately after you are likely to get exhausted, so you take a 15 - 30 minute break before starting other light activities
- You no longer do heavy housework such as vacuuming or cleaning the bathroom; the most you manage now is to stand for a few minutes to wipe the counter tops or some light dusting; you find standing for more than 10 minutes to complete activities makes you very tired and have to rest for at least an hour and you are unable to do any other activities during this time

- You stopped using the hob about 2 years ago after several instances of forgetting the pans on the hob and setting the alarm off as you felt so tired and mentally drained
- You have had no further accidents in the kitchen as you are aware of the risks when feeling tired
- You are able to use the microwave or toaster to prepare light snacks on the bad days, but not on the very bad days as you feel too tired
- You walk to the local shop about 5 minutes away at a slow pace; you never get anything heavier than a loaf of bread or 2 pints of milk as walking back with too many items makes you tired
- You are able to walk back from the local shop but then you need to take a rest for about an hour or two depending on the day; you would never attempt the trip in a bad week or first thing in the morning as you feel too tired
- You are unable to go to the supermarket for shopping now; you tried but found it too tiring and had to go and sit down for a rest in the cafe after less than 10 minutes walking around; you had to go to bed on returning home as you were very tired
- You are unable to go to new places unaccompanied; the prospect of going out makes you very anxious quite apart from feeling tired; for example you attempted to travel to the next town to see a counsellor alone but you were unable to make the journey due to anxiety
- You find crowds overwhelm you and make you more anxious; if you have to go to hospital appointments, you prefer quiet times and you are usually accompanied (your friend was unable to stay with you today, but s/he had arranged for you to have an appointment at a quiet time – despite using relaxation techniques your counsellor suggested, you still felt very anxious in the waiting room)
- You always have to prepare yourself to even say a few words to a stranger if this is absolutely necessary; this leaves you mentally drained afterwards
- Apart from today, you have only managed to say a few words with strangers twice in the last 4 months; you made a few more attempts to do so but all were unsuccessful due to the anxiety
- Although you know the local shop keeper and staff, you would not go into the shop if there are more than one or two other customers in the shop as you just don't want to chat with or come into contact with strangers as this makes you very anxious
- You sit to watch TV, most days you can manage about 30 - 45 minutes at most as even sitting for too long makes you feel tired and you would just recline or lay down on the sofa after. You just have the TV on in the background but do not really watch it on a really bad day

- You always like to have things planned out so you can balance your energy as much as possible; you hate it when things change suddenly and get very upset; when you found out your last hospital appointment was cancelled on the same day you got very upset and you remained anxious for the rest of the day

Scenario 2 – Role Play – Semi-Structured Interview Practice

The following case scenario is fictitious and has been solely designed to support learning activities.

Points for the interviewing HCP

- You have been asked to interview a claimant living with a diagnosis of systemic lupus erythematosus (SLE)
- The questionnaire has indicated problems with the following physical functions: moving around and using steps; sitting/standing; picking up and moving things; and manual dexterity; no problems in the mental/cognitive/intellectual capabilities
- Take an appropriate history for this claimant

Scenario 2 – Role Play – Semi-Structured Interview Practice

The following case scenario is fictitious and has been solely designed to support learning activities.

Points for the “claimant”

(This is not an exact script but provides some points you may wish to provide during the interview if probed. *You are not expected to provide a verbatim response.*)

- You were diagnosed with systemic lupus erythematosus (SLE) 4 years ago
- You currently see the specialist every 3 months
- You are on regular medication – hydroxychloroquine daily and paracetamol as required; you had to use steroids in the past during really bad flare ups; you last had steroids 9 months ago
- Really bad flare ups are not as frequent as before however, you still get pain in multiple joints and feel fatigued; this is under review with the specialist for consideration of other management options
- You get pain in multiple joints and areas; your specialist thinks you may be developing fibromyalgic type pain as part of the SLE
- You had physiotherapy 6 months ago and this helped you a bit
- You feel fatigued every day; some days are worse than others – you find it difficult to quantify, but you estimate you get about 2 - 3 bad days every 2 weeks or so
- You describe your fatigue as your limbs feeling heavy and liken it to carrying sacks of stones forever, even after resting; your body feels drained like you are having the worse possible flu
- The remaining days are generally average; you cannot say these are good as you always have some pain and feel fatigued
- You also feel fatigued during the day with late afternoon and evenings being especially bad and have to take a nap
- Your joints are generally more stiff and painful in the morning; medications help ease this a bit but never really take the pain away
- You try your best to be active, but the fatigue and pain limits what you can do and you take breaks in between any tasks and avoid heavy tasks such as gardening
- During the bad days the fatigue and pain is more intense and you reduce all activities; you do not leave the house on the really bad days and your activities are more limited
- On average days you are able to get out of bed slowly without help or aids

- On bad days you require help from your partner / sister to get out of bed in the morning (you get up later on these days due to the pain)
- You are able to shower (walk in shower), wash and dress yourself on the average days; you just take your time to do these activities
- On the bad days you have a quick wash at the sink and wear loose fitting clothing such as jogging bottoms and t shirts
- You are able to climb up and down the stairs about twice a day using the hand rails; however, if it is a bad day you would just manage to go downstairs and remain there for the entire day; you use the downstairs bathroom and sleep on the sofa in the lounge on the bad days
- On average days you are able to make light snacks for yourself and can manage a simple meal such as pasta and sauce; you may be able to peel a few vegetables but never enough for a full meal
- You are able to load and unload the dishwasher; you are careful to make sure you grip the items well as you sometimes your grip is affected by the pain
- You manage about 15 – 20 minutes of light housework such as dusting; and are able to change the sheets and pillow cases on the bed; you never change the duvet cover as you find this too painful and have to manage lots of buttons or clasps if doing so
- You tried vacuuming with a lightweight cordless vacuum, but the most you manage is one small room or half the lounge due to pain and fatigue– so your sister / partner does all the heavy housework including the laundry
- You would never attempt housework in the late afternoon as you find the fatigue is worse then
- On bad days you are unable to manage any housework or kitchen activities as you find you risk dropping things due to pain; you are not able to hold on to use the handrails making it unsafe to use the stairs
- You sit for about 30 - 40 minutes at most for activities such as watching the TV or using the tablet to view things online; you cannot manage longer than this as you get too stiff and the pain worsens; you have to get up and move around to stretch the legs
- You are able to use the remote to select channels; you can use the touch screen on the tablet to type short e mails but you never spend more than 5 minutes typing as this makes the fingers sore even if you use the keyboard in the tablet case
- On a bad day after sitting for about 30 minutes you just lay down on the sofa as getting up to stretch and move around is too much
- You are able to walk slowly to the local shop or post office; you walk for about 5 minutes then take a break for about 5 minutes (sit at the bus stop) before

walking another 5 minutes; you manage this about 1 - 2 times a week on an average day only

- If you walk the full distance to the shop in one go, you find you get too fatigued and the pain intensifies and resulting in having to take a very long break for several hours after
- You select very quiet times if you have to go to the post office as you find it difficult to stand in the queue for more than 5 - 10 minutes; standing longer makes it even more difficult to walk back home
- You no longer use public transport as you can never guarantee that you will get a seat on the bus; so you get a lift or use a taxi
- You no longer walk around the supermarket, but instead accompany your partner / sister there and sit in the cafe while your sister / partner does the main shopping
- After dinner you watch TV or chat with your partner / sister before going to bed

Scenario 3 - History

The following case scenario is fictitious and has been solely designed to support learning activities.

25 year old female

MED 3 – Ulcerative Colitis

No other medical evidence on file / MSRS

Questionnaire – has indicated problems with the following physical functions – moving around and using steps; standing and sitting; manual dexterity; controlling your bowels and bladder - ticked multiple boxes (yes - weekly; yes – monthly; yes – less than monthly; yes – but only if I cannot reach a toilet quickly) also made comments in the free text box, “I cannot really tell you which one of the choices is best for my bowels as sometimes I can go weeks without an accident and at other times I just have accidents many times a week. I always have to be close to a toilet just in case.)

She wrote in free text box, “I always feel tired and low in energy”.

No problems with mental/intellectual/cognitive capabilities

Information at Assessment

Ulcerative Colitis

No other conditions

Ulcerative Colitis diagnosed 3 years ago. This was confirmed by tests and colonoscopy with biopsy. She is currently attending outpatient gastroenterology clinic on a regular basis - previously every 8 weeks but more often recently as she commenced Infliximab infusions and has had 2 doses already. She is due for her third dose in 2 weeks time. She is awaiting an appointment with the dietitian from the gastroenterology team as she has lost lots of weight over the last year.

After initial diagnosis, she was using azathioprine tablets to help control the condition. However, even with this she was getting 2 - 3 bad flare ups per year each lasting about 2 - 3 weeks and she required hospitalisation for several days for hydration and steroids. Her last severe flare up was 4 months ago. After that, she agreed to commence biological therapies as she was initially reluctant to start this type of treatment or have surgery. She is unsure if the infusions will stop the frequent stools; but she has not had a very bad flare up since starting the infusions. However, she still gets bouts of diarrhoea and may need to empty her bowel anything between 3 to 4 times in a day and has to remain close to the toilet. This is a slight improvement on her previous average non-flare up day when she would have between 5 - 7 stools per day. Even during the average days, she still has one or two accidents a month requiring a change of clothing. Bad days are mainly associated with flare ups. During the bad flare ups, she would have diarrhoea more than 10+ times daily with blood and mucus in her stools. She would have bowel accidents

within the week resulting in soiled clothing despite using pads supplied by the nurse.

She also gets abdominal pain. This is worse on bad days when it is usually constant and makes it difficult to do activities. During the average day, the abdominal pain is present mainly with less intensity, but may get a bit more prominent just before a bowel movement. The pain in itself does not stop activities during the average day, but the constant fatigue from the condition makes it difficult to do activities. She tries to balance her energy by doing things in small bits and taking breaks to rest. However she can never tell what her energy reserves would be like for a given day as sometimes even with careful planning, the simplest task can leave her feeling drained. This is especially pronounced on bad days when she feels really drained of energy and weak. She does not think her poor appetite helps the overall situation.

Over the last 2 years she developed intermittent pain and swelling in the joints of her feet and hand. This is especially pronounced around the bad flare ups and tends to last for up to 3 - 4 weeks. She was told this is related to her bowel condition and hopefully would settle once the bowel condition is controlled. Outside of the flare ups, the joint pain is less intense and does not really stop her from doing particular activities. During flare ups, the joint pain adds to the fatigue and makes it even more difficult to do activities especially walking for prolonged distances or grip things tightly.

Today is an average day.

Current medication

Paracetamol 2 x 500 mg tablets up to 4 times daily

Vitamin D and calcium supplements daily

Previously on other anti-inflammatory medication, but stopped these after medication review and commencing Infliximab infusions

Social and Occupational History

Got a lift to the assessment centre – journey took about 20 minutes.

She came into the interview alone – brother stayed in the waiting room.

She lives with her parents in a four bedroom house with one flight of stairs and bathrooms on both floors.

She last worked 3 years ago as a floor manager at a department store. Stopped working due to the ulcerative colitis. She is not currently working. She is currently doing an online accounting course requiring studying up to 6-8 hours a week.

Typical Day

She goes to bed around 9 pm most nights but may go to bed much earlier if she is feeling especially tired during the bad flare ups. During the bad flare ups, she gets up due to abdominal pain and needing the toilet. On the night of an average day, she rarely needs to get up due to having abdominal pain or needing the toilet. She wakes

up around 7.30 am. She gets out of bed on her own and usually goes to the bathroom to use the toilet within the first half hour.

She is able to manage all of her bathroom activities on her own; however, when she is having a bad flare up, she sits in the shower rather than stand as she finds standing for the usual 10 minutes to shower and wash her hair leaves her feeling exhausted. Added to this, she usually has to have multiple showers in the day if she has an accident during a flare up.

She manages to dress herself unaided all the time. She estimates it takes her about 15 minutes to get dressed and also brush/comb her hair on an average day. However, during a flare up she estimates it can take her about 45 minutes to get dressed and brush/comb her hair as she feels more tired and her joint pain makes it more difficult to manage; she takes a 10 -15 minute break midway within the 45 minutes.

She is able to use the handrails to manage the stairs at home outside of a flare up. She moved to the downstairs bedroom with an en suite bathroom as she was finding it too tiresome to climb up and down the stairs during a flare up.

She only manages to study on average days; even then the time she is able to spend varies. About half the time, she manages to sit and study for about 1 hour before feeling tired and needing a break. She lies down on the sofa during the break. On other days, this may be reduced to half an hour as she feels tired sooner. She finds the shorter study days usually follow other activities such as going out to the shopping centre or attempting housework. She has had to have extensions for assignments as a result. She also had to defer an online evaluation exercise during the last flare up. She was aiming to finish the online course within the usual 10 month period, however, due to the extensions and deferral, she has been given an extra 6 months to complete all the activities.

She likes to help keep the home clean and tidy and attempts some housework activities on one or two average days. She tries to pace herself doing this and does tasks for about 10 minutes and may be able to repeat doing lighter tasks for a similar time after taking a rest for an hour or so. She would do a bit of dusting and vacuum a room or two depending on the size; she never attempts a series of “heavy tasks” such as vacuuming and scrubbing the bath back to back as this would make her too tired. She tried this a few times and ended up having to go to bed and rest for a few hours.

She attempts some kitchen tasks and is able to make herself a quick breakfast. She is able to load and unload the dishwasher. She does not stand by the hob to make meals as she finds standing for more than 10 - 15 minutes repeatedly makes her very tired. Instead, she contributes by sitting to help peel and chop vegetables or measuring ingredients for her mum if she is baking.

She tries to eat about 5 small meals per day and drinks lots of water. During a flare up due to the abdominal pain, discomfort and feeling lethargic, she finds it difficult to manage the 5 small meals even if she sticks to a low residue diet as advised.

Wherever she goes, she makes sure she knows the location of the toilets. If a toilet is not likely to be readily accessible, she avoids the location if at all possible. Otherwise she may have to really restrict her eating and fluid intake in an attempt to reduce the chance of needing the toilet. However, this does not always work for her and also leads to her feeling more tired. She no longer goes to the park for walks as there is no readily accessible toilet. Similarly, she no longer goes to the cinema as she is concerned she would be unable to make it to the toilet on time if needed.

She called ahead to the Assessment Centre to ask about toilets before confirming her appointment.

She visits the shopping centre about twice a month on an average day. She never attempts this on a bad day. She gets a lift there to avoid taking the bus as the local service is not reliable and she may end up having to stand 15 – 20 minutes at the bus stop after walking there. She knows the shopping centre well as she worked there and knows where the toilets are. She tends to avoid going at weekends as the centre is busy and the toilets may be in use. She has had to use these on several occasions when out shopping and has had some close calls and also had a few bowel accidents at weekend shopping trips.

She carries wipes and a change of clothes whenever she goes out. She walks for about 5 -10 minutes at a slow pace shopping and browsing before taking a rest for about 5 minutes on one of the benches. She then gets up and resumes shopping keeping to the alternating pattern of walking and resting but makes the walking time shorter and shorter before resting. She only stays for about an hour in the shopping centre as she knows if she tries to stay much longer she would get very exhausted.

On the average day, before going to bed she spends the evening sitting watching TV in the living room and chatting online with friends. She manages to sit for about an hour or hour and a half, unless she needs to get up to go to the toilet or go to the kitchen for a drink. On a bad day, she may forego watching TV in the living room and lie in her bed just to watch the news highlights as she feels too tired and may be having abdominal pain.

Scenario 4 – History & Examination Findings

The following case scenario is fictitious and has been solely designed to support learning activities.

28 year old male

MED 3 – Psychosis

No other medical evidence on file / MSRS

Questionnaire – no problems with any of the physical functions.

Mental/intellectual/cognitive capabilities: has indicated problems with awareness of hazards or danger; starting and finishing tasks; coping with changes; going out; coping with social situations; and behaving appropriately.

He made the following comment in the free text for starting and finishing tasks: “I can do some things but it all depends on my mood. My mood varies and sometimes I get very restless. This affects my behaviour and how I do things; sometimes I lose focus and may damage things or have an accident. My family help me from day to day.”

Information at Assessment

Psychosis

No other conditions

Fourteen months ago he was admitted to the mental health unit under section for 6 weeks due to a psychotic episode. He was hallucinating hearing multiple voices, agitated and pacing around the town centre. He was also suicidal and had a stock of tablets and alcohol when he was sectioned. This was his first psychotic episode. He was homeless for several months at the time, but now lives with his uncle and two cousins. He is currently seeing the Early Intervention Team every 4 - 6 weeks and is due for a family conference and care plan review at his next visit. He was told he probably has underlying schizophrenia but the diagnosis is not confirmed as yet. He was using cannabis regularly in the three years prior to the psychotic episode but he stopped after the admission.

He prefers to describe his weeks as bad and average rather than good. His mood varies over the weeks, and the best estimate of a pattern is a lowering of mood over a 6 - 8 week period or so; the bad episodes may last for just over a week but often extend to about two. During the average week, although his mood is low, he is usually motivated to do things. During the bad weeks, he feels so low he is not motivated to do things and needs encouragement from his uncle or cousins to do basic self care tasks daily. He does not know what triggers these bad days. During the bad weeks, he is even more reluctant to speak with strangers and would isolate himself. If pressed to engage with people he gets anxious and agitated but not physically or verbally aggressive.

He does not hear voices anymore, but always feels suspicious of strangers; this makes him restless and anxious. During the bad weeks, this is worse and as a result he tends to isolate himself and only keeping in contact with close relatives. He was unable to say exactly why he feels suspicious but does not think the strangers want to physically harm him.

His memory is not as sharp as before; however, he tries to make notes of things and uses reminder sticky notes to help. He thinks the concentration is more of a problem. His concentration is always poor. He sometimes finds himself drifting off in thoughts but denies any hallucinations. He just thinks he loses focus. He is unsure how many times in a day this may happen, but it happens most days and results in him being slower at doing any task. His cousin estimates it takes him about twice as long to complete the task if he attempts it. They keep an eye on him when he is doing some kitchen activities.

He has had no further thoughts or plans of self harm since.

Today is an average day.

Current medication

Quetiapine 300 mg twice daily
No side effects reported

Social and Occupational History

His cousin gave him a lift to the assessment centre – journey took about 20 minutes. He attended the interview with his cousin. He lives with his uncle and cousins. He last worked 3 years ago as in the ticket office at a mainline station as a customer service representative. He got sacked due to misconduct. He is currently not working or studying.

Typical Day

On the average week, he goes to bed between 10 pm and midnight and gets up between 7am and 8am. He usually sleeps well unless he has an appointment the following day and has to leave home. He tends to think about the appointment and this may result in him getting up in the middle of the night. He gets up on his own with no encouragement from his relatives. However, this pattern changes during a bad week as he tends to go to bed much earlier and usually requires prompting and encouragement to get up, get washed, have food and his medication due to poor motivation. During the average week, he does not usually require such prompting as he is more motivated to do activities and manages to get around to getting washed, select appropriate clothing and get dressed, and eat in a reasonably timely manner; he also remembers to take his own medication.

He copes by keeping a list of daily tasks to complete. He knows his mood tends to be lower in the morning, so he makes sure he checks his list by mid morning to make sure he is keeping on track. However, he is unable to manage this in the bad weeks despite having his usual list.

During the average week by mid morning he usually makes toast and uses the kettle to make a cup of tea for himself at breakfast as his mood starts to lift a little. Some mornings he also microwaves oats from a packet for breakfast. He previously did a regular fry up at the weekend, but he no longer does this as he got distracted and forgot the pan on the hob a number of times setting the smoke alarm off. He stopped using the hob on his own 8 months ago. He is aware he must wait until his cousin is in the kitchen to use the hob. His cousin confirmed that on occasions he still has to remind him to watch the pan as he sometimes just loses focus and wanders off. This does not happen on every occasion but he estimates it may happen one weekend in the month. Outside of the average week, he does not do any activities within the kitchen.

He likes to read novels and does so during the average week. Years ago, he would be able to sit for hours and read a novel within a few days. Now he finds he cannot sit for more than half an hour or so at a time to read a novel so it takes him about 2 weeks to complete a novel. He finds he loses focus and then has to re-read segments if he tries to read for longer periods. He is able to order books online and opts for the electronic version to read on his tablet once the electronic format is available. If he has to get a printed copy, he makes sure the order is delivered when one of his relatives is at home as he finds answering the door and speaking to the delivery driver makes him anxious. His cousin clarified that this anxiety is not only with delivery drivers, but anyone knocking at the door unexpectedly or any stranger who has to come to the house. Relatives tend to visit about twice a month and stay for dinner; he joins them if he is having an average week. However, if one of his cousin's friends visits, he gets anxious and goes to his room even if his cousin tells him about the visit beforehand.

Due to his anxiety, he is unable to go to new places on his own and only goes out alone in his local area. About 3 days in the average week, he walks locally along the canal towpath. He never speaks to strangers along the route even if someone attempts to say hello. He may also walk to the small local metro supermarket, but he only uses the self service checkouts as he is too anxious to speak with the staff there. His cousin clarified the staff at the supermarket are hardly ever the same so he never got accustomed to them and he would leave rather than ask for assistance if he was unable to find an item.

One of his relatives accompanies him to all appointments. He usually gets a lift as he gets stressed taking public transport with strangers. If the time of his appointment changes on the day or it is postponed unexpectedly with only a few hours notice; this upsets him and causes him to become anxious and restless and may take him a few hours to calm down. This has happened on two occasions over the last 4 months with the CMHT appointments. Both appointments were rescheduled for the following

week and he managed to attend once he eventually calmed down and was prepared for the new appointments. He is generally ok signing in and dealing with receptionists at the GP surgery or at the mental health team as he is familiar with them.

However, if he has to go to converse with new people he finds it very hard to manage and gets anxious about it. His cousin helped him sign in at reception today and had reassured him about the assessment in the days prior to today. Beforehand, he agreed with his cousin to chat at the interview and ask his cousin for help if he was getting stressed. His cousin confirmed it would take him a long time and several visits seeing the same person before he would attempt interacting and chatting on his own. That was one of his concerns for the visit today. Despite the reassurance, his cousin reported he was more restless and anxious than usual, although overall, it is an average week otherwise.

As part of his daily check list task, he would read any correspondence and any expected mail on his own. If he needs to call a business place and speak to a stranger, his cousin does this on his behalf.

In an average week, after dinner, he takes his evening dose of medication and then sits and chats with his uncle or watch TV for about half an hour. He prefers old situation comedies as he finds it easier to follow these; he finds it difficult to follow the plot for dramas and longer programmes. During the bad weeks, he would not watch TV during these periods as he prefers to stay in his room.

Mental State

Casually dressed, well kempt

Reduced eye contact and facial expressions

Speech: quiet voice, normal rate and content, in short sentences

Difficult to establish good rapport as remained tense throughout the assessment and had to seek reassurance from his cousin throughout

Noted to be fiddling with his fingers and was a bit sweaty even though it was not a warm day

General cognition: concentration was reasonable although he required some prompting to provide answers; orientated in time, place and person; adequate memory

No self harm ideation at interview

Good insight – knows he is unwell and the condition impacts on his function

No disrupted thoughts or perception at interview

Managed to calculate £1 -75p

Managed to register 3 items and recall all 3 after 5 minutes

Although completed slowly, he managed 3-stage command

Able to spell 'world' backwards

Declined serial 7s subtraction (said this would be too difficult and stress him as does not like maths) but was able to manage days of the week in reverse order

Noted to walk hesitantly from the waiting room to the assessment room and needed reassurance from his cousin

Appendix C - Learning Experience and Reflections Note (LEARN form)

Name:

Activity Completed:

Activity Date:

Time Spent on Activity:

Venue:

Why did I engage in this learning activity?

(Consider any particular learning need you identified etc)

What are my key learning points from this activity?

(Consider knowledge, skills, attitude and behaviour etc)

How will I apply this learning to my role?

(Consider value added to your skill set and professionalism)

Are there any other learning needs identified due to this activity?

(Consider points to clarify, further study etc. Also consider adding how when and where you plan to address the other learning needs.)

To access an electronic version of the form please click on the icon:



Appendix D - Level 1 and 2 Evaluation Form

For use only when electronic completion is not possible.

Participants Name:		Base Location:															
Event Title:		Date Attended/Completed:															
1. Were the event/distance learning product objectives met?	Please tick a box below																
	Yes		No														
2. How enjoyable was the event/distance learning product?	Very	Moderately	Not at all														
3. How relevant was the event/distance learning product to your role?	Extremely Relevant		Not at all Relevant														
	↓ Please circle a number below ↓																
	1	2	3	4	5	6	7	8	9	10							
4. (a) Was this the right learning tool for you i.e. trainer led/distance learning for this particular development?								Yes		No							
(b) If you have answered NO please comment.																	
5. Please list at least two key learning points.																	
6. Describe how you will apply this learning to your workplace.																	
7. Describe what you or anyone else could have done to make the event/product more effective.																	
Suggested Improvement(s)								Responsibility									
8. Standard of the facilitator (trainer led events only)								Very good		Good		Adequate		Poor			
9. Indicate your overall rating for the event/distance learning product								Very Effective		Effective		Ineffective					
								↓ Please circle a number below ↓									
								1	2	3	4	5	6	7	8	9	10

To be returned to the local Training Support Manager on completion.

Observation form

Please photocopy this page and use it for any comments and observations on this document, its contents, or layout, or your experience of using it. If you are aware of other standards to which this document should refer, or a better standard, you are requested to indicate this on the form. Your comments will be taken into account at the next scheduled review.

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