Disability Support Pension Impairment Tables Questionnaire

Response: 213

Emerge Australia

11a Select the key theme of the proposed changes to the Impairment Tables that is the most important to you

Fatigue

11b Select the theme of the proposed changes to the Impairment Tables that is the second most important to you

Fully diagnosed, treated and stabilised (FDTS) requirement

11c Select the theme of the proposed changes to the Impairment Tables that is the third most important to you

Medical evidence requirements

12a (i) The removal of the term 'permanent condition' provides greater clarity that a condition must persist for two years as part of the DSP eligibility criteria

Agree

12a (ii) The proposed changes more clearly describe the requirements of diagnosis, treatment and stabilisation of conditions for DSP assessment

Strongly disagree

12b Please provide any additional comments regarding changes to the FDTS requirement

Emerge Australia strongly supports the change to this definition. While most patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) are severely disabled by this disease for their entire lives, a lack of research funding means supporting data is minimal. This change acknowledges fluctuating conditions and sets expectation of assessors that individual does not need to have undertaken every single treatment.

The ongoing issue people with ME/CFS face is getting diagnosed in the first place. It is common for it to take 2-5 years for a diagnosis, and for many people it takes a lot longer. For these people, how do they get support? Also, will people need to prove they're still eligible every two years?

13a (i) The inclusion of additional defined terms provides greater clarity around terminology used in the Instrument

Agree

13a (ii) Simplification in Part 2 of the Instrument improves the guidance and readability of the section

Agree

13a (iii) The proposed changes to Table introductions and descriptors has made it easier to understand the requirements of Tables

Strongly agree

13a (iv) The additional guidance in appropriate Tables provides greater clarity when considering functional impairment. For example an additional guidance point to all Tables on fluctuating and episodic conditions

Strongly agree

13a (v) The updating of references to relevant assistive technology provides clearer guidance and modernises the Tables

Agree

13a (vi) The broader range of examples in the Tables illustrates how a person's functional impairment may impact their ability to work

Strongly agree

14a The proposed changes recognise and capture the functional impacts relating to alcohol, drug and other substance misuse in appropriate Tables

Strongly agree

15a The addition of guidance recognises the impacts of ongoing side effects from prescribed medication and treatment

Strongly agree

16a (i) Proposed changes better represent the functional impact of pain

Agree

16a (ii) Additional examples of pain related conditions that result in functional impairment provide more clarity around the types of conditions that may be assessed against a Table

Strongly agree

16b Please provide any additional comments regarding changes about pain.

Chronic pain and fibromyalgia are common comorbidities for people with ME/CFS and Long COVID. We are pleased to see it included as an example of a condition a person may provide evidence for to be assessed under Table 1.

17a Additional examples of chronic illnesses that result in functional impairment provide greater clarity around the types of conditions that may be assessed against a Table

Agree

17b Please provide any additional comments regarding changes about chronic illness.

Emerge Australia is pleased to see ME/CFS recognised as an illness in tables 1 and 6. We urge the department to implement training in using the new impairment tables for conditions like ME/CFS, related to physical stamina. This extends to the new patient cohort, those with Long COVID, who also experience PEM.

We raise this concern, because our patient community have told us about the ongoing misunderstanding or disbelief some DSP assessors have about ME/CFS. There are two areas we specifically highlight:

"Assigning an impairment rating": This rating should focus on whether the individual can perform the activity repetitively, not just once. PEM means a person who can perform and activity one day, may not be able to repeat this the next day, or the day after that. However, many people with ME/CFS have their DSP applications rejected because the impact of PEM on their capacity to undertake activities regularly is not fairly considered. Additionally, it is critical that an assessment of ability includes meeting basic daily needs. Such as, a person may be able to sustain clerical work for 3 hours a day, 5 days per week but lacks the capacity to also shower, or cook a meal.

"Assessing episodic and fluctuating conditions": Impairment rating should assess overall impact of the condition. Currently, people with ME/CFS are often unfairly assessed based on their best days, not their overall functioning and impact of PEM over the week.

18a Additional examples of renal conditions that result in functional impairment provide more clarity around the types of conditions that may be assessed against a Table

Strongly agree

19a (i) Additional examples of fatigue related conditions that result in functional impairment provide greater clarity around the types of conditions that may be assessed against a Table

Strongly agree

19a (ii) The inclusion of a personal care descriptor captures the functional impacts of fatigue on a person's ability to undertake personal care activities

Strongly agree

19a (iii) Proposed changes better represent the functional impact of fatigue related conditions

Agree

19b Please provide any additional comments regarding changes about fatigue.

As the national patient organisation for people with ME/CFS and Long COVID, we are extremely pleased with all of the changes to this 'Fatigue' section. Recognition of post-exertional malaise (PEM) is an important step to obtaining support for more people from our community. This change will help assessors recognise that ME/CFS is a legitimate condition and PEM is a disabling symptom. It will also help the Long COVID patients who are starting to become eligible for DSP, some having been sick for two years already.

We responded "disagree" to question c for two reasons. These reasons also closely relate to the comments we made in response to Q17, about training to fairly and accurately assess fluctuating conditions like ME/CFS.

First, the examples provided for 'mild' functional impact may not reflect the capacity of some 'mild' people with ME/CFS. This is because, for people with ME/CFS, the accepted definition of 'mild' is up to 50% of pre-illness functioning. Even a 'mild' patient can be significantly impacted by this disease. Further, due to the fluctuating nature of the disease, some people may move between categories from day to day, or week to week. Further clarification should be provided about activity expectation, consistency of activity and safety when performing the activity.

Second, although post exertional malaise is listed, the wording could be improved. We suggest "or mild post-exertional malaise, [during or after] performing physically demanding activities". We suggest this change because PEM, and its associated loss of capacity due to increased symptoms, can be delayed for up to 72 hours after activity.

We note that "treatment" is listed as one of the details required in a report from the medical specialist. There are no proven treatments for people with ME/CFS. Graded exercise therapy and cognitive behaviour therapy were recommended as treatments in the past, however these have since been proven ineffective and potentially harmful.

Further, calling ME/CFS a fatigue-related illness perpetuates misunderstanding of what this disease actually is. ME/CFS is a multi system disease, with the hallmark symptom of post-exertional malaise. PEM is not just fatigue, but an exacerbation of all symptoms including brain fog, pain, orthostatic intolerance, etc.

20a Additional examples of cancer and subsequent conditions that result in functional impairment provide more clarity around these types of conditions that may be assessed against a Table

Strongly agree

21a (i) Additional examples of specific pieces of evidence that may be used to support a claim assists individuals to identify the accepted range of medical evidence that can be provided

Strongly agree

21a (ii) Additional examples of professionals assists individuals identify the range of appropriate practitioners who are able to provide medical evidence in support of their claims

Agree

21b Please provide any additional comments regarding changes to medical evidentiary requirements.

Emerge Australia broadly supports the changes to medical evidentiary requirements. In particular, actimetry linked blood pressure and heart rate monitoring will help provide evidence of PEM.

However, often patients are asked for a specialist report but ME/CFS does not belong to a specialty, and there are few specialists trained and knowledgeable enough to assess. By comparison, the proposed Impairment tables will allow reports from generalist psychologists (rather than only clinical psychologists) as accepted evidence for impairment under mental health table, recognising their skills and training. Similarly reports from GPs with skills and training in ME/CFS should be acceptable.

In addition, accepted reports from Occupational Therapists are expensive, a cost that is often out of reach of our patient community.

We note that much work still needs to be done with the medical community – including all of those professions added to this list – to educate them about how to diagnose ME/CFS. Research suggests up to 90% of people with ME/CFS are undiagnosed. Even for those who do obtain a diagnosis, disbelief and stigma remains in the medical community about the existence of the disease, and the severity of symptoms and disability.

22a (i) Addition of descriptors better capture shoulder function in Table 2 - Upper Limb Function

Unsure

22a (ii) The addition of descriptors for the loss of function of a dominant limb under Table 2 – Upper Limb Function better recognises functional impacts of losing a dominant upper limb

Unsure

22a (iii) Additional examples of specific skin conditions that result in functional impairment provide more clarity around the types of conditions that may be assessed against a Table

Unsure

22b Please provide any additional comments regarding changes about musculoskeletal and skin functions.

People who have ME/CFS and Long COVID should be included in this category. There is some evidence that this group of patient experience reduced cardiac output that worsens when standing for a period of time, thus impacting their capacity to safely use their lower limbs for mobility.

Emerge Australia would encourage that ME/CFS and Long COVID be included in this table. Below is a suggestion for examples to include in each section:

Mild - stand unsupported in a line at the shops for 15-25min

Moderate - noticeable increase in heart rate or decrease in blood pressure after 8minutes of standing

Severe – an increase in heart rate or decrease in blood pressure after 3-8min Extreme – a significant increase in heart rate or decline in blood pressure within the first three minutes of standing.

23a The proposed changes better capture the functional impacts of balance, dizziness and a person's ability to stand

Disagree

23b Please provide any additional comments regarding changes about balance.

There is inconsistency in the way different disabilities are treated in tables 1 & 3. We acknowledge other criteria need to be met for both tables, but the inclusion of wheelchair or other assistive technology (AT) in table 1 isn't included in table 3 in the same way.

Comparing 20 points on Tables 1 and 3, if a person with ME/CFS can't walk around the shops, but they can mobilise around the shops if they have a scooter or wheelchair, then they don't meet the definition of a 20-point impairment rating on Table 1. The AT is a necessary mobility aid due to their disability, and they can't manage without it. The same qualification isn't made for a person with a lower limb disability in Table 3. Including wheelchair/AT in Table 1 is indicating that, if the person's limitations are at least partially overcome with a wheelchair, then they're not impaired. This is inconsistent, and biased.

The impairment should be that the person can't walk around without needing rest, assistance or AT.

24a The proposed change will better support individuals by providing a broader range of medical professionals allowed to provide corroborating evidence in support of a diagnosis of a mental health condition for assessment under Table 5 – Mental Health Function

Strongly agree

25a The proposed changes improve alignment with other recognised mental health assessment tools (including the World Health Organization Disability Assessment Schedule –WHODAS, Diagnostic and Statistical Manual of Mental Disorders – DSM, World Health Organization International Classification of Diseases - ICD)

Strongly agree

26a (i) Proposed changes better reflect conditions on the spectrum of neurodiversity

Strongly agree

26a (ii) The addition of a new social skills descriptors in the table relating to brain function recognise difficulties a neurodivergent person may experience in social situations

Strongly agree

26b Regarding the proposed change on Table 6 – Brain Function to better recognise social skills difficulties, would you prefer to:

keep the current list of descriptors and require a person to meet only one descriptor for the relevant impairment rating to be assigned

27a The proposed changes better recognise the need for culturally appropriate assessments

Strongly agree

28 In accordance with the Privacy Collection Notice, please select one of the following.

I would like my submission to be published with identifying information (including name or name of organisation as provided in the questionnaire)