Senate Community Affairs References Committee

Inquiry into Disability Support Pension

SUBMISSION

ME/CFS Australia Ltd

30 July 2021

Contents

Executive Summary

The historical experience of ME/CFS and the Disability Support Pension is somewhat chequered and riddled with systemic barriers.

The DSP system is one that is dependent upon the assumption that medical and healthcare system is functional, knowledgeable and available to people with conditions that are disabling.

In the context of ME/CFS, the DSP system assumes practitioners have the knowledge, competence, desire and availability to assist applicant with ME/CFS of all degrees of severity and circumstance. Additionally, it assumes that those who have ME/CFS comprehend the DSP requirements and the financial means to provide the medical evidence. It also assumes that someone with ME/CFS can actually leave their premises to do what needs to be done.

Unfortunately, the reality is that none of the above assumptions are remotely true. Moreover, the DSP operates on the basis of a ME/CFS policy that has always been flawed and is simply not reflective of the reality of the condition, or the contemporary medical thought.

ME/CFS Australia’s main points are:

- There are inherent barriers unique to ME/CFS that prevent applicants with a genuine disability from demonstrating their disability and accessing the DSP;
- The policy and understanding of Centrelink is not fit for purpose and requires updating in conjunction with the peak body;
- There is a genuine need to provide a system of access that allows for the unique circumstances of ME/CFS, particularly those who are bedbound and housebound;
- There is a need to revise Table 1 to better describe and capture the Post-Exertional Malaise component of ME/CFS;
- There is need to remove the differentiation between under and over 35’s;
- There is a need to remove the differentiation between 20 points in one Table or across multiple Tables;
- There is a need to increase the rate payable under the DSP, particularly in the context of the Covid 19 pandemic;
- There is a need to improve the scope and funding of Medicare to enable access to medical treatment;
- There is a need to improve accessibility to the NDIS to improve the support of people with ME/CFS;
- There is a need to provide a rate that reflects Australia’s obligations to protect the various rights guaranteed under various Conventions, such that people have quality of life, dignity and the ability to afford to remove themselves from violent and/or abusive relationships;

ME/CFS Australia has enclosed 26 key recommendations below and relies upon those submissions.

Kind regards

Geoffrey Hallmann *BBus(Hons), LLB(Hons), DipLegPrac, DipFinPlan*
Chair - ME/CFS Australia

ME/CFS Australia Ltd
ABN: 23 088 896 299
ACN: 088 896 299
Postal: PO Box 6176, Upper Mount Gravatt QLD 4122
Registered Office: 13 Forestoak Way Goonellabah NSW 2480
Email: info@mecfs.org.au **Website:** www.mecfs.org.au

Summary of Recommendations

ME/CFS Australia make the following recommendations:

(1) **Recommendation 1** –The DSP rate should genuinely comply with Australia's obligation to allow people with a disability to have a decent level of living, such that it allows access to medical care, housing, participation in society, quality of life and human dignity.

(2) **Recommendation 2** – The DSP process needs to be simplified so that it is understood by applicants and doctors alike, removes barriers to application, and provides realistic time frames (with backdated benefits).

(3) **Recommendation 3** – The Department of Social Security should engage with the peak body for ME/CFS to update their policies and understanding of ME/CFS to reflect contemporary medical knowledge.

(4) **Recommendation 4** – The Department of Social Security should utilise Independent Examiners who have an up-to-date comprehension of ME/CFS based upon the current accepted criteria and evidence base.

(5) **Recommendation 5** – The Department of Social Security should remove any requirement for treatment for ME/CFS – particularly Graded Exercise Therapy and Cognitive Behavioural Therapy.

(6) **Recommendation 6** – The Department of Social Security needs to provide funding to applicants to enable them to gather the necessary medical evidence in accordance with the Tables.

(7) **Recommendation 7** – The Department of Social Security needs to provide a system of assessment for housebound and bedbound applicants who cannot otherwise access the necessary requirements of the system.

(8) **Recommendation 8** – The Department of Social Security needs to provide ME/CFS specific training to staff members, medical assessors and health care assessors, so that the disability can be properly and fairly assessed.

(9) **Recommendation 9** – The Department of Social Security needs to engage with the peak body in order to formulate an up to date policy with respect to ME/CFS (with regular reviews).

(10) **Recommendation 10** – The Department of Social Security needs to provide access to advocates to assist people to engage in the review process.

(11) **Recommendation 11** – The Department of Social Security needs to provide access to funding for legal representation in all tiers of the AAT.

(12) **Recommendation 12** – The Department of Social Security needs to provide an alternative pathway of assessment for those in rural and isolated communities with limited or no access to medical services.

(13) **Recommendation 13** – The Department of Social Security needs to scrap the requirements for under 35's with respect to ME/CFS.

(14) **Recommendation 14** – The Department of Social Security needs to scrap the differentiation between 20 points across 1 Table and 20 points across multiple Tables.

(15) **Recommendation 15** – The Department of Social Security needs to scrap the Program of Support requirements for ME/CFS.

(16) **Recommendation 16** – The Department of Social Security needs to refine Table 1 to ensure that better descriptors are provided to capture Post Exertional Malaise and other ME/CFS functional characterics.

(17) **Recommendation 17/22** – The Department of Social Security should allow 178 working credits to carry over each week in order to all those who are boom/bust earners to have the same deduction free threshold as those who can work regular part time work.

(18) **Recommendation 18** – The Department of Social Security needs to allow those on the DSP who work, a greater proportion of the monies they earn to incentivise increased work hours where capable.

(19) **Recommendation 19/21/23** – The Department of Social Security needs to review the current rate of the DSP to bring it into line with the real cost of living and real needs of individuals.

(20) **Recommendation 20** – There is a need for incentives to be provided to employers to encourage them to facilitate variable hours and enable them to limit disruption to their businesses from absences.

(21) **Recommendation 24** – The NDIS needs to improve the assessment process for ME/CFS to enable those with the condition who meet the criteria, access to the system.

(22) **Recommendation 25** – The Medicare system needs to improve in order to facilitate lower gaps payments so that people with ME/CFS can access medical doctors, investigations, tests, imaging and care plans.

(23) **Recommendation 26** – The Department of Social Security should adhere to the rights and obligations under the various Conventions to which Australia is a signatory, and provide a DSP that is sufficient to ensure dignity and quality of life, as well as the ability to protect one's self from abusive and exploitative relationships.

About ME/CFS Australia

ME/CFS Australia is the peak body representing all people in Australia living with or affected by ME/CFS. One of our key goals is to influence national healthcare decision makers to improve the care, disability services and treatment of people with ME/CFS.

Our members are ME/CFS organisations in Australia, primarily comprising the state ME/CFS organisations.

Every state and territory ME/CFS association has a director seat on the board open to them to participate in the decision-making of the national body. ME/CFS Australia works with these organisations in moving the national agenda forward.

ME/CFS Australia Ltd is a not-for-profit organisation, a registered charity and has Deductible Gift Recipient (DGR) status. We were formally incorporated in 1999.

Our current member organisations are as follows.

- ME/CFS & FM Association NSW, Inc. – state member organisation for New South Wales
- ME/CFS/FM Support Association Qld, Inc. – state member organisation for Queensland
- ME/CFS South Australia, Inc. – state member organisation for South Australia
- ME/CFS and Lyme Association of WA, Inc. – state member organisation for Western Australia
- Bridges & Pathways Institute – located in South Australia
- Far North Coast ME/CFS Association – located in New South Wales

About ME/CFS

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (‘ME/CFS’) is a severe, complex, acquired illness with numerous symptoms related mainly to the dysfunction of the brain, gastro-intestinal, immune, endocrine and cardiac systems. ME has been classified as a neurological disorder in the World Health Organisation’s International Classification of Diseases since 1969 (ICD 10 G93.3).

Symptoms include overwhelming post-exertional malaise from mental or physical activity; dysfunctional sleep; pain; neurocognitive dysfunction; problems with memory; visual issues; sensitivity to touch and sound; problems with standing and balance; problems with body temperature and weight; problems with circulation; neurological dysfunction; and recurrent flu-like symptoms;

The condition impacts children and adults.

ME/CFS affects up to 1% of the Australian population. The condition is permanent.

Our Experience

Our organisation and members have received numerous complaints from, and been involved in discussions with, applicants in the social security system. There are some distinct patterns of concerns about the approach of Centrelink to ME/CFS during the process of applying for and reviews of, the Disability Support Pension.

We draw upon that experience in providing this submission. We draw upon skills-based knowledge of the system and various investigations into the specifics of the scheme.

Terms of Reference

ME/CFS Australia acknowledge the terms of reference are as follows:

1. the purpose of the DSP;
2. the DSP eligibility criteria, assessment and determination, including the need for health assessments and medical evidence and the right to review and appeal;
3. the impact of geography, age and other characteristics on the number of people receiving the DSP;
4. the impact of the DSP on a disabled person's ability to find long term, sustainable and appropriate, employment within the open labour market;
5. the capacity of the DSP to support persons with disabilities, chronic conditions and ill health, including its capacity to facilitate and support labour market participation where appropriate;
6. discrimination within the labour market and its impact on employment, unemployment and underemployment of persons with disabilities and their support networks;
7. the adequacy of the DSP and whether it allows people to maintain an acceptable standard of living in line with community expectations;
8. the appropriateness of current arrangements for supporting disabled people experiencing insecure employment, inconsistent employment, precarious hours in the workforce; and inequitable workplace practices;

9. the economic benefits of improved income support payments and supports for persons with disabilities, their immediate households and broader support services and networks;

10. the relative merits of alternative investments in other programs to improve the standard of living of persons with disabilities; and

11. any related matters

Submissions

Purpose of the DSP

Obligations

The United Nations Office of the High Commissioner of Human Rights ('OHCHR") provides a summary of the various rights and intent with respect to the right to social security:

> *The right to social security is recognized in numerous human rights instruments, including the Universal Declaration of Human Rights and the International Covenant on Economic, Social and Cultural Rights and is crucial for guaranteeing a life in dignity. A fundamental human right, social security is a potent tool to combat discrimination and an essential instrument for reducing poverty and promoting social inclusion. It aims to provide income security and support at every stage of life for everyone, with particular attention to the most marginalized.*[1]

The OHCHR outlines that the essential aspects of this right include:

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[1] UN Office of the High Commissioner, 'OHCHR and the Right to Social Security', OHCHR, (Web Site, 1996-2021) <https://www.ohchr.org/en/issues/rightsocialsecurity/pages/socialsecurity.aspx>; The right to social security is recognized in numerous human rights instruments including the *Universal Declaration of Human Rights* (art. 22) and the *International Covenant on Economic, Social and Cultural Rights* (arts. 9 and 10). Article 11 of the *Convention on the Elimination of All forms of Discrimination against Women* recognizes the right to social security for women, especially in cases of retirement, unemployment, sickness, invalidity, old age or other incapacity. In addition, article 11 recognizes the right to paid leave. Article 26 of the *Convention on the Rights of the Child* recognizes the right of the child to social security and social insurance. Article 27 of the International Convention on the *Protection of the Rights of All Migrant Workers and Members of Their Families* sets out the right of all migrant workers to social security on an equal footing with nationals, as well as to reimbursement of contributions if they cannot access benefits. Article 28 of the *Convention on the Rights of Persons with Disabilities* recognizes the right of persons with disabilities to social protection without discrimination on the basis of disability and enumerates steps to be taken by States to safeguard and promote the realization of this right. See CESCR, general comment No 19.

- *Availability: A social security system needs to be in place under domestic law to* ***ensure that benefits are effectively administered and supervised****.*

- *Adequacy: Benefits, whether in cash or in kind, must be sufficient in quantity and duration so that everyone may realize his or her rights to family protection and assistance,* ***a reasonable standard of living and access to health care****.*

- *Affordability: Costs and charges associated with contributions to social security must be economical for all, and must not compromise the realization of other Covenant rights.*

- *Accessibility: A social security system should cover all persons, especially those belonging to the* ***most disadvantaged and marginalized groups, without discrimination****. Benefits should also* ***be physically accessible****.*

The Social Security Guide distils it down to a very basic statement:

> *DSP is an income support payment (1.1.I.80) for people who are unable to work (1.1.W.60) due to permanent physical, intellectual or psychiatric impairment*.[2]

From a human perspective, the DSP is the lifeline of all those who are, through no fault of their own, reliant upon it for their day-to-day existence. It is this latter consideration that should be at the core of comprehending the DSP. It pays for the absolute essentials of modern life:

- Food
- Utilities (Phone, Electricity, Internet, Gas)
- Rental Accommodation/Rates
- Household Expenses
- Travel/Transport
- Medical
- Health insurance
- Other day-to-day expenses

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[2] Australian Government, ‘ Guides to Social Policy Law: Social Security Guide”, *Department of Social Security* (Web Page, 1 July 2021) <https://guides.dss.gov.au/guide-social-security-law/1/2/5/10>.

The poverty line for Australia was $457.00 for a single person in 2020.[3] This was 50% of median income before deducting housing costs. The basic DSP for a single person is currently $434.15 per week.[4]

The purpose of the DSP has therefore been to provide a basic level of tax-free income to people with a disability.

The DSP does not allow a person with a disability to live dignity. There is no ability (for the majority) to normally participate in the economy through the usual means – home ownership, superannuation, private health insurance, savings, etc.

The current standing of the DSP falls well short of its true purpose of meeting our obligations to people with a disability, in accordance with out international obligations. The purpose should be to meet the obligations to which Australia has committed – particularly the *Declaration on the Rights of Disabled Persons*, which states:

> *7. Disabled persons have the right to economic and social security and to a* ***decent level of living****. They have the right, according to their capabilities, to secure and retain employment or to engage in a useful, productive and remunerative occupation and to join trade unions.*
>
> *8. Disabled persons are* ***entitled to have their special needs taken into consideration at all stages of economic and social planning****.*

Survey Feedback

ME/CFS Australia surveyed members of the ME/CFS community for the purpose of this submission. On the specific issue of the adequacy of the DSP to maintain their standard of living, 69.32% (n = 122/176) of the respondents agreed or strongly agreed that the DSP in inadequate to meet an acceptable standard of living (see: Figure 1 below).

Only 12.5% (n = 12/176) felt that the DSP is currently adequate.

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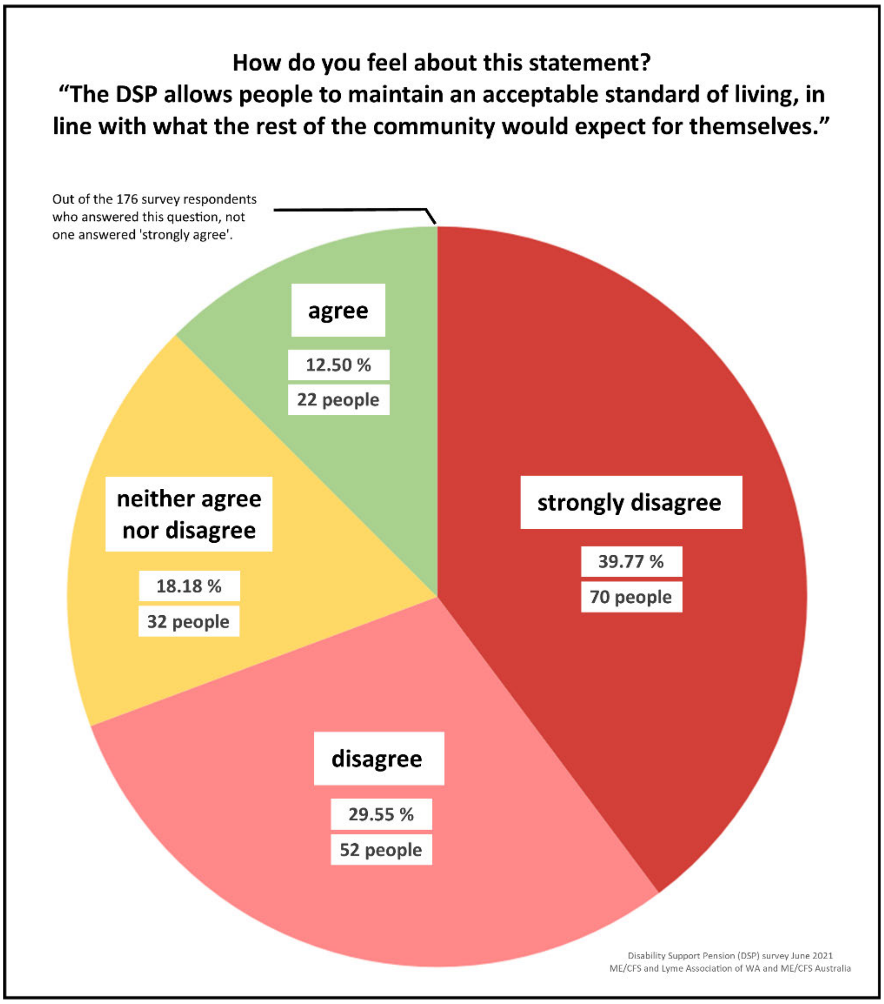
[3] P Davidson, P Suanders, B Bradbury and M Wong, 'Poverty in Australia 2020: Part 1, Overview. ACOSS/UNSW Poverty and Inequality Partnership Report No. 3', *ACOSS*, (Report, 2020) <http://povertyandinequality.acoss.org.au/wp-content/uploads/2020/02/Poverty-in-Australia-2020_Part-1_Overview.pdf>.

[4] Australian Government, 'Payment Rates', *Services Australia* (Website, 1 April 2021) <https://www.servicesaustralia.gov.au/individuals/services/centrelink/disability-support-pension/how-much-you-can-get/payment-rates>

Figure 1 – Appropriateness of



Out of the 176 survey respondents who answered this question, not one answered 'strongly agree'.

Disability Support Pension (DSP) survey June 2021
ME/CFS and Lyme Association of WA and ME/CFS Australia

<u>Consumer View</u>

> *I first obtained the DSP in 2001 when I was in my early 30's. No one expects to be of a disability pension. I barely had enough for accommodation and food. I couldn't afford my health insurance – which I really needed due to my condition.*
>
> *Being on the DSP meant that I was living hand-to-mouth every fortnight. My bills accumulated. I needed to see my doctor regularly and couldn't afford to. I needed medication and I couldn't afford that. I needed to see specialists and I could not afford it. I extinguished my saving, my superannuation and my credit cards to the point where interest was equivalent to a week's DSP. I couldn't repair the car when I needed to.*

> *My budget was always one unexpected bill away from disaster. I had no social life.*
>
> *My circle of friends diminished.*
>
> *The pressure of never making ends meet, the constant phone calls from private numbers chasing money, the inability to get medical care – it simply caused decline in my disability.*
>
> *At a time I am trying to improve my function to a point where I could work, the structural deficiencies of the DSP were causing me to decline. This was the opposite of what the DSP encourages people to do.*

Recommendations

Recommendation 1 – The DSP rate should genuinely comply with Australia's obligation to allow people with a disability to have a decent level of living, such that it allows access to medical care, housing, participation in society, quality of life and human dignity.

Intent

At the core of the DSP is the intent to provide Australians who have a bona fide disability that meets the criteria contained within the *Social Security (Tables for the Assessment of Work-related Impairment for Disability Support Pension) Determination 2011* ('the Tables'), access to a specific benefit (with attached allowances, tax benefits, supplements, medical support etc).

ME/CFS Australia submits that the system is so inherently prohibitive, it is failing to provide the intended support to those who need it, simply because the applicants cannot navigate the system.

Consumer View

> *I experienced difficulty meeting 20 points the first time I apply (sic) because they only gave a certain time to provide all evidence was unable to get a specialist letter in on time (no apmts etc) and when I applied the 2nd time this letter included and I met the 20 points criteria no issue*

Recommendations

Recommendation 2 – The DSP process needs to be simplified so that it is understood by applicants and doctors alike, removes barriers to application, and provides realistic time frames (with backdated benefits).

DSP Eligibility

Background

ME/CFS Australia has reviewed the past 10 years of Administrative Appeals Tribunal (‘AAT’) cases that have involved ME/CFS or CFS. Within that case law are dozens of cases where the applicant has a very clear case of ME/CFS but could not navigate the system in order to successfully raise and application. The primary reasons for failure were:

- Not fully diagnosed;
- Not fully treated;
- Not fully stabilised; and
- Not permanent;

Whilst these reasons for declination are not unusual in terms of the cases that come before the AAT with respect to the DSP, the cases do reveal a variety of ME/CFS specific issues that are acting as a barrier.

Some of these barriers include:

- ***Reasonable Treatment Misconception*** *- Assertions by Centrelink that Cognitive Behavioural Therapy and/or Graded Therapy are “reasonable treatment” within the definition of Section 6(7) required in order to demonstrate the condition is fully treated.*

  The criteria under Section 6(7) assert a treatment if reasonable if it “can **reliably be expected to result in a substantial improvement in functional capacity**”; “is regularly undertaken or performed”; “has a high success rate”; and “**carries a low risk** to the person”. Despite this requirement there has never been any study that demonstrates CBT/GET reliably results in “**substantial improvement**” or has “a **high success rate**”.

At its best GET (in a heavily flawed study[5]) reached the bar of "may" have some benefit[6] – no study has in the evidence base has ever shown "substantial improvement" or reliable "substantial improvement", nor ever had "a high success rate". Not one – EVER!

The most significant study relied upon (the 2011 PACE trial[7]) has been completely discredited because of misconduct in the presentation of the outcomes, effected by way of altering protocols to create statistical significance and misleading efficacy, where the application of the original protocol demonstrated no significant impact at all for both CBT and GET.[8]

The Cochrane review for GET removed that and other studies in 2019 and produced inconclusive, ambiguous results that don't come close to meeting Section 6(7).[9]

In 2020 these treatments have been walked back to the point of removal from recommendation from the UK and US.[10]

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[5] P.D. White, K.A. Goldsmith, L. Potts, et. al 'Comparison of Adaptive Pacing Therapy, Cognitive Behaviour Therapy, Graded Exercise Therapy, and Specialist Medical Care for Chronic Fatigue Syndrome (PACE): A Randomised Trial' (2011) 377(9768) *The Lancet* 823.

[6] Ibid.

[7] Ibid.

[8] T. Kindlon, 'Reporting of Harms Associated with Graded Exercise Therapy and Cognitive Behavioural Therapy in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome' (2011) 19(2) *Bulletin of the IACFS/ME* 59; T. Kindlon, 'Do Graded Activity Therapies Cause Harm in Chronic Fatigue Syndrome? (2017) 22(9) *Journal of Health Psychology* 1146; D.F. Marks, 'Treatment Harms to Patients with ME/CFS' (2021) Qeios; M. Vink, 'The PACE Trial Invalidates the Use of Cognitive Behavioral and Graded Exercise Therapy in Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: A Review' (2016) 2(3) *Journal of Neurology and Neurobiology* 1.

[9] L. Larun, K.G. Bruberg, J. Odgaard-Jensen, and J.R. Price, 'Exercise Therapy for Chronic Fatigue Syndrome', (2019) 10(10) *Cochrane Database Sys Rev* 1; M. Vink and A. Vink-Niese, 'Graded Exercise Therapy for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is Not Effective and Unsafe. Re-analysis of a Cochrane review' (2018) 5(2) *Health Psychology Open* 1; C. Wilshire, T. Kindlon and A. Matthees (2017). 'Can patients with Chronic Fatigue Syndrome Really Recover after Graded Exercise or Cognitive Behavioural Therapy? A critical Commentary and Preliminary Re-analysis of the PACE Trial' (2017) 5(1) *Fatigue BioMedical Health Behavior* 43.

[10] NICE, 'Guideline: Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and Management (Draft for Consultation)', *National Institute for Health and Care Excellence, London* (Guidelines, November 2020). <https://www.nice.org.uk/guidance/gid-ng10091/documents/draft-guideline> (NB Final Draft due 18 August 2021); Centres for Disease Control and Prevention 'Myalgic Encephalomyelitis/Chronic Fatigue Syndrome - Treatment', *CDC* (Website, 28 January 2021) <https://www.cdc.gov/me-cfs/treatment/index.html>; Bastian, H. (2021, May 31). Cochrane Exercise and ME/CFS Review Update: May 2021. Retrieved from Cochrane Community: https://community.cochrane.org/organizational-info/people/central-executive-team/editorial-methods/projects/stakeholder-engagement-high-profile-reviews-pilot/cochrane-exercise-and?fbclid=IwAR3jxwTRM0E4NaQaS0VYZ5n-yPgNrSiDb9OVE8iZrr5iuA21luf_J-lr-pw>; J.R. Price, E. Tidy, and V. Hunot, 'Editors Note (2021): Cognitive behaviour therapy for chronic fatigue syndrome in adults', *Cochrane Library* (Article, 2008).

With respect the consideration of whether a treatment “carries risks”, there is credible evidence that GET can cause harms,[11] hence should not be used at all as a treatment.

The most significant issue of concern is the fact among all the research carried out, none has been involve the severe to very severe ME/CFS cohort. These are the 25% of patients with ME/CFS who are housebound and bedbound – and the most likely to apply for the DSP.

Despite the fact there is no evidence base to support the use of GET on this cohort and absolutely no evidence base to suggest CBT has any effect on the condition – CBT and GET is being required

Aside from the waste of money – these requirement can potentially devastate the health of a person with ME/CFS permanently.

- ***<u>Fatigue Based Condition</u>*** *- Assertions by Centrelink that ME/CFS or CFS is disabling because of fatigue alone.*

  ME/CFS is a condition comprising multiple symptoms that cause disability in their own right. Post-Exertional Malaise (‘PEM’) is one of the most disabling – and comes on following activity.[12]

  In a number of cases there has been a claimant that has had another conditions that creates fatigue (eg Sleep apnoea or depression) that was not fully treated.

  Centrelink has consistently argued that the ME/CFS or CFS is not fully diagnosed because the other condition(s) required treatment in order to see if the fatigue from those conditions eliminated all fatigue before the diagnosis of ME/CFS could be upheld (even when the other conditions did not arise until after or as a result of the ME/CFS).

  Whether or not the fatigue is treated does not preclude the fact the remaining symptoms cause disability – yet claimants are unnecessarily declined.

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[11] Forward ME Group, ‘CBT and GET Survey Results Published by Forward-ME Group’, *MEAction* (Article, 2019) <https://www.meaction.net/2019/04/03/cbt-and-get-survey-results-published-by-forward-me-group/>.

[12] B.M. Carruthers, A.K. Jain, K.L. De Meirleir, et al, ‘Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols’ (2003) 11(1) *Journal of Chronic Fatigue Syndrome* 7; B.M. Carruthers, M.I. Van de Sande, K. De Meirleir, et al, ‘Myalgic encephalomyelitis: International Consensus Criteria’ (2011) 270(4) *Journal of Internal Medicine* 327 (‘Carruthers et al’); Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome Advisory Committee, ‘Report to the NHMRC Chief Executive Officer’, *NHMRC* (Report, 30 April 2019) <https://www.nhmrc.gov.au/file/14332/download?token=qKIBRFLf> (‘NHMRC Committee’).

Centrelink continues to believe that ME/CFS is merely fatigue, when that simple is not the case.

Applicants are then forced into treatment they don't necessarily want or can afford in order to reapply.

- ***Misapplication of the Tables*** *- A failure by Centrelink to comprehend the impact of ME/CFS on activities following activity.*

The current accepted International Criteria for ME/CFS are based on the 2003 and 2011 Carruthers et al papers. There is a great more detail than the 1994 Fukuda criteria – which is long outdated. Since 2019, the National Health and Medical Research Council ('NHMRC') have endorsed these criteria. The cardinal symptom of ME/CFS is actually PEM (as well as autonomic symptoms).[13] Fatigue is NOT the sole consideration.

There are multiple cases where the applicant has been declined because of illustrations of activity results in a lower rating under *Table 1 - Functions requiring Physical Exertion and Stamina*. The assessment focused solely on the activity in isolation, without taking into account the pre-planning for the activity, or the disproportionate loss of function following the activity.

In a recent case of *Caine and Secretary, Department of Social Services (Social services second review)* [2020] AATA 2089 the AAT took on board exactly this argument in overturing the decision of the Department.

The AAT looked beyond the activity to take account of the impact of PEM when assessing the Applicant's eligibility for 20 points under the criteria in Table 1. The test applied to the interpretation of activities most suited under each point level is described in paragraph 11(3) of the tables.

> *When determining whether a descriptor applies that involves a person performing an activity, the descriptor applies if that person* ***can do the activity normally and on a repetitive or habitual basis and not only once or rarely****.*

The AAT concluded that the applicant could not engage in activity on a **repetitive or habitual basis**, but could be considered to it **once or rarely**:

> *55. Having regard to Ms Caine's evidence and Ms Steele's reports, the reasonable conclusion is that* ***the arbitrary but prescriptive activities required for 20 points*** *in Table 1*

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[13] Ibid.

> ***could at most be repetitively performed over a sustainable period once every three days****. Ms Caine has given evidence that she has* ***learnt to carefully manage her activities to balance her physical limitations*** *with the requirement to perform essential tasks such as shopping. There is* ***no evidence to suggest that there is capacity or ability to increase the physical demands*** *she places on herself.*
>
> *56. Having reached this conclusion, it is not reasonable or accepted by the Tribunal that* ***an activity which consumes 45 minutes but requires three days almost entirely dedicated to the preparation, performance and recovery*** *should be described as being habitual or regular.* ***It is more accurately classed as one which can be performed <u>once or rarely</u>.*** *Having reached this conclusion, it is appropriate to award Ms Caine 20 points under Table 1 of the Impairment Tables.*

The current understanding and approach of Centrelink is partially based upon outdated criteria and advice, and partially upon the stereotyping of the condition as fatigue.

- ***<u>Unqualified/Inexperienced Examiners</u>*** *- A failure by Centrelink to use appropriately qualified/experienced medical practitioners to give an independent opinion about ME/CFS*

  In a number of cases, Centrelink utilised an Independent Medical Examiner or Independent Healthcare Provider, to assess the applicant. On more than one occasion, these examiners have stated that the condition is psychological. ME/CFS is not a psychological condition. It is classified under the World Health Organisation’s International Classification of Diseases at G.93.3 under neurological conditions.

  It is simply not appropriate for the Department to source alleged experts to label the applicant with assertions about their condition that have no basis in reality, and moreover, diminish the physical disabilities that they are experiencing.

  Despite this inappropriateness, this is what is occurring.

- ***Outdated Criteria*** *- A failure by Centrelink to understand that the current accepted international criteria for ME/CFS are the not the 1994 Fukuda criteria*[14]*.*

  On multiple occasions the criteria cited in cases is based upon the outdated criteria. Similarly, a number of cases where the Centrelink appointed independent assessor refers to the long outdated 2002 RACP Guidelines and the reference to GET and CBT.[15]

  Aside from a lack of understanding of ME/CFS, there is now awareness of the fact that more accurate criteria exist to describe the condition, including the 2011 International Consensus Criteria, which was constructed in Australia.[16]

The above outline provides an insight into just some of the systemic hurdles that apply within the application process with Centrelink.

These kind of hurdles are turning people off the process altogether because they are hearing horror stories from others with ME/CFS. Within our survey, there were a number of responses that indicated a reluctance to apply because of the stories that they had heard about the difficulties of the process.

Consumer View

> *Consumer 1:*
>
> *I experienced difficulty because the assessor found an incidental reference to knee pain and decided I must have a second undiagnosed and treated condition, even though the entirety of my application addressed how I met 20 points on CFS alone.*
>
> *Consumer 2:*
>
> *I have put off applying because I have heard nightmare things about the process and don't want to put my family through it. I have also heard of lots of people with ME/CFS being declined. An accessible disability pension would make a significant difference to me and my family and I'm so frustrated by how inadequate the current system is. I've also had a lifetime of being disbelieved about my disability and I'm reluctant to invite that.*

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[14] K. Fukuda, S.E. Straus, I. Hickie, et al, 'The Chronic Fatigue Syndrome: A Comprehensive Approach to its Definition and Study' (1994) 121(12) *Annals of Internal Medicine* 953.

[15] Royal Australasian College of Physicians 'Chronic Fatigue Syndrome: Clinical Practice Guidelines' (2002) 176(Suppl) *Medical Journal of Australia* S23.

[16] Carruthers et al (n 12).

> *Consumer 3:*
>
> *I have not yet applied because I am frightened I will not have the energy, resources, or medical contacts to satisfy Centrelink's criteria. This is because of stories I've been reading about how disabled people are regularly denied financial support.*

Recommendations

Recommendation 3 – The Department of Social Security should engage with the peak body for ME/CFS to update their policies and understanding of ME/CFS to reflect contemporary medical knowledge.

Recommendation 4 – The Department of Social Security should utilise Independent Examiners who have an up-to-date comprehension of ME/CFS based upon the current accepted criteria and evidence base.

Recommendation 5 – The Department of Social Security should remove any requirement for treatment for ME/CFS – particularly Graded Exercise Therapy and Cognitive Behavioural Therapy.

Specific Issues

The unique nature of ME/CFS creates a multitude of barriers and hurdles to the ability of people with the condition to access the DSP. The surprising aspect of this whole process can be summarised in terms of their lack of understanding and accommodation of disability.

There appear to be a number of systemic assumptions that Centrelink appears to be operating on:

- Applicants have access to a medical practitioner;
- Applicants can obtain accurate medical evidence from a knowledgeable practitioner;
- Applicants have the ability to leave the home to obtain the necessary evidence;
- Applicants have the funds to be able to obtain the evidence required to demonstrate entitlement under the tables;
- Applicants have the ability to participate in the above process of evidence gathering;
- Applicants have the ability complete the application or access to someone else that can assist them in the process.

Despite the fact that the Department of Social Security is subject to the *Disability Discrimination Act 1992* (Cth), it doesn't actually appear to have in place and reasonable accommodations to assist an individual of limited to no capacity, to engage in the application process.

These issues will be elaborated upon further.

ME/CFS Australia submits that there are a significant number of systemic hurdles to the application process and presents them as follows:

Eligibility Criteria

The eligibility criteria is broken down into a number of components:

- The access criteria
- The impairment criteria

The access criteria, as set out in the previous section, requires that the applicant demonstrate that a condition is fully diagnosed, fully treated and fully stabilised.

The impairment criteria requires an assessment in accordance with the tables, across all the relevant tables.

ME/CFS Australia submits that there are number of challenges for the ME/CFS community with respect to this process:

1. The criteria assumes that a medical practitioner is willing to diagnose a person with ME/CFS (even when someone has been previously diagnosed with the condition). There are a dearth of medical practitioners in Australia that actually comprehend the condition and have the confidence to diagnose.[17] Whilst there are some who accept the condition, they do not necessarily have the confidence or the desire to commit that to an application;

2. There are a substantial number of medical practitioners who still do not believe that ME/CFS is real, or are of the misconception that it is a psychological condition;

3. The medical community is not up to date, and many still wish to recommend GET and/or CBT under the false belief that it is an acceptable treatment for ME/CFS, that offers a cure or substantial improvement, when in fact it does not;

4. For people who are housebound and/or bedbound, there is no ability to obtain a regular medical practitioner to do home visits such that they build and

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[17] NHMRC Committee (n 12).

understanding of the patient, let along sufficient background to be able to complete the application form and/or accompanying report;

5. The process of getting a report from a medical practitioner is costly and many doctors are simply unwilling to commit the time or energy to complete the paperwork;

6. Even if a prospective applicant has a competent and/or knowledgeable doctor who is willing the address the paperwork:

    - Most don’t understand the comorbidities that accompany ME/CFS such as Fibromyalgia, Orthostatic Intolerance, Sleep Apnoea, Neurocognitive deficits/brain injury, sexual dysfunction, substance abuse, Depression, visual or hearing;
    - Most do not understand what they are filling out;
    - Most do not understand that there are a set of Tables under which an applicant can be assessed, and that their report should address the criteria of those tables to assess the level of impairment;
    - Most do not comprehend how to assess the function of the applicant in accordance with the relevant Table, taking account of things such as the duration of the activity, the preparation for the activity, and the time period it takes to recover from the activity;
    - Most do not comprehend that there are multiple Tables that ME/CFS extends across, and why that would occur, hence could allow an applicant to accumulate 20 points across multiple tables;
    - Most do not comprehend the medical evidence that needs to be acquired from appropriate healthcare providers set out in the Tables;
    - How to assess permanency;

7. The applicant themselves is not knowledgeable about the application process, hence they don’t:

    - Comprehend how to express their own impairment in terms of how activity causes impairment because of PEM;
    - Comprehend that they can be assessed across multiple tables and that such tables require specific assessments (eg Table 7 – Brain function, can rate cognitive impairment, but it requires a neuropsychologist to conduct the assessment);
    - Comprehend that there are scans and assessments by specific healthcare providers that
    - Comprehend that the age of their medical evidence is relevant;

  - Comprehend that they need to identify to their medical practitioner that they have engaged in medication or treatment, and how to explain the outcome and the need to explain why it was stopped;
  - Comprehend that a treatment is not reasonable if they cannot afford it, or cannot travel due to illness, to get to it, or that participation may well cause deterioration and prevent their ability to get home);
  - Etc, etc

8. Even if the applicant is aware of all the evidentiary requirements, they are usually so financially distressed, that they cannot financially afford to carry them out to prove the impairments that they have;

9. In the cases of the housebound and bedbound, they cannot attend the necessary locations in order to do the investigations, scans or tests necessary to prove the issues that they have, rule out alternative conditions, or any other form of engagement necessary to gather medical evidence;

10. An applicant may not have the functional or neurocognitive capacity to negotiate the process of the paperwork requirements;

As set out in the background, there are many cases in the AAT in which applicants have failed because they cannot navigate the requirements.

The criteria assume that there is a functional medical system in which applicants are an active participant with the ability, knowledge and funds to obtain the relevant medical evidence to meet the requirements of the Tables.

In ME/CFS, this simply isn’t the case. ME/CFS is very much a marginalised condition that is heavily neglected and/or misunderstood by the medical and healthcare professions.

Presently the DSP application process does not allow for the reality of a condition such as ME/CFS.

There is a significant need for the process to supply funding to allow people to obtain the medical evidence that is required. There is a definite need for a process to enable those people who are housebound and bedbound, to have an assessment by a knowledgeable practitioner so that they can access the system.

Assessment

The assessment process for ME/CFS is subject to a Centrelink policy that is not overtly disclosed to the public. As part of that internal policy, there is a decades old belief that the condition is primarily fatigue based, and able to be substantially improved/cured by GET and CBT.

Despite the science and the criteria moving into the 21st century, Centrelink has not. Moreover, the Department actively utilises this approach when engaging applicant in the AAT using Independent Assessors with a belief about the condition that accords with their policy, but not the current understanding and reality of the condition.

Centrelink has made no attempt to engage the ME/CFS peak body to work with us to review the suitability of the policy or gauge the impact upon applicants.

In our experience, having been privy to numerous applicant feedback on the DSP assessment process, there are a variety of assessors that operate within Centrelink:

- The sympathetic – These assessors either understand, or are empathetic to the condition and the applicant;
- The ignorant – These assessors have no comprehension of the condition and say and do things that don't accommodate the condition or recognise its seriousness;
- The discriminatory – These assessors have offensive/abusive opinions about the reality of the condition, stereotypes, and can be quite obstructive to the process.

In the early 2000's, our Queensland member organisation's president was actively involved with the Brisbane offices of Centrelink and attended a number of staff development sessions to educate their staff and assessors about the reality of ME/CFS. As a direct result of that first-hand experience and visual understanding of the functional impairment and lived experience, the claims experiences of applicant encountering these staff members was more sympathetic and positive.

Health Assessments

The feedback to members of ME/CFS Australia with respect to health assessments is mixed. Among some of the feedback we have heard across the years are:

- Centrelink required the applicant to attend despite their functional incapacity and if they didn't, they wouldn't get accepted;
- The assessors rooms did not accommodate the condition in terms of light, sounds, noise and smell sensitivities, or the need to lay down;
- Some have been ignorant and judgemental about the condition, including assertions it was psychological, or simply not as severe as the applicant was experiencing;
- Some had absolutely no knowledge of the condition and provided a negative report based upon their lack of knowledge or personal beliefs;
- Some failed to obtain an accurate history or failed to record what was discussed;
- Some were rude, judgemental and dismissive;
- Some were very understanding and took the person at face value;

- Some did not comprehend the symptoms experienced or the effect of activity and how PEM would cause them disability;
- Some approached it from a psychological perspective and put it down to depression;
- Some asserted that GET and CBT was required and would likely cause substantial improvement;

The common theme among the experiences related to the organisation over the years has been the absence of knowledge from those carrying out the health assessments, and their misconceptions as to the nature of the condition and the effectiveness of treatments.

Many had been declined because of these assessments. Many had been certified fit for various hours of work on the basis of what the assessor believed they could do, with no regard for the PEM that such activity would cause, and the subsequent inability to work.

There is a significant need for appropriately knowledgeable assessments based upon the reality of the condition and not the beliefs or lack of knowledge of the assessor.

Medical Review

Much like the health assessments, the medical reviews resulted in many adverse outcomes due to the poor knowledge of the practitioners, and/or their misconceived beliefs about the condition.

There is a significant need for appropriately knowledgeable assessments based upon the reality of the condition and not the beliefs or lack of knowledge of the assessor.

Determination

In the context of ME/CFS, determinations would include successful, unsuccessful and successful with requirements.

The unsuccessful outcomes often reflect the reasons experienced in the background provided above. The lack of comprehension of how to navigate the requirements often results in a failure to address such requirements, or gather the evidence.

Determinations often reflect the inability of the applicant to demonstrate their disability. This can be the result of the absence of adequate medical support, or medical evidence, adequate assistance with the applicant, or an impaired ability to fund that which is necessary.

For those who had to move to Newstart they have the added burden of being very ill and disabled, yet still having to meet the requirements of Newstart with no or limited functional capacity to do so.

In determinations with additional requirement, such as the Under 35's or those who achieve 20 points across multiple tables, the disability of the individual is ignored. Again, despite little to no functional capacity, they are being required to comply with obligations.

The effect of denying access to the DSP is, in some case, for people to fall out of the system. There are patients who are simply not on any support because they cannot access the DSP nor comply with Newstart.

Right of Review

Whilst there is a right of review within the DSP, the ability of lay people to comprehend the decision, or identify flaws in a decision, makes the internal review a self-reinforcing decision process. In many cases those who ask for the review, end up with the same outcome.

ME/CFS by its very nature can create a prohibition to the request for a review because they are not able to must the physical and mental resources to raise an argument or a request for a review. Unless they have an advocate, family member or carer to step in for them, certain applicants will fail to act on their rights.

Given the review stage is an excellent opportunity for the applicant to 'cure' their claim in a non-legal forum, there is a need for access to qualified, knowledgeable advocates to assist the applicants to engage in the process.

The use of advocates at this point in time:

- Provides a level playing field for applicants to engages Centrelink;
- Can cure applications without the need to recommence the process, engage in legal dispute or fall out of the system;
- Enables people with disabilities the ability to have someone argue their case when they are not capable of doing so themselves;

The purpose of the DSP is to allow people with disabilities to access the system that is there as a safety net when they need it. By assisting those who are entitled, to access the system when they are entitled, is congruent with the purpose of the DSP, and fulfills Australia's obligations under the Conventions.

Appeal

The appeals process involves an applicant raising a dispute via the AAT.

This is a formal legal process in which an individual with a physical disability that impairs memory and neurocognitive functions, is expected to identify appeal points, complete the application paperwork, fund an application fee, gather the evidence, then come before the AAT against a fully funded Centrelink legal practitioner, and be expected to comply with procedural requirements, on time, and in the AAT itself. Furthermore, they are then expected to formulate a legal argument, with cross referenced evidence, to argue their case.

This is an inherently discriminatory process that is grossly unfair from beginning to end. It is an obvious disparity of power.

There is a significant need for applicants who have to engage in AAT disputes, to have access to Legal Aid and therefore, legal representation. This enables the vulnerable individual without the mental, physical and legal capacity to be forced into an arena where the process itself will deteriorate the condition, and the balance of power is weighted to the Department.

Aside from the obligation under the Convention, there is a more obligation to allow applicants a fair go, as well as an obligation to remove an obviously discriminatory barrier that offends the very essence of the *Disability Discrimination Act 1992*.

Again, the purpose is to allow genuine claimants with a disability to access the DSP system. This is the purpose of the DSP.

Legal representation can assist to cure claims that are genuine, but deficient. Access to the DSP is not intended to be determined by the ability or inability of an individual to advocate for their own rights. Applicants should be accorded the opportunity to demonstrate that entitlement on the same terms as the Department.

Legal representation can also save the public purse by preventing unwinnable cases moving to the AAT, only to fail and cost the system the expense of unnecessary hearings.

Consumer View

> *Consumer 1:*
>
> *Was on DSP 2008-2015, was then deemed ineligible resulting in further deterioration. Went through a Program of Support, finally reapplied and accepted 2019.*
>
> *Consumer 2:*
>
> *Couldn't find a helpful GP.*
>
> *Consumer 3:*

I'm struggling to fill in the paperwork and get adequate support from medical professionals

Consumer 4:

Doctors and specialists didn't know how to write the reports for the impairment tables or were not willing to do so.

Consumer 5:

I suspect I would have had more difficulty but I got a really good assessor who worked to get me approved as she could see I really needed the DSP. She told me any other person in the office would have put me through the ringer just for the sake of it.

Consumer 6:

GPs & specialists should know what is required to qualify & what information is needed for the application to be successful. They are the experts on our health, quality of life & whether we need support. They are also bound by oath so should be trusted by CL

Consumer 7:

Appointments difficult as have to stand in line and have POTs and get dizzy, lack of initial seating damages my health. No way to be in line without standing. Long times waiting for appointments damage health unnecessarily. Phone lines often busy or long waiting times. Take a huge toll on health. This all provides a barrier to people accessing needed financial assistance when in order to access you are required to damage your health and make disability worse

Consumer 8:

It's nearly impossible to find decent ME/CFS literate doctors, and this is coming from someone who's had it nearly 20 years. As far as I can tell there has been ZERO education or improvements within the medical community for people like me over the last two decades, and the rare few doctors who do know what they're talking about are impossible to get into. I wouldn't trust any government-appointed person to genuinely understand my illness and situation or to assess it appropriately, let alone compassionately. At one stage I had to attend a job capacity assessment which was incredibly traumatic. The guy was saying if it was going to take e.g. 6 years to get 100% better, then at the 3 year mark I should be 50% better, and able to work part time.

> *THAT IS NOT HOW THIS ILLNESS WORKS. Pushing too hard can cause a collapse which sets back health by months and years all over again.*
>
> *Consumer 9:*
>
> *It was the most de-humanizing and stressful experience of my life. To have a stranger tell me I can do something when my specialists and my GP (who know me well) and myself say I can't, it's demoralizing. I had to find the energy to appeal and reapply, only for the 2nd assessor to do the same thing. It took 2 years of fighting for it but I eventually was granted the DSP based on my original medical records. I should have been granted in the first place. The whole process worsened my condition and made me sicker.*

Recommendations

Recommendation 6 – The Department of Social Security needs to provide funding to applicants to enable them to gather the necessary medical evidence in accordance with the Tables.

Recommendation 7 – The Department of Social Security needs to provide a system of assessment for housebound and bedbound applicants who cannot otherwise access the necessary requirements of the system.

Recommendation 8 – The Department of Social Security needs to provide ME/CFS specific training to staff members, medical assessors and health care assessors, so that the disability can be properly and fairly assessed.

Recommendation 9 – The Department of Social Security needs to engage with the peak body in order to formulate an up to date policy with respect to ME/CFS (with regular reviews).

Recommendation 10 – The Department of Social Security needs to provide access to advocates to assist people to engage in the review process.

Recommendation 11 – The Department of Social Security needs to provide access to funding for legal representation in all tiers of the AAT.

Impact of Demographics

Background

ME/CFS impacts people of all ages, sexes, gender, ethnicity, geographic and socioeconomic status.

Specific Issues

There are a number of specific issues of relevance to the DSP.

Geography

ME/CFS occurs far and wide in Australia. Given the post-viral nature of a percentage of those who suffer it, there are likely certain geographic locations where certain viral outbreaks are common or episodic (eg locations with Ross River fever, Dengue fever, Barmah Forest).

For those people who are in rural and remote areas, the ability to access knowledgeable medical assistance, or the necessary testing to establish elements of disability in accordance with the Tables.

Additionally, the historical expectations of Centrelink that applicants participate in CBT and GET can place an artificial and unrealistic barrier to geographic locations where the applicant has no access to such services, hence must then prove such a fact.

Age

ME/CFS impacts people of all ages. The degree of incapacity is not dependent upon age, nor is the duration of the condition. Children can and do get ME/CFS. A child who contracted the condition at age 5 could have the condition for 25 years with no possible chance of employment. Where is the point of subjecting them to a Job Capacity Assessment?

The DSP’s current differentiation between those above and below 35 years of age has no bearing upon the ability of an applicant with ME/CFS to enter the workforce. The current obligations for the under 35’s places an onerous requirement upon people with ME/CFS and can cause drop outs from those who cannot comply due to the severity of the condition.

ME/CFS is of the view that this differentiation requires scrapping.

Characteristics

ME/CFS is a condition which can be experienced along a spectrum of severity, in addition to variation in symptoms and comorbidities. Compounding these characteristics is the fact that variation in symptoms/severity can occur throughout the day, and as a response to stimuli such as temperature, smells, noise, light, activity, foods or stressors.

The assessment process under the tables has two specific issues of relevance.

Firstly, an individual can be assessed with an impairment under a variety of Tables (eg Table 1 - Functions Requiring Physical Exertion and Stamina; Table 5 - Mental Health Function; Table 7 – Brain Function). An applicant who doesn't achieve 20 points under a single table, but does achieve a combined 20 points between tables, is treated differently for the purposes of the DSP. The latter requires an individual to enter a Program of Support ('PoS') for a period of 18 months. The PoS seeks to improve an individual's ability to work. In the context of ME/CFS, no amount of support is likely to improve that ability to work. It places an onerous requirement of mutual obligation requirements on the applicant that can cause them to fall of the system if they cannot provide sufficient medical certificate or obtain an exemption. Until an applicant completes a PoS, they do not received the higher rates under the DSP.

The second consideration related to the impairment rating accorded to an applicant who engages in functional activities that offend Table 1, but result in PEM, and therefore days or more of no function. As *Caine* demonstrated above, this type of variation can fulfill the Table, however it required an AAT dispute to demonstrate the entitlement.

There is a need for clearer direction within the Tables to address such conditions.

Consumer View

> *I experienced difficulty meeting the 'participation in a program of support' criteria, because there are no programs of support that I know of for cfs, fibromyalgia or lyme disease in Western Australia. Meeting the other requirements is difficult because for these conditions there is no set way, in the government or the medical system, to recognise, diagnose, treat or manage these diseases effectively, or to support people with these diseases because both the diseases and the people with them are ignored. The evidence is ignored. There are no up to date guidelines for medical practitioners to follow confidently. Even when medical evidence is provided, it can be rejected by a government dsp assessor, as it seems they are given different guidelines to*

> *follow. It is my suspicion that government appointed assessors are also under pressure to reject more applications than they approve, for monetary reasons, instead of medical ones. This is evidenced by the guidelines themselves (or lack of) and the experiences I have heard of from people who have worked as government appointed assessors.*

Recommendations

Recommendation 12 – The Department of Social Security needs to provide an alternative pathway of assessment for those in rural and isolated communities with limited or no access to medical services.

Recommendation 13 – The Department of Social Security needs to scrap the requirements for under 35's with respect to ME/CFS.

Recommendation 14 – The Department of Social Security needs to scrap the differentiation between 20 points across 1 Table and 20 points across multiple Tables.

Recommendation 15 – The Department of Social Security needs to scrap the Program of Support requirements for ME/CFS.

Recommendation 16 – The Department of Social Security needs to refine Table 1 to ensure that better descriptors are provided to capture Post Exertional Malaise and other ME/CFS functional characterics.

Impact on Employment

The unpredictable nature of severity fluctuations and PEM in ME/CFS, as well as the various potential comorbidities, make the prospect of employment difficult for the majority.

The reality of the labour market is that disabilities of a fluctuating nature are rarely accommodated.

For those who can work, the employment can be sporadic – boom/bust. Under the current system of the DSP, there are deductions when the income goes beyond the initial threshold. An individual can have nothing for weeks at a time, hence that threshold is wasted. Whilst there is an allocation of 48 work credits, their value of $48 is well below the income $ 178 threshold allowed each week. In short an ME/CFS Boom/Bust earner is significantly disadvantaged compered to a person who can work regular part time work.

The presence of the $ 178 threshold and 50 cents reduction thereafter acts as a disincentive to working longer hours because it reduces the DSP. There is a need for a greater incentive to work more hours, by increasing the threshold. This will alleviate elements of the Boom/Bust income disparity and incentivise more hours where it is possible.

Consumer View

> *Consumer 1:*
>
> *There are a lack of disability friendly organisations - businesses who are willing to offer supportive work environments to people with disabilities. I require flexible, part-remote work and this is very challenging to find..*
>
> *Consumer 2:*
>
> *Not enough accommodations in the workforce to assist people with chronic and disabling conditions. Also discrimination against the chronically ill and disabled in the workforce.*
>
> *Consumer 3:*
>
> *Employers arent looking for disabled workers.for 3 hours a fortnight.*

Recommendations

Recommendation 17 – The Department of Social Security should allow 178 working credits to carry over each week in order to all those who are boom/bust earners to have the same deduction free threshold as those who can work regular part time work.

Recommendation 18 – The Department of Social Security needs to allow those on the DSP who work, a greater proportion of the monies they earn to incentivise increased work hours where capable.

Capacity of DSP to Support

ME/CFS Australia reiterate its submission above and rely upon Figure 1. The DSP is not currently sufficient to support people with disabilities. Additionally, with the advent of Covid 19, people with DSP have incurred greater expenses. People who are immunocompromised, overweight or have a disability are at an increased risk of death if they contract Covid 19. For this reason those with the condition have had to incur additional costs:

- Avoiding crowds on public transport by taking taxi's or ride share vehicles;
- Incur delivery costs of items and medications in order to avoid leaving the home and exposing themselves;
- Incurred increased utility costs due to being home for a greater amount of time;
- Incurring costs for PPE;
- Incurring increased costs arising from rental increases, increased grocery prices and other price increases;
- Those individuals with ME/CFS who were able to work, lost their employment with no JobKeeper support to replace it.

The government provided small one off payments during the initial stages of the pandemic, however these did very little to offset the actual costs.

From the perspective of ill-health, the DSP is not sufficient to allow a person with ME/CFS the ability to properly manage the condition. The DSP does provide some Medicare support, however the usual cost of ME/CFS specialists is usually hundreds of dollars above Medicare because the doctors have a specialist knowledge and the management of people with ME/CFS usually requires extended appointments.

In terms of meeting the costs of supports, the DSP makes it difficult to incur large costs such as a CPAP, Oxygen supply, wheelchair, or multiple other supports that can be required in the house (noting people with ME/CFS are often not able to access the NDIS due to systemic barriers).

Consumer View

> *Consumer 1:*
>
> *During the pandemic I was homebound. The cost of a home delivery service for Groceries was prohibitive. I lost employment within my casual business. I could not make that income up. I had credit cards and a home loan to pay and less income.*
>
> *The price of everything went up. Groceries. Medication. Utilities. Despite this my DSP did not change. Financially I went backwards and I cannot catch up.*

Recommendations

Recommendation 19 – The Department of Social Security needs to review the current rate of the DSP to bring it into line with the real cost of living and real needs of individuals.

Discrimination in Labour Market

As outlined under the Impact on Employment point, there is next to no support within the labour market to accommodate the special needs of ME/CFS. The unpredictable nature of the condition, the sporadic period of down time that can be hours, day, weeks or more, all make for barriers to accessing the labour market.

Some people with ME/CFS turn to volunteering in order to test their capacity and/or keep their skills up to date. Volunteering helps to restore a sense of self-worth and contribution to society.

Flexibility within an employment environment is essential but rarely provided.

Some have taken on board employment on a casual or part-time basis, however when they started to encounter issues. The employer has applied pressure. As a consequence, the ME/CFS declined. When they couldn't do as they were required, the job ceased.

Consumer View

> *Consumer 1:*
>
> *I returned to work with the assistance of the Commonwealth Rehabilitation Service. The program required CRS, my doctor, my prospective employer and I to arrive at a guide for hours of employment and degree of flexibility.*
>
> *Soon after I commenced, the employer changed the goal posts and began increasing demands upon me for extra hours. Pressure. Bullying. Failure to adhere to the agreement. In the end I spiralled downwards and hard to leave.*
>
> *Consumer 2:*
>
> *Lack of finances to support work eg transport, household assistance. All energy used for activities of daily living. Difficulty accessing ndis for this type of support. Lack of part time flexible jobs for people with health difficultie. Lack of accessible buildings*

> *- eg stairs, somewhere to rest during the work day so health doesn't deteriorate, government jobs that provide flexibility in hours and ability to rest*

Recommendations

Recommendation 20 – There is a need for incentives to be provided to employers to encourage them to facilitate variable hours and enable them to limit disruption to their businesses from absences.

Adequacy of DSP

The DSP rate is below the poverty line. In the real world, people with ME/CFS often cannot rent with others because of their special needs and limitations. When a patients with ME/CFS is chemically sensitive, or has issues with noise or light, the ability to live in shared accommodation is prohibitive. The cost of rental accommodation is quite high throughout Australia, but more so in various capital city and other locations.

Public housing is very limited. Poor quality housing with cheaper rents often have issues such as mould or a shared within units where the sensitivities of the individual are triggered.

As established above, the DSP does not allow a person to meet unexpected costs or allow for savings, superannuation or the purchase of a home.

ME/CFS itself is demanding in terms of the needs for access to the GP or specialists, or indeed medications or investigations/scans. This prohibits the ability of people with ME/CFS to manage their condition, address deteriorations, or treat those issues which are treatable.

The ME/CFS community has provided significant feedback that financial pressures add to the pressure of everyday life, hence cause deterioration in the condition. For those who are forced to taken on employment, there can be a constant boom/bust pattern to their lives as they work, deteriorate, then recover

The standard of living in ME/CFS is therefore quite poor. There are examples within the community of becoming homeless. On some occasions, people with ME/CFS have turned to sex-work in order to supplement their income.

There is a definite need for the level of the DSP to be raised.

Consumer View

Consumer 1:

DSP just enables one to live but can not afford to see specialist on it

Consumer 2:

I have talked to another person on welfare where we talked about how we were so desperate we'd both independently considered prostitution to try and make some more money, as we are just too sick to work an actual job but are so desperate for a livable wage that we wonder if it's the only option available to us if only we could stomach it. Neither of us could; already being vulnerable because of chronic illness we couldn't also put ourselves in an even more vulnerable position. I'm personally revolted by the idea, and yet living in this kind of hopelessness year after year made me consider it. I seriously doubt we're the only ones on welfare who have wondered if we'd be willing to try prostituting ourselves in order to get by. The government should be ashamed that it has pushed us to this level of desperation that we can become easy targets for abusers.

Consumer 3:

MOSTLY it's LACK OF FINANCES. I have had several promising treatment options come up over the last couple of decades and I have NEVER been able to afford ANY OF THEM. I feel totally locked into illness and despair with no way to get out because I live in poverty and have no way to access treatments or therapies, not even an occasional massage which would help relieve my physical pain, NOTHING, FOR NEARLY TWO DECADES.

Consumer 4:

The abusively low amount I have to live on on DSP has made my health WORSE and my road to small improvements much harder, much longer, and after every hard-won gain I find myself going backwards again because I'm living in such poverty that the stress and lack of choice strips any and every gain I make. I still hold out hope that I can get better, I would've committed suicide years ago rather than keep living in this hell of poverty if I didn't, but there's no way to get better while I'm on the "existence-only" DSP payment. There is no quality of life or

> *chance of improving your health on the rate that the DSP is now. It keeps me suffering in poverty when all I want is to improve my health so I can get off DSP and live a full life. If the DSP was a higher rate that actually helped people access treatments they could get well and get off DSP and it would end up saving the government more money in the long run. If I'd received twice as much money on the DSP I'd have been off it years ago, instead of being reduced to still living payment to payment trying to survive and hoping I can avoid winding up in a mental hospital because of how I'm forced to live. Because the DSP is too low to pay rent prices I ended up becoming homeless. And no social housing is built to the standard needed for someone with a chronic illness (basic things like safety, privacy, heating, cooling, not being amongst stressful dangerous druggie abusive neighbours). It took 7 years for me to finally get into adequate housing, and over all those 7 years my health got worse. I completely lost seven entire years of my life because the DSP couldn't keep me housed, and it will take years more to undo all the additional health issues and stress I've suffered because of having to go through all that.*

Recommendations

Recommendation 21 – The Department of Social Security needs to review the current rate of the DSP to bring it into line with the real cost of living and real needs of individuals.

Appropriateness of Current Supports

As outlines in the above, the current supports are simply deficient. There is nothing to encourage employers to take on people with ME/CFS who have inherent inconsistency as a result of their condition. Moreover, there is an inherent disadvantage in terms of the amount of money people on a boom/bust work cycle get to keep.

There is a need to carry forward unused thresholds of $ 178 to apply equity to the system when compared to a week to week employee.

Consumer View

> *One fortnight I would work 60 hours and lose all my DSP. Then I would take 4 weeks to recover, and that almost $650 of wasted threshold. Someone working 60 hours across 6 weeks might lose about 20% off their DSP. I lose 33.3% across 6 weeks. How is that fair?*

Recommendations

Recommendation 22 – The Department of Social Security should allow 178 working credits to carry over each week in order to all those who are boom/bust earners to have the same deduction free threshold as those who can work regular part time work.

Economic Benefits

For those who acquire ME/CFS at a point in their life where they are working and have debt commitments, the condition can be financially devastating. The prior ability to service debt fails away.

For those with no financial commitments, the condition is equally devastating if the do not own their home, or a vehicle.

For those whoa are younger, the loss of the working life leaves them vulnerable from the standpoint of acquiring the things that we usually associate with a normal life – superannuation, car, house, holidays, family.

The DSP as it currently stands, provides no pathway to address these issues. It allows existence. It does not allow for dignity or quality of life. It perpetuates financial distress.

When the Government increased the benefits of those who were on Jobseeker, there was a unique benefit that arose. People on jobseeker were able to pay their bills, eat better and enjoy some quality of life. For parents they were able to meet the costs of their kids, including clothes and school excursions. These people became consumers in the market place, which buoyed the economy as a whole.

Consumer View

> *Nearly 20 years of living in pain and illness and disability and all I have been able to do is survive in the most crude and basic*

> *sense of the word. It is impossible to get any quality of life while on DSP. The meager pittance that is the DSP that I've had to live on in all that time has pushed me into homelessness, I have no savings, no superannuation, no assets, and I have years of dental work that needs to be done but I can't afford. I have given up looking for treatments and therapies because I I can't afford the doctors I want to see or the treatments I want to do. I can't afford a car, I have no furniture except for my bed, I can't afford to install AC in my unit despite having severe sensitivity to heat and cold due to my ME/CFS, I can't even afford to buy organic food to help myself in that way.*

Recommendations

Recommendation 23 – The Department of Social Security needs to review the current rate of the DSP to bring it into line with the real cost of living and real needs of individuals.

Alternative Programs

For ME/CFS the best alternative programs are the NDIS and the Medicare system.

The problem is, the NDIS is utilising a policy with respect to ME/CFS that is based on outdated knowledge and outdated beliefs that GET and CBT can resolve the condition – despite no research ever coming close to demonstrating this.

The NDIS can help people to have the support they need to build capacity. The NDIS offers the potential for people to ease their distress and achieve an element of quality of life.

For those who cannot access the NDIS, there is a substantial gap with respect to supports and services that can be provided to assist people with ME/CFS in their day to day life. Despite the presence of players in the market who provide community supports, they do not see ME/CFS as 'worthy' or view the condition with the seriousness that it deserves.

With respect to the Medicare system, there are currently significant gaps in the system that leave people with ME/CFS without access to the investigations, tests and treatment that they require.

The Medicare system currently leaves significant gaps payments that are prohibitive – especially in the case of ME/CFS because of the need for longer appointments. The DSP accords some reduction of costs, but there is a significant need to make these things accessible. People should not have to chose between food and seeing a doctor.

And finally, access to Medicare allows for interventions of elements of the condition that are treatable, to improve health. It can also assist to identify missed diagnosis, or comorbidities that need to be addressed.

A failure to treat the treatable causes unnecessary decline.

Consumer View

> *Consumer 1:*
>
> *I don't qualify for any disability services, they all tell me I have an illness not a disability, and as far as I know I still don't qualify for NDIS to be able to get some help that way.*
>
> *Consumer 2:*
>
> *If I had access to financial and NDIS support earlier, I probably could have hobbled along working part-time. Fighting the system broke me, and bar some miracle, I'll never work again.*
>
> *Consumer 3:*
>
> *Lack of finances to support work eg transport, household assistance. All energy used for activities of daily living. Difficulty accessing ndis for this type of support. Lack of part time flexible jobs for people with health difficulties. Lack of accessible buildings - eg stairs, somewhere to rest during the work day so health doesn’t deteriorate, government jobs that provide flexibility in hours and ability to rest*

Recommendations

Recommendation 24 – The NDIS needs to improve the assessment process for ME/CFS to enable those with the condition who meet the criteria, access to the system.

Recommendation 25 – The Medicare system needs to improve in order to facilitate lower gaps payments so that people with ME/CFS can access medical doctors, investigations, tests, imaging and care plans.

Related Matters

In closing, there are a number of final issues that ME/CFS wish to raise.

First, there is the issue of the right for a person to live their best life. This is a term that is one of the cornerstones of the NDIS. In the case of ME/CFS the condition can rob individuals of entire lifetimes. The things that we take for grant – education, family, relationships, employment, a family home, holidays – they are all stripped away for many. More so if they were young at the time of onset. To lose a life that the rest of society takes for granted is devastating.

Secondly, there is the issue of domestic violence.

For many females (and some males), ME/CFS can leave them vulnerable to exploitation and abuse from partners. The financial inability to escape and abusive relationship is a very common, and very real concern. No person should be trapped by their circumstances and beholden to another simply because they cannot afford to live independently, or gather the funds necessary to leave.

As the DSP currently stands, both of these circumstances are being facilitated and perpetuated.

As outlined in the background to this submission, Australia is a signatory to various Conventions to protect the various rights of individuals, particularly women and people with a disability, it is submitted that it is imperative that the DSP facilitate those freedoms.

The DSP as it currently stands does not address the above circumstances. Indeed it can act as a precipitator of violence and abuse.

Consumer View

> *A really important thing to mention is that I have recently moved states, and why. Despite it being an additional and almost unbearable burden on my health to make the move, the reason I moved was to escape from toxic family relationships. The DSP had kept me locked into abusive relationships the entire time I've had ME/CFS, and moving was a last ditch attempt to avoid committing suicide. I have spent my entire adult life with this illness, and I have missed out on going to university, having friends, having a career, having a spouse and children, buying a home, doing the overseas trip I always dreamt of, going out on the weekends, having hobbies, reading books, buying clothes that I like (I can only afford Big W/Target/Kmart), doing any kind of self-care at all, eating out at restaurants, going to concerts and*

> *events, taking a taxi instead of public transport, buying comfortable shoes, taking classes. I can't afford to go to the hairdresser, I have to cut my own hair. How I wish I could afford to buy some lego so I could have a self-soothing activity to do at home, but I can't even afford that. It's been horrible and traumatising living with this chronic illness, but the desperation of living in poverty on DSP is what has truly ruined my life. I have had my options and my dignity stripped from me by the severely low rate of DSP and I don't know if I'll ever have the ability to undo all the harm that it has caused me.*

Recommendations

Recommendation 26 – The Department of Social Security should adhere to the rights and obligations under the various Conventions to which Australia is a signatory, and provide a DSP that is sufficient to ensure dignity and quality of life, as well as the ability to protect one's self from abusive and exploitative relationships.