**PREAMBLE**

This submission is made on behalf of a group of people with chronic illness and disability that fall within the illness cluster ME/CFS/FM – Myalgic Encephalomyelitis; Chronic Fatigue Syndrome; Fibromyalgia.

The two main concerns of this group are:

* that income support is currently inadequate to meet medically recommended health and daily living conditions; and
* that mutual obligations for have historically proven to be detrimental to short and long term health for people who struggle with Postexertional Malaise (PEM) which is a defining feature of ME and CFS, as well as a common difficulty in FM.

Please see the information provided at the end of this submission to clarify the nature of PEM.

**Pillar One: Simpler and sustainable income support system**

* Should people with a permanent impairment and no capacity to work receive a separate payment from other working age recipients?

Working age payments assume suitability for employment. This does not apply to an individual with permanent impairment and no capacity to work.

If people with permanent inability to work were to receive the same payment as other working age recipients there would need to be substantial exemptions in place regarding both mutual obligations and reporting systems.

Example: Before I got my Disability Support Pension I was required to make fortnightly reports. I cannot afford the internet and had to make the reports in person. This was very difficult and expensive as I had to get dressed and make the trip by taxi. The time spent waiting at Centrelink was extremely tiring and painful for me.

There is an issue with the terminology “no capacity to work.” In the past this has variously meant a capacity for less than fifteen hours of work or less than eight hours of work. If a payment is received based on a requirement of zero hours capacity, this creates a disincentive for recipients to attempt return to work activities.

* How could supplements be simplified? What should they be?

People with chronic illness and disability have expenses relating to their health care as well as to the adaptations to living circumstances that are required to meet their self-care needs. These expenses apply irrespective of the level of capacity to work.

The UK PIP scheme is made available based on personal need rather than source of income support. It covers general expenses as well as mobility expenses, which are assessed separately and at high or low need. An assessed high need for PIP is used as the assessment criterion for access by family carers to a carer payment. People with lengthy but not permanent conditions can also access PIP.

Example from the UK: I use my PIP to pay for a weekly house cleaner, someone to help me shower and dress in the morning, and to buy the nutritional supplements recommended by my specialist physician. I use the mobility PIP to pay for the taxi to and from my medical appointments. I am trying to save money from my PIP to buy a mobility scooter.

Example of need from Australia: I don’t get the DSP because my husband works. He has had to cut his work hours to care for me and the children. I cannot drive and we cannot afford taxis – this makes it extremely difficult to arrange to get to medical appointments. I cannot do housework, prepare meals or care for the children and we cannot afford paid help. Our house is filthy, I only shower once a week, and the children cannot participate in extracurricular activities as there is no one to take them.

Example of need from Australia: I cannot afford private health care and I am on very long waiting lists for public specialists, which is delaying treatment. I cannot afford compression stockings which I need if I am to stand up. I cannot afford all my medications because one of my children has medical needs and I pay for her medications first.

Example of need from Australia: My husband works seventy hours a week to help pay my medical expenses. My pharmacy bill varies from $200 to $400 a week. My total out of pocket medical expenses for the previous tax year were $8848.13, not counting taxis.

Example: I needed a mobility scooter so I sold my car to pay for one. Now I cannot afford to get to medical appointments because I need taxi fares.

* How could Rent Assistance be better targeted to meet the needs of people in public or private rental housing?

We were pleased to note the concern of the Review to allow people to maintain stable housing. To this end, we propose that assistance should be provided to ensure that people in need of financial support receive a supplement that addresses their housing expenses, whether those are public rental, private rental or mortgage.

The current system effectively provides a subsidy to landlords by supporting the private rental market. Mortgagees are attempting to provide stable housing for themselves and their families. There is little benefit in forcing mortgagees into the private rental market when a supplement equivalent to Rental Assistance could keep families in their own homes.

Housing is a major concern for people with chronic illness and disability.

Example: Rent is my biggest expense. This is despite living in the cheapest rental accommodation available in Hobart. Since 1999 when I was put onto DSP, I’ve lived in one-bedroom apartments, the cheapest I could find. For many years I lived in a substandard rental apartment with inadequate heating because I could not afford to move into something better. Because of my health conditions it is too difficult for me to share a house.

**Pillar Two: Strengthening individual and family capability**

* How should participation requirements be better matched to individual circumstances?

People who are not meeting their own personal and health needs in terms of self-care should not be harmed by activity requirements that would further undermine their capacity for self-care.

Example: I agreed to attempt two hours of voluntary work on Mondays, Wednesdays and Fridays. In order to manage the voluntary work I did no other activity on those days. I did not shower or clean my teeth, nor did I prepare food, relying on packets of biscuits and a bottle of water that I kept on my bed.

Example: I can’t clean my house, I can’t make my bed, I can’t wash my clothes, I can’t shower without help or shop for food. There is no way I could meet any activity requirements.

Example: I agreed to do a part time TAFE course. While I did the course I did no housework. I did not maintain any order in my bills and other personal paperwork. Years later my house is still in disarray and my papers are loose in a growing pile. I am not able to redress this mess as I cannot cope with day to day needs, let alone fixing up past untidiness.

People who have a health condition that would be exacerbated by additional activity should be exempt from undertaking additional activity.

Example: I agreed to attempt to return to university part time, as I had a standing offer of post-graduate entry. My health deteriorated, which has remained the case for years afterward, and I did not complete the course of study. I now have less capacity for self-care than I had before attempting to return to study. I also believe the attempt to study contributed to my illness becoming permanent.

Please see the statement on Postexertional Malaise at the end of this submission.

* What is the best way of ensuring that people on income support meet their obligations?

There must be provision for variation and flexibility of obligations built into the system, to ensure the obligations are appropriate for the recipient. The first stage in addressing non-compliance should include reassessment of the obligations.

Maybe a broader interpretation of mutual obligation could include an obligation to address health needs for people with chronic illness and disability, with no capacity to work.

Assessment of mutual obligations should include assessment of the obligations of the organisation to the recipient, especially where these impact on the ability of the recipient to meet their obligations.

**Pillar Three: Engaging with employers**

No comment

**Pillar Four: Building community capacity**

No comment

Thank you,

Penelope McMillan

Anne Fleuren

**Postexertional Malaise (PEM)**

“PEM represents a real and debilitating symptom complex.”

J.M. VanNess, (2010)[[1]](#footnote-1)

In layman’s terms, PEM is the inability to function physically or mentally following even slight physical or mental exertion. It incorporates significant pain as well as muscle weakness and cognitive dysfunction.

From J. Spotila 2010[[2]](#footnote-2):

Post-Exertional Malaise is unique to ME/CFS/FM. It is a full body assault that is not the result of deconditioning.

Studies on the effect of moderate physical exercise by ME/CFS sufferers show that such exercise lowers the pain threshold through an abnormal central nervous system response and reduces the capacity for cognitive processes.

Recovery from exercise is greatly delayed with muscles weaker a day after exercise. Muscle stress is evident through higher levels of lactate.

Current research into PEM includes research into abnormal gene expression.[[3]](#footnote-3)

At present there is no treatment for PEM. Management involves maintaining physical and mental activity well below the individual’s capacity. Over-exertion exacerbates PEM and further reduces capacity.

1. J.M. VanNess, ‘Postexertional Malaise in Women with Chronic Fatigue Syndrome,’ *Journal of Women’s Health* vol 19, no 2, 2010 p5 [↑](#footnote-ref-1)
2. J. Spotila, *Post-Exertional Malaise in Chronic Fatigue Syndrome* CFIDS Association of America, 2010 pp2-6 [↑](#footnote-ref-2)
3. A.R. Light, L. Bateman et al, ‘Gene expression alterations at baseline and following moderate exercise in patients with Chronic Fatigue Syndrome, and Fibromyalgia Syndrome,’ *Journal of Internal Medicine*, vol 271, no 1, 2012 pp64-81

 Meyer et al, ‘Post-exertion malaise in chronic fatigue syndrome: symptoms and gene expression,’ *Fatigue: Biomedicine, health & Behaviour*, vol 1, no 4 pp190-200 [↑](#footnote-ref-3)