



## Providing hope & help for people living with ME/CFS

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Committee Secretary  
Senate Standing Committees on Community Affairs  
PO Box 6100  
Parliament House  
Canberra ACT 2600

Emerge Australia welcomes the opportunity to comment on the Social Security (Administration) Amendment (Continuation of Cashless Welfare) Bill 2020.

Emerge Australia is the national organisation providing information, support and advocacy for people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Our work gives hope and help to more than 250,000 Australians living with ME/CFS.

ME/CFS is a complex and disabling disease that affects many parts of the body, including the brain and muscles, as well as the digestive, immune and cardiac systems, among others. It is classified as a neurological disorder by the World Health Organization.

The impacts of ME/CFS can be devastating, leaving 25% of patients housebound or bedbound, with many people unable to work or participate in community life. People living with ME/CFS often feel invisible due to the unknown cause of the condition, lack of effective treatment options and limited community awareness, leading many to 'go missing' from their own lives.

### Emerge Australia's position on the cashless debit card

The cashless debit card (CDC) is not fit for purpose for a chronically ill and disabled population like people living with ME/CFS. The aim of the CDC is to create behaviour change, namely to reduce alcohol consumption, use of illicit drugs and gambling, in people receiving social security payments. But the program is not targeted and captures many people who do not exhibit the problem behaviours that the CDC is designed to address. There is no evidence that people with ME/CFS have higher rates of alcohol consumption, illicit drug use or gambling than the general population, nor any evidence that they lack the ability to budget or manage their finances, therefore this program is unwarranted in this population.

Given the unintended consequences of the program, including increased financial hardship, reduced emotional wellbeing and loss of freedom and dignity, we strongly recommend that the CDC is not imposed on people living with chronic illnesses including ME/CFS, as it creates additional hardship and stigma for people whose lives are already difficult. At the very least, the program should not be mandatory. A voluntary program would allow those who might benefit from the program to opt in, while respecting the rights of Australians with disabilities to choose what is right for them.



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### Not fit for purpose

The stated aim of the cashless debit card (CDC) is to 'reduce the levels of harm underpinned by alcohol consumption, illicit drug use and gambling by limiting Trial participants' access to cash and by preventing the purchase of alcohol or gambling products (other than lottery tickets)'.<sup>1</sup>

There is no evidence that ME/CFS patients as a cohort have any greater issue with alcohol consumption, illicit drug use or gambling than the general public. In fact, many ME/CFS patients are alcohol intolerant and sensitive to pharmaceutical drugs, which makes them less likely to have issues with alcohol or illicit drugs. Where an individual does have an addiction, we believe it should be addressed as a health issue, not through compulsory income management.

In a speech to parliament on 8 October, 2020, Assistant Minister Evans said that the objective of the CDC was to reduce 'immediate hardship and deprivation, helping welfare recipients with their budgeting strategies and reducing the likelihood that they will remain on welfare and out of the workforce for extended periods.'<sup>2</sup>

While Australians with ME/CFS are chronically ill and disabled, this does not mean that they are incapable of managing their finances and in need of help with their 'budgeting strategies'. For many with the condition, ME/CFS is lifelong as recovery rates are low (estimated to be just 5-10%<sup>3</sup>). In Emerge Australia's 2019 Health and Wellbeing Survey of more than one thousand Australians with ME/CFS, 89% of respondents indicated that they had stopped or reduced work as a result of their condition.<sup>4</sup> Australians living with ME/CFS are therefore very likely to be on social security payments and out of the workforce for extended periods. Given that the CDC will not improve the health or functional capacity of chronically ill or disabled Australians, it will therefore not help them move off social security, nor help them return to the workforce.

### Unintended consequences

While the CDC seeks to address a problem which does not exist within the Australian ME/CFS patient community, it has significant unintended consequences, including loss of freedom, increased financial hardship, and reduced mental and emotional wellbeing.

#### Loss of freedom

##### Mandatory nature of the program

In making the program mandatory, the Commonwealth Government is implying that Australians with disabilities and chronic illnesses like ME/CFS are incapable of knowing what they need and unable to make

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<sup>1</sup> Orima Research (2017). *Cashless debit card trial evaluation: Final evaluation report*.

<sup>2</sup> Commonwealth, Parliamentary Debates, House of Representatives, 8 October 2020, 3 (Trevor Evans, Assistant Minister for Waste Reduction and Environmental Management)

<sup>3</sup> Cairns, R., & Hotopf, M. (2005). A systematic review describing the prognosis of chronic fatigue syndrome. *Occupational medicine*, 55(1), 20-31.

<sup>4</sup> Emerge Australia (2019). *Lifelong Lockdown: Lessons Learned from the Health and Wellbeing Survey of Australians Living with ME/CFS*. <https://www.emerge.org.au/health-and-wellbeing-survey-2019>



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good decisions for themselves. Australians with ME/CFS already live with severe restrictions imposed by the debilitating nature of their condition, which limits their freedom to make choices about many aspects of their lives. Rather than empowering Australians with disabilities to live independently and with dignity, the mandatory nature of the CDC program adds further restrictions and is disempowering.

While the program offers an exit pathway, this too adds additional burden to chronically ill people who would have to 'demonstrate reasonable and responsible management of their affairs, including financial affairs',<sup>5</sup> in order to exit the program. This is a punishing and humiliating process for people whose capacity to manage their own affairs has never been deemed inadequate.

At the very least, the CDC should not be a mandatory program.

### Freedom to choose where to shop

The CDC cannot be used everywhere, restricting where Australians with disabilities can choose to spend their money. Many Australians with ME/CFS rely on the cash economy, through markets or op shops, to make ends meet, but the quarantining of 80% of social security payments makes this difficult. Instead, people on the CDC are forced to shop at approved retail sites.

### **Increased financial hardship**

Emerge Australia's 2019 Health and Wellbeing Survey of Australians with ME/CFS<sup>6</sup> revealed a dire picture of poverty among people living with ME/CFS. Almost 95% of our survey respondents earn below the Australian average income, and more than two thirds live below the poverty line. While the incomes of Australians with ME/CFS are well below average, their financial expenses are typically high due to the costs of their medical care.

Independent research into the experience of people on the CDC found that participants commonly report not having enough money for essential items, difficulty providing for children and family members, difficulty participating in the cash economy and difficulty paying rent and other bills,<sup>7</sup> meaning that the CDC will add to the already high level of financial hardship faced by Australians with ME/CFS.

### **Reduced mental and emotional wellbeing**

Independent research into the experiences of people on the CDC found that the majority reported a reduction in their mental and emotional wellbeing since being put on the CDC.<sup>8</sup> Many people placed on the card felt that it was unfair and felt shame and stigma because, like most Australians with ME/CFS, they had no history of substance abuse or gambling, nor any difficulty with financial management. The experience of being on the card was described as both humiliating and infantilising.<sup>9</sup>

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<sup>5</sup> Department of Social Services. *Cashless Debit Card*. Accessed 22 Oct, 2020. <https://www.dss.gov.au/families-and-children/programmes-services/welfare-conditionality/cashless-debit-card-overview>

<sup>6</sup> Emerge Australia (2019). *Lifelong Lockdown: Lessons Learned from the Health and Wellbeing Survey of Australians Living with ME/CFS*. <https://www.emerge.org.au/health-and-wellbeing-survey-2019>

<sup>7</sup> Marston, G., Mendes, P., Bielefeld, S., Peterie, M., Staines, Z., & Roche., S. (2020). *Hidden costs: An independent study into income management in Australia*.

<sup>8</sup> Ibid.

<sup>9</sup> Ibid.



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Emerge Australia seeks to support and empower Australians with ME/CFS to live with dignity, despite their significant limitations. We are very concerned that the CDC will have a significant negative impact on the emotional wellbeing of Australians living with chronic illnesses like ME/CFS, who already carry the burden of the stigma of an illness which is misunderstood, and the emotional toll of living with a debilitating health condition.

### Recommendations

Emerge Australia recommends that people with chronic illnesses like ME/CFS and other disabilities who are receiving social security payments which would be covered by the CDC be excluded from the program, because it is not fit for purpose, does not address a need within this population, and creates significant additional hardship. At the very least, the CDC should not be a mandatory program. A voluntary program would allow people who might benefit from the program to opt in, while respecting the rights of Australians with disabilities to choose what is right for them.

Given the high poverty rate among people with disabilities like ME/CFS, we also encourage the government to consider raising the rate of social security payments such as JobSeeker and Disability Support Pension, as sufficient income, not further restrictions, is the most effective way to reduce 'immediate hardship and deprivation' among Australians with ME/CFS.<sup>10</sup>

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<sup>10</sup> Commonwealth, Parliamentary Debates, House of Representatives, 8 October 2020, 3 (Trevor Evans, Assistant Minister for Waste Reduction and Environmental Management)