



Making connections, changing lives for people with  
ME/CFS and associated conditions

## Emerge Australia 2019-20 Federal Pre-Budget Submission

The Hon Josh Frydenberg, MP,  
Federal Member for Kooyong,  
Treasurer of Australia,  
PO Box 6022,  
House of Representatives,  
Parliament House,  
Canberra, ACT 2600

The Hon Greg Hunt, MP,  
Federal Member for Flinders,  
Minister for Health,  
PO Box 6022,  
House of Representatives,  
Parliament House,  
Canberra, ACT 2600

Dear Mr Frydenberg and Mr Hunt,

### PRE-BUDGET SUBMISSION 2019-20

From *Emerge Australia*:

**Mission:**

*To support, provide information and advocacy for people associated with Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS).*

**Vision:**

*Universal awareness and acknowledgement of ME/CFS as a medical condition.*

**Values:**

*To serve the best interests of people affected by ME/CFS with integrity, compassion and empathy.*

**Emerge Australia respectfully requests that the 2019-20 budget includes sufficient spending to enable implementation of all recommendations in the National Health and Medical Research Council (NHMRC) Draft Report on ME/CFS to the NHMRC Chief Executive Officer dated December 2018, copy attached <sup>1,2</sup>.**

We believe that the NHMRC report into ME/CFS is an excellent piece of work by Government. It is the most up to date and comprehensive report on ME/CFS prepared by a Government and an expert

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<sup>1</sup> NHMRC Draft Report submitted as supporting doc; p23 has details of recommendations.

<sup>2</sup> Please note the report is in draft form pending public consultation.

advisory committee in over two decades. We believe that this report is a prudent starting point for spending decisions.

ME/CFS is a severely debilitating and serious medical condition which affects a large number of Australians (up to 240,000 Australians based on a prevalence estimate of 1%<sup>3</sup>) who deserve full and fair funding in the 2019-20 budget.

We have set out below Emerge Australia's major spending recommendations, supporting information, and a concluding summary.

Thank you for the opportunity to make this submission.

## MAJOR RECOMMENDATIONS FOR SPENDING

### **A. Emerge Australia submits that the 2019-20 budget for ME/CFS research and health services should reflect the proportion of Australians who have the illness, and the significantly disabling and debilitating impact it has on them:**

The annual spending recommendations below provide a benchmark to assist decision making on the appropriate scale and proportion of spending needed to address the impact of this significant health condition.

All figures are calculated in proportion to the NHMRC population prevalence estimate of 1.0%<sup>4</sup> of all Australians having ME/CFS.

1. \$8.5m of additional annual funding from NHMRC grants<sup>5</sup>.
2. \$13m of additional funding from the Government's \$1.3 billion Health and Medical Industry Growth Plan, announced in the 2018 – 19 Budget<sup>6</sup>
3. \$790m of additional Health funding from total Federal Budget - estimated annual expenditure on Health of \$78.8 billion for 2018-19<sup>7</sup>.

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<sup>3</sup> Carruthers, B. M., & van de Sande, M. I., (Eds). (2012). *Myalgic Encephalomyelitis – Adult & Paediatric: International Consensus Primer for Medical Practitioners*.

<sup>4</sup> Prevalence of 0.2-1.0% from NHMRC Report p15 e.g. ME/CFS affects between 48,000 and 240,000 Australians. It is noted that "the estimates of Australian prevalence and burden of ME/CFS would benefit from being updated."

<sup>5</sup> NHMRC Annual Report 2018, p119, total NHMRC grants in the 2017-18 year were \$848m.

<sup>6</sup> Budget Paper No. 2, 2018 – 19, p116 –20

<sup>7</sup> Table 8, Summary of Expenses – Statement 6, Expenses and Net Capital Investment, Health, Budget Paper No 1 2018-19

4. In addition to this we submit that the total disease burden of ME/CFS is greater than just making an equivalence from the proportion of people afflicted. Up to 25% of patients with ME/CFS are so severely affected they are bedbound or housebound, with most unlikely ever to return to work full time. These patients also have an above-average vulnerability to self-harm<sup>8</sup>. Recent research indicates that people with ME/CFS are more disabled than people with Multiple Sclerosis, they are relatively less able to work and, subsequently, have lower income levels<sup>9</sup>.

**B. There is a large “payback” to the budget from increased Federal spending**

1. Spending \$10m in the upcoming 2019-20 budget would be fully paid back to the budget if only 1.3% of those with ME/CFS make a substantial recovery. This is an exceptionally low threshold for financial break-even<sup>10</sup>.
2. Spending \$10m per annum offers an exceptional potential “payback” to the budget: if spending \$10m per annum can help just 5% of those with ME/CFS to recover, then the payback to the budget would equal \$38.7m per annum, or 3.9x benefit versus cost.
3. If spending \$10m per annum helps just 10% of those with ME/CFS to recover, then the payback would be \$77.5m per annum or 7.8x benefit versus cost.
4. The estimated direct cost of ME/CFS to the national health budget is \$765m per annum, and the estimated total community cost of ME/CFS is \$3.7 billion per annum<sup>11</sup>.

**C. Emerge Australia respectfully submits that additional or “catch up” spending is appropriate for ME/CFS research, health, disability and welfare spending. We believe that ME/CFS has not had a “fair go” i.e. has not benefitted from a fair share of spending over recent decades.**

1. The Federal Government has spent less than \$100,000 per year over each of the last 18 years on research into ME/CFS via the NHMRC<sup>12</sup>. This is less than 0.02% of total NHMRC grant spending<sup>13</sup>, despite the fact that around 1.0% of Australians struggle with ME/CFS.

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<sup>8</sup> Bedbound / housebound and unemployed numbers from NHMRC Report page 15. Self-harm data see para D5 herein

<sup>9</sup> Kingdon, C. C., Structural Status and Wellbeing of People With ME/CFS Compared With People with Multiple Sclerosis and Healthy Controls, Pharmacoeconomics Open 2 – 381, 2018

<sup>10</sup> Only 619 people need to recover out of 48,000, or 3,097 out of 240,000 (reflecting the prevalence range of 0.2 – 1.0%). Payback figures are of course indicative-only and require appropriate qualification: they are based on \$765m annual cost plus the additional \$10m annual spending cited in the example.

<sup>11</sup> RACP Clinical Practice Guidelines 2002 cost estimates, updated using Reserve Bank of Australia inflation calculator. See Loblay, R. et al., 2002, RACP Clinical Guidelines, pS33 for cost data

<sup>12</sup> Ministerial correspondence 1 May 2017 - letter from the Hon. Greg Hunt.

2. We respectfully submit that this is 50 times less than a 'fair go', based on the number of Australians who have the illness, and how serious and debilitating it is.
3. We contend that this level of general underspending is also reflected in health services, disability and welfare spending.
4. We further submit that levels of expenditure and policies in health, disability and welfare systems regarding ME/CFS are based on outdated information. It is extremely difficult for ME/CFS patients and carers to access support, and in our opinion, this perpetuates the perception that Government and the healthcare system are, at best, ill-informed and at worst do not believe that ME/CFS is a real illness with physiological causes.
5. The fact that ME/CFS is a physiological or biological illness, and not a psychiatric condition, has been widely accepted in official and scientific literature <sup>14</sup>. See, for example, Centers for Disease Control (CDC) guidance<sup>15</sup> updated in 2018, and Institute of Medicine (IOM) 2015 report on ME/CFS <sup>16</sup>.
6. A consequence of the significant underfunding for ME/CFS has been the impact on official Australian clinical practice guidelines. These guidelines, on how to diagnose and treat ME/CFS, were published in 2002 (17 years ago)<sup>17</sup>. We are confident that if appropriate funding were forthcoming this situation would be speedily rectified with direct, and immediate benefits to patient welfare.
7. The lack of investment by Government in up to date guidance for clinicians is seriously disproportionate to the number of Australians who have the illness, and the debilitating impact that it has.
8. Recent international research, based on an international and Australian sample population, reports a high level of stigma experienced, and consequent negative health impacts, in people with ME/CFS <sup>18</sup>. Emerge Australia respectfully submits that the stigma experienced by patients with ME/CFS can be significantly reduced by Government if the upcoming budget addresses prior underspending on the condition.

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<sup>13</sup> NHMRC Grants Funding 2000 - 2016 Summary.

<sup>14</sup> See USA DHHS IOM Report, Beyond Encephalomyelitis/Chronic Fatigue Syndrome, Redefining An Illness, 2015. A useful summary is in Maxmen, A, Biological Underpinnings to Chronic Fatigue Syndrome, news article in Nature, 30 March 2017, p 602

<sup>15</sup> <https://www.cdc.gov/me-cfs/index.html>

<sup>16</sup> <http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>

<sup>17</sup> RACP Clinical Practice Guideline: Chronic Fatigue Syndrome, Med Journal of Aust, 2002; 176(9): 17–55

<sup>18</sup> Terman, J. M. et al., Confirmatory Factor Analysis of a Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Stigma Scale, Journal of Health Psychology, 1 – 10, 2018, pages 3,4,7 and 8.

9. The NHMRC Draft Report on ME/CFS offers Government a prudent basis on which to make a significant 2019-2020 budget allocation, both to “catch up” on prior low levels of spending and to make a significant improvement in the lives of some 240,000 Australians, and their carers.

## SUPPORTING INFORMATION

### D. Large numbers of Australians are seriously harmed by ME/CFS:

1. Up to 240,000 (1.0%) of Australians have ME/CFS, according to the estimates in the NHMRC Draft Report [for footnote NHMRC Draft Report page 15].
2. Up to 60,000 are bedbound or housebound [NHMRC Draft Report page 15] and largely dependent on carers. Many of these patients are isolated and subsequently vulnerable to a range of serious health problems associated with loneliness and isolation, including cardiac disease and self-harm.
3. Up to 148,000 are unemployed [NHMRC Draft Report page 15].
4. Up to 180,000 women have ME/CFS in Australia, making ME/CFS a serious women’s health concern. [Footnote USA DHHS IOM Report, Beyond Encephalomyelitis/Chronic Fatigue Syndrome, Redefining An Illness, 2015, page 2]
5. Preliminary research from the USA and UK report that ME/CFS patients are at serious risk of self-harm and suicide. Potential for suicide was indicated at a ‘sevenfold’ increase in a UK study<sup>19</sup> and at 17-18 times increase as compared to national averages, in a USA study<sup>20,21</sup>.
6. Resolution on ME – question put and agreed to by UK parliament on 24/1/19

*Resolved,*

*That this House calls on the Government to provide increased funding for biomedical research for the diagnosis and treatment of ME; supports the suspension of Graded Exercise Therapy and Cognitive Behaviour Therapy as means of treatment; supports updated training of GPs and medical professionals to ensure that they are equipped with clear guidance on the diagnosis of ME and appropriate management advice to reflect international consensus on*

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<sup>19</sup> Kaupur, N. et al., in The Lancet 2016 p1596

<sup>20</sup> p4-6 Dimmock, E. M. et al., Estimating the Disease Burden of ME/MECFS in the United States and its relation to research funding, Journal of Medicine and Therapeutics, DePaul University Chicago, USA, Vol 1 pp 1–7, 2016

<sup>21</sup> NB the authors note that results were ‘rough estimates’ and ‘first approximations’ with low sample size.

*best practice; and is concerned about the current trends of subjecting ME families to unjustified child protection procedures.*<sup>22</sup>

## E. SUMMARY RECOMMENDATIONS

**Emerge Australia requests that the 2019-20 budget includes spending to enable implementation of all recommendations in the National Health and Medical Research Council (NHMRC) Draft Report on ME/CFS to The NHMRC Chief Executive Officer dated December 2018, copy attached.** [footnote NHMRC Report page 23 has details of recommendations.]

**Emerge Australia respectfully submits that the requested spending is fair, urgent, and critically needed. A large number of Australians urgently require help.**

Yours sincerely,

Dr Heidi Nicholl  
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<sup>22</sup> <https://hansard.parliament.uk/Commons/2019-01-24/debates/FA1BBC27-37A7-4BFD-A2C0-A58B57F41D4D/AppropriateMETreatment?highlight=health%20debate%202018#contribution-758188D8-B537-433F-BE8B-ED2D33ABC4F3>