



# Cost of Living Inquiry

*Senate Select Committee on Cost  
of Living*

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**SUBMISSION**



AUSTRALIA

**RESEARCH  
ADVOCACY  
CURE**

# Cost of Living Inquiry

**Associate Professor Des Graham**  
**President**

**Rohan Greenland**  
**Chief Executive Officer**

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MS Australia is Australia's national multiple sclerosis (MS) not-for-profit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the national champion for Australia's community of people affected by MS.

MS Australia represents and collaborates with its state and territory MS Member Organisations, people with MS, their careers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Provide the latest evidence-based information and resources
- Help meet the needs of people affected by MS.

Multiple Sclerosis (MS) is the most acquired neurological disease in younger adults around the world with over 2.8 million people affected. More than 33,300 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern of disability. MS robs many people of quality of life, primarily driven by the impact of MS on pain, independent living, mental health, and relationships.

## Cost of Living Inquiry

MS Australia welcomes the opportunity to make a submission to the Senate Select Committee on Cost of Living.

MS Australia has drafted a range of submissions relating to the cost of living, including:

- [The extent and nature of poverty in Australia](#) – February 2023
- [Developing the National Housing and Homelessness Plan](#) – October 2023

This submission draws on the experiences and expertise of MS Australia's [Lived Experience Expert Panel](#) (LEEP), a diverse group of people across Australia who either live with MS or are a carer for someone living with MS, to ensure that lived experience formed the basis for this submission.

People living with MS are facing heightened financial strains amid the ongoing cost of living pressures, exacerbated by the increasing costs of living with disability, including MS specific costs such as high energy bills. The current cost of living crisis has the potential to escalate into a significant health crisis for many people grappling with chronic diseases like MS, exerting long-term repercussions on their disease progression and overall well-being. Australians experiencing financial hardship, while also contending with MS, find themselves not only struggling to afford basic necessities but also forced to make difficult choices regarding the management of their health condition. Many are compelled to postpone or forego necessary medical care.

MS Australia makes the following recommendations:

### MS Australia Recommendations

- A review of the cost of health care services for people with a disability including access to bulk billing services, eligibility for Pensioner Concession Cards and Health Care Cards and access to private health insurance.
- Improving affordability of allied health by increasing the number of allied health services available under Medicare Chronic Disease Management Plan items.
- Funding to increase the MS nurse workforce by an additional 65 MS Nurses for the people living with MS currently without access in Australia.
- Supporting more GPs to bulk bill their patients, especially those patients living with a chronic condition who require regular, lengthy and ongoing appointments.
- Providing more significantly subsidised specialist appointments for chronic illness patients which means they will need to see a specialist in that field for a prolonged period, or for the rest of their life.
- Providing additional subsidised psychology appointments on Mental Health Treatment Plans and allied health appointments on Chronic Disease GP Management Plans.
- Commonwealth Government, state and territory governments and energy regulators work to streamline and unify the energy concessions framework, explore the barriers to accessing energy concessions and find ways to better support Australians to access these concessions including automatic applications, improved communication and reduced administrative burden.

- State and territory governments enact energy concessions reform tailored to their respective jurisdictions, aiming to effectively address people's evolving energy requirements and circumstances.

- Commonwealth, state and territory governments explore the options for improving public and private housing outlined in the [ACOSS Summer Health Survey 2024 Report](#).

A review of income support payments including:

- The Commonwealth Government accept and implement the recommendations of the Community Affairs Reference Committee inquiry into the extent and nature of poverty in Australia including:
  - ❖ **Recommendation 1:** The committee recommends that the Australian Government take urgent action so that Australians are not living in poverty, including through considering the suitability, adequacy, and effectiveness of the income support system.
  - ❖ **Recommendation 2:** The committee recommends that the Australian Government take action to better support applicants and recipients of the Disability Support Pension and ensure people can participate in their communities and cover their living costs.
  - ❖ **Recommendation 3:** The committee recommends the Australian Government consider asking the Economic Inclusion Advisory Committee to review Commonwealth Rent Assistance, to determine effectiveness and appropriateness at alleviating cost of living pressures.
- A review of the cost of healthcare services for people with a disability including access to bulk billing services, eligibility for Pensioner Concession Cards and Health Care Cards and access to private health insurance.
- Suspend participation and mutual obligation requirements while the Disability Employment Services program is being reviewed.

## a. the cost-of-living pressures facing Australians

### Case Study – Jo

*Jo lives with her partner and two teenage sons in regional Victoria. Jo was diagnosed with progressive MS 6 years ago and her mobility is decreasing rapidly, she will most likely be using a wheelchair by next year. Living with progressive MS means that the future is uncertain for Jo, she says that her health is “on my mind every single day, how will my MS keep evolving?”.*

*Jo needs to work financially to help support her family and she enjoys work as she feels as though she is contributing to her community and maintaining a sense of purpose in her life. Jo wants to manage her MS well, so she can keep working for as long as possible. However, her earning capacity is less due to her MS symptoms and she must have flexible working arrangements such as working from home and flexible hours to help manage her symptoms such as fatigue and incontinence.*

*Jo has a NDIS plan that covers many of the supports that she needs, however she still faces significant out-of-pocket expenses in managing her MS. Jo sees an optometrist as she has declining eyesight due to MS, which is not covered by her plan. Additionally, Jo has a pre-existing*

heart condition that is exacerbated by MS and pays \$300 per visit to the cardiologist out-of-pocket.

Jo experiences severe constipation as a symptom of MS, and while the appointments with a Dietician are covered by her NDIS plan, the supplements recommended by the Dietitian are not. Similarly, to manage urinary incontinence Jo pays for Botox treatment in her bladder twice per year through a urologist, this treatment significantly improves her quality of life.

These additional medical costs add up to thousands of dollars across the year and Jo has found herself having to prioritise family and household costs over preventative health treatments. Currently Jo can't afford to see the chiropractor, which impacts her ability to move well as she has limited mobility on her left side.

In this cost-of-living crisis Jo is also cutting back on services like the hairdresser when the medical bills are piling up.

When it comes time to do the weekly grocery shop, Jo has a budget of \$200 for her family of four. Last week she was only halfway through her grocery list when she realized that the items in her trolley already totaled \$197.

Jo says that she "feels as though what happens with my MS should come second to my sons and family" and that living with MS is a significant financial burden.

### *The financial cost of MS*

People with disability face sizeable additional costs because of their disability.<sup>1</sup> For people living with MS and their families the main drivers of poverty are high living and health care costs and reduced employment and economic opportunities<sup>2</sup>. Analysis of MS Australia's Australian MS Longitudinal Study (AMSL)<sup>3</sup> shows that the annual cost of a person living with MS is \$ 73,457. This figure is a \$5,075 increase in costs from 2017, with many of these being direct costs borne by the person living with MS and their carer. It also includes indirect costs from lost wages, informal care, and early retirement. For those with 'severe disability', the costs are more than triple at \$123,333 compared with those living with low or no disability (\$32,829).

Out-of-pocket costs for health care with MS are high, from specialist fees to medicines, imaging and allied health appointments. Additionally, there are costs for travel to appointments, parking, time away from paid work, childcare, access to exercise and dietary costs.

A member of MS Australia's LEEP who lives in regional QLD outlines the issue:

*"My GP does not bulk bill, so the out-of-pocket costs associated with attending appointments quickly build up, particularly if the situation is complex and requires multiple long appointments to determine treatment direction and gauge progress.*

*The cost of visiting specialists is often very high, in the magnitude of hundreds of dollars. Whilst rebates are available from Medicare, patients are often still left hundreds of dollars out-of-pocket. I'm fortunate to be in a position currently where I see a neurologist through the public system, so it doesn't cost me anything, but my previous neurologist operated from a private practice and many other people living with MS are also in that position. When you need to see that practitioner at least once every 6 months (and often more, especially if your condition changes) it can become very costly."*

Similarly, a member of the LEEP who lives in Tasmania and does not have a NDIS plan explains:

*“You are always spending money on your health, on medications and allied health appointments – when having a relapse, I see my GP first and by the time I have seen my osteopath then my neurologist I am \$250 out-of-pocket. I need more appointments to be subsidised.”*

### *Health outcomes and costs*

The best medical care for MS requires early intervention and a multidisciplinary approach, including MS nursing and allied health services, coupled with regular evaluations, ideally overseen by a neurologist specialising in MS. In Australia, public neurology or MS clinics, often offering free services, are typically the most suitable facilities to deliver comprehensive MS care. However, in many parts of Australia these services are not available or are privately operated so incur costs.

One-third of Australians living with MS (equivalent to 8,000 people) do not have access to life-changing MS nurse care and have consistently worse health outcomes.<sup>4</sup> MS Nurse care reduces the need for other, more costly health professionals, such as GPs and neurologists and prevents emergency department presentations and potentially, hospital admissions. If every Australian with MS had access to MS Nurse care as part of their ongoing MS management plan this would result in substantial cost savings for MS healthcare in Australia and for the individuals.

Medication costs are largely controlled once listed on the Pharmaceutical Benefits Scheme, but for someone experiencing multiple symptoms that require management through medication, or who is living with multiple conditions, the cost of purchasing several medications on a regular basis can still be significant.

Similarly, the cost of accessing mental health support is very high. This is especially important to consider when a person living with MS is undergoing their diagnosis journey or if they have a relapse, these are the times when people are most vulnerable and most needing support.

People with MS can lessen the impact of the disease by managing modifiable lifestyle factors such as physical activity, diet, gut health, supplements, weight and obesity and other medical conditions. Often there is an increased cost associated with managing these lifestyle factors. For people who are unable to access the NDIS, the cost of regular allied health support to improve their health can be prohibitive.

A member of MS Australia's LEEP who lives in the ACT outlines the issue:

*“The increased cost of living is making it more difficult to live well with MS. Managing my MS and living well with MS depends on eating well (and the cost of fresh fruit & veg has gone up), maintaining regular exercise (I do Pilates-like classes with a blend of strength, balance and mobility that are \$30 per class) and keeping regular medical appointments with my neurologist and GP. While the NDIS covers specific disability-related costs, it doesn't cover these things that are so important for managing my MS but are considered an everyday expense.”*

### *The NDIS*

MS Australia found through feedback from the LEEP that the people living with MS who were not feeling the pressures of the cost-of-living crisis had a NDIS plan that covered the majority of their health expenses. In these instances, access to NDIS appears to mitigate against the impact of cost of living crisis. This highlights the importance of ensuring access to the NDIS for people who need the support. There are currently 33,300 people living with MS in Australia and as of 31 December 2023

there were 10,728 people living with MS who have an approved NDIS plan<sup>5</sup>. With only one third of people living with MS in Australia accessing the NDIS and many who are not sufficiently funded, people are bearing the cost of living with MS themselves due to difficulty navigating the system or ineligibility for the NDIS.

A member of the LEEP who lives in QLD and uses a wheelchair explains:

*"I am in a fortunate position that the cost-of-living crisis has had little impact on me due to sound financial decisions made earlier in life before MS and I have a really good NDIS plan and the majority of my expenses relating to MS are covered under my NDIS plan."*

### **MS Australia recommends:**

- A review of the cost of health care services for people with a disability including access to bulk billing services, eligibility for Pensioner Concession Cards and Health Care Cards and access to private health insurance.
- Improving affordability of allied health by increasing the number of allied health services available under Medicare Chronic Disease Management Plan items.
- Funding to increase the MS nurse workforce by an additional 65 MS Nurses for the people living with MS currently without access in Australia.
- Supporting more GPs to bulk bill their patients, especially those patients living with a chronic condition who require regular, lengthy and ongoing appointments.
- Providing more significantly subsidised specialist appointments for chronic illness patients which means they will need to see a specialist in that field for a prolonged period, or for the rest of their life.
- Providing additional subsidised psychology appointments on Mental Health Treatment Plans and allied health appointments on Chronic Disease GP Management Plans.

## **b. the Government's fiscal policy response to the cost of living**

MS Australia wholeheartedly welcomes the Government's initiatives aimed at reducing the cost of medications and enhancing bulk billing for GP appointments. The tripling bulk billing incentive and increasing the maximum dispensing quantity initiatives for pharmacies that were announced in the 2023-2024 Budget, are policy responses that have reduced the cost of medicines and GP visits for some people living with MS. However, further action is required to address health inequity.

### **Access to Energy Concessions**

Living with MS means high energy use and high energy bills. Approximately 60–80% of people living with MS suffer temperature sensitivity where neurological symptoms can temporarily become exacerbated by increases (or decreases) in body temperature for example during heatwaves, causing a worsening of symptoms.<sup>6</sup> As such, people with MS run their air conditioners 15 times more than average households.<sup>7</sup> This high energy use, combined with rising energy costs, results in significant energy expenses for people living with MS and their families. A member of the LEEP provides the following insight:

*“Living with MS has definitely increased the pressures on our cost of living. Electricity has been the main issue for our budget. The need for utilising the fans or air conditioning in the house has increased substantially, as the heat severely impacts myself and my MS symptoms. With extra usage and rising costs of electricity in general, we have noticed a definite impact on our budget.”*

A recent report by ACOSS found that hot homes can significantly harm both the physical and mental well-being of individuals. Such conditions can exacerbate existing medical conditions and disabilities, adversely affecting the productivity of household members, especially those who work or study from home. Additionally, the heat can contribute to increased tensions among household members.<sup>8</sup>

Similarly, a member MS Australia’s LEEP who lives in regional QLD outlines her concerns about high energy bills:

*Living with MS, and looking into the future, I am quite concerned with the need for continued extra use of the air conditioning. I believe the impact on our budget will continue. Unfortunately, I am unable to access any other government support such as the Disability Support Pension or Health Care Card. This means that I am also unable to access the QLD Government's electricity concession for medical cooling. We are a family who are not on a huge income, and the rising costs and need for extra use of electricity is a real concern for us, likely to impact other spending in our budget. I would like there to be a chance for review into the medical heating/cooling concession schemes to include those people who aren't currently receiving any other government support payments and can prove their electricity costs are rising due to their disability.*

A report by the Consumer Policy Research Centre (CPRC)<sup>9</sup>, Mind the Gap: Identifying the gap between energy concession eligibility and concessions received, estimates that more than 35 per cent of Australians eligible for concessions on their energy bills may not be receiving them. As concessions are not automatically applied to bills, the onus lies with the eligible person to ensure it is applied to their bill. MS Australia supports the recommendations made by the CPRC to streamline and improve access to energy concessions.

Feedback from MS Australia LEEP members highlights that the Government's Energy Price Relief Plan implemented from July 2023 have eased cost of living pressures for people living with MS. A member of the LEEP stated that *“the Government's cost of living rebates on electricity have been a huge help with the payment of our electricity bill each month. We are thankful for this assistance”*.

#### **MS Australia recommends:**

- Commonwealth Government, state and territory governments and energy regulators work to streamline and unify the energy concessions framework, explore the barriers to accessing energy concessions and find ways to better support Australians to access these concessions including automatic applications, improved communication and reduced administrative burden.
- State and territory governments enact energy concessions reform tailored to their respective jurisdictions, aiming to effectively address people's evolving energy requirements and circumstances.
- Commonwealth, state and territory governments explore the options for improving public and private housing outlined in the [ACOSS Summer Health Survey 2024 Report](#).



### c. ways to ease cost of living pressures through the tax and transfer system

The economic circumstances for people with disability are vastly different to those without disabilities. For instance, more than half (56%) of Australians with disabilities rely on income support payments as their primary source of income, in contrast to only 13% of those without disabilities.<sup>10</sup> Consequently, when living expenses increase, people with disabilities bear a disproportionately heavier burden.

The statistics on unemployment underscore the need for focused efforts aimed at boosting employment rates and consequently the incomes of people with disability. People with disability face lower employment prospects, as evidenced by the fact that in 2018, only 53.4% of working-age people with disability were part of the workforce, in contrast to 84.1% of their counterparts without disabilities.<sup>11</sup>

As outlined in our [submission](#) to the Senate inquiry into the extent and nature of poverty in Australia (Poverty Inquiry), MS Australia supports reviewing income support payments, particularly the Disability Support Pension regularly. This would be of great value to recipients of income support in terms of assisting with out-of-pocket medical expenses. Many people living with MS struggle to access the Disability Support Pension. The current application process is difficult and lengthy, and assessment is inconsistent and not undertaken by staff with a good understanding of disability, especially progressive degenerative or 'indivisible' disease such as MS.

The final report of the Poverty Inquiry<sup>12</sup> references MS Australia's submission and includes recommendations that support improving the rate of and access to income support payments, including the Disability Support Pension.

#### **MS Australia recommends a review of income support payments including:**

- The Commonwealth Government accept and implement the recommendations of the Community Affairs Reference Committee inquiry into the extent and nature of poverty in Australia including:
  - ❖ **Recommendation 1:** The committee recommends that the Australian Government take urgent action so that Australians are not living in poverty, including through considering the suitability, adequacy, and effectiveness of the income support system.
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- Suspend participation and mutual obligation requirements while the Disability Employment Services program is being reviewed.

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