Submission to the Inquiry into the Support at Home Program

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Committee Secretary

Senate Standing Committees on Community Affairs

Ngunnawal / Ngambri Country

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This submission is made to the Senate Inquiry into the Support at Home Program in relation to aged care reform, with a focus on Motor Neurone Disease (MND), First Nations carers, and system design impacts on progressive illness.

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1. Introduction

I am a Baramadagal Darug (Aboriginal) woman and carer to my mother who lives on Wiradjuri Country in Wagga Wagga, and who was diagnosed with Primary Lateral Sclerosis Motor Neurone Disease (MND) on 20 November 2025. I make this submission having the lived experience of navigating the aged care system on behalf of my Mum as her daughter and Power of Attorney, under conditions of rapid neurological decline, alongside the systemic analysis reflected in MND Australia's submission and broader sector commentary.

MND encompasses a range of progressive neurological conditions. Some forms, including ALS, have an average life expectancy of approximately 27 months from diagnosis. It is characterised by rapid functional deterioration, high care complexity, and escalating dependency. The nature of the disease requires a system capable of anticipatory, flexible, and immediately responsive care.

The current aged care architecture, including the proposed Support at Home program, is not designed for conditions that move at this pace. Instead, it is structured around slow administrative cycles, static assessments, and cost-containment logic that shifts burden onto families, or in our case a sole family member.

Unlike people diagnosed with MND before the age of 65, who may receive NDIS packages worth hundreds of thousands of dollars annually, older Australians with the

same condition are directed into the aged care system and subjected to fundamentally different support arrangements that inadequately respond to MND.

I was approached to write for the Power to Persuade platform detailing our specific circumstances and public advocacy regarding the 1 November Reform failures. You can read that here: *https://www.powertopersuade.org.au/blog/the-robodebt-of-aged-care-mnd-reveals-that-aged-care-and-ndis-are-systems-built-to-miss-the-point/14/4/2026*

2. Access to services: structural delay as system design failure

Access to care is not primarily limited by service availability alone, but by systemic delay embedded in assessment, approval, allocation, and reassessment processes, with little meaningful capacity for decision-makers to exercise discretion in response to clinical urgency.

The system assumes stability and takes time. MND produces the opposite and steals time.

By the time assessments are completed and packages are approved, needs have often changed significantly before support is allocated, creating a continuous lag between need and response. This forces unpaid carers to substitute for formal care systems. The Daily Telegraph published our story here: https://img1.wsimg.com/blobby/go/e8e56810-fda3-49ec-8a55-be380b7bcaa4/Daily%20Telegraph%20MND%20advocacy-7f92c8f.pdf

Given women continue to undertake the majority of caring responsibilities, these delays transfer the costs of care from government to families. The result is lost income, reduced superannuation accrual, interrupted careers, and increased risk of poverty later in life, with impacts that can extend across generations.

3. Case Study: A Sixteen-Month Trajectory to Level 8

It took 16 months of advocacy on my part, including appeals and administrative escalation for us to receive the highest level of support that clinicians had consistently indicated was required.

I spoke about that on Channel Seven's National Live News here:
https://www.youtube.com/watch?v=RVVlpPIkQY4&t=2s

I provide a detailed chronology of our efforts in the table set out on the following page.

Assessment date	Dept	Level / Action	Approval	Allocation	Wait time	Notes:
16 February 2018	My Aged Care	1	2018	2018	Standard	Initiated due to fall prior to MND symptoms.
January 2020	My Aged Care	2	7 January 2020	September 2020	Standard	MND Symptoms started in 2020 but not identified as MND yet. Although Level 2 deemed necessary at the beginning of 2020 but not allocated until September.
8 January 2025	Baptist Care and Right at Home	3	8 January 2025	22 October 2025	Standard	Need for higher level obvious but told not to ask for re-assessment until 3 came through or we would risk going to back of the line on a 2 to wait for a level potentially higher than a level 3.
November 2025	Murrumbidgee Local Health District	3	Denied higher level			Told that level 3 is sufficient. We objected directly to Murrumbidgee Local Health District.
November 2025	Murrumbidgee Local Health District	SAH 7 (equivalent of old system 3)	28 November 2025	Never allocated	Standard	
6 December 2025	Appealed to Systems Governor					6 December 2025 – I appealed to Systems Governor seeking increase to level 8 on an urgent basis not standard. 27 March 2026 - Decision upheld to maintain level 7 on a standard wait time, told urgency could only be determined on cognitive decline and homelessness.
18 March 2026	AT-HM Scheme	Murrumbidgee Local Health District	15 January 2026	18 March 2026	Medium	Applied for $30k total ($15k home mods and $15k assistive tech) under the AT-HM Scheme, which was allocated. Have been unable to access it at time of writing (June) due to package provider having technical issues preventing approval of invoices.
27 March 2026	Application lodged to Administrative					Told I had to pay $100 to have lodgment accepted. I queried this given several other types of review

	Review Tribunal for review of Systems Governor decision					applications incl. against NDIS decisions require no fee payment. Told that they were investigating internally but current situation is that fee must be paid. I was told they would confirm to me the course of action. No response received or lodgment actioned at time of writing.
18 May 2026	Re-assessment w/ Murrumbidgee Local Health District	SaH 8	25 May 2026	26 May 2026	Urgent	At time of writing, we still do not have the benefit of the funds because the package provider is having internal difficulties drawing the funds and making time to review care plan.

The significance of this outcome is not that the system eventually approved and allocated with genuine urgency, a Level 8 package. The significance is that it took sixteen months of advocacy, reassessments, objections, complaints, and review processes to arrive at a conclusion that clinicians had consistently indicated was required, all while being the primary caregiver to my mum. It's been extremely difficult for both of us.

4. Co-payments and commodification of essential care

Co-payment structures effectively reframe essential care as discretionary consumption. For people living with MND, services such as hygiene, mobility support, and feeding assistance are not optional.

Co-payments function as a rationing mechanism, resulting in reduced service use based on affordability rather than clinical need, it's undignified and waiting until October 2026 to rollback this requirement on essentials i.e., showers is unreasonable and negligible.

5. Pricing escalation and erosion of package value

Evidence indicates significant increases in provider pricing, in some cases up to 84%, resulting in reduced care hours despite nominal package stability. This creates a net decline in service delivery capacity.

In January 2026 I was told by Home Made, the Care Partner we self-manage with, that they would pay for us to fill hours with a domestic support worker from the platform Hire Up. I re-confirmed this advice several times as I knew they owned the platform Mable as was constantly re-assured. Then a month into that arrangement they told us that they would not pay workers retained through Hire Up and suggested that we pick workers from Mable. As a result, I privately pay to maintain the Hire Up Domestic Support worker because my Mum had already built a good rapport with her before the invoicing issue was raised. I pay $172.73 a week for 2.5 hours of support if that day falls on a public holiday the same service costs $390.08.

6. Financial hardship mechanisms: misalignment with illness trajectory

Financial hardship mechanisms are not designed for progressive terminal illness. Costs accumulate rapidly through care needs, equipment, and loss of income and

superannuation accrual for those affected by the illness and family members who stabilise the situation at their own cost.

This results in depletion of savings and sustained financial pressure on households. Given women are most likely to step up to caring responsibilities and are already impacted by gender pay gaps when working, this has long-reaching impacts that undermine the stability and progress of women in society.

7. System downstream impacts: hospitalisation and residential care

Inadequate home support increases hospital presentations and earlier residential care entry. For MND, delays in assistive technology can lead to avoidable crises. This reflects system inefficiency rather than demand pressure.

I have experienced significant difficulty arranging short-term respite care for my Mum due to the backlog of older people waiting for residential aged care placements. This has reduced respite availability and made it difficult to secure short-term support. Where placements have been offered, they have generally required minimum stays of two to four weeks at a cost of at least $65 per day, despite providers being unable to guarantee availability more than two weeks in advance. I spoke about these issues on ABC Radio National here: https://www.abc.net.au/listen/programs/lifematters/how-can-carers-get-true-respite-when-the-system-is-broken-/106664568

8. Transition from Home Care Packages to Support at Home

Transition processes risk inconsistent reassessment outcomes and effective downgrading of support despite increased need. This is inconsistent with the Government's stated commitment that older Australians would be "no worse off" because of the transition to Support at Home.

This creates structural misalignment between clinical progression and funding systems.

9. Thin markets and geographic inequity

Regional and rural areas experience limited provider availability, higher costs, and delayed access to services, compounding inequity.

10. First Nations impacts

First Nations communities experience additional barriers including lack of culturally safe navigation, system complexity, and misalignment with kinship-based care models.

The system does not adequately reflect Aboriginal and Torres Strait Islander models of care and collective responsibility, nor does it have regard to Social and Emotional Wellbeing Frameworks.

11. System design critique

The aged care system operates as a cost containment and compliance system rather than a care delivery system.

Different systems for the same diagnosis

For rapidly progressive conditions, this results in predictable harm due to structural misalignment between need and response.

The distinction between aged care and disability support systems produces profoundly different outcomes for people with the same diagnosis.

A person diagnosed with MND before the age of 65 may receive NDIS supports worth hundreds of thousands of dollars per year and access a scheme specifically designed around disability, functional decline, and individualised supports. A person diagnosed after the age of 65 is instead directed into the aged care system, where support is

capped, subject to waiting periods, co-contributions, and restrictive assessment processes.

The result is that two Australians with the same diagnosis, prognosis and care needs can receive dramatically different levels of support based solely on the age at which they enter the system. This raises serious questions of equity, dignity, and consistency in public policy.

Barriers to review and accountability

Even to review a decision of the Department of Ageing Health and Disability at the Administrative Review Tribunal attracts lodgment costs of between $100 - $1,148. Yet someone with MND who is under 65 would be dealt with by NDIS, where there is no application fee. This contributes to the “have and have not” divide in the MND community and is generally a form of systems abuse targeting Older People, given that some Older People cannot even afford co-contributions to access showers let alone pay to access reviews of algorithm-determined outcomes.

Provider accountability and regulatory enforcement

Concerns about accountability extend beyond funding levels and assessment processes. During our engagement with a previous Care Partner, a charge of $508 that had been declined by Services Australia was subsequently passed on to my Mum. After I challenged the charge on the basis that it appeared inconsistent with the Provider Handbook, the Care Partner's accounts staff acknowledged the breach in writing.

I subsequently referred the matter to the Aged Care Quality and Safety Commission (ACQSC). The ACQSC also had difficulties obtaining clear and consistent explanations from the business owner, as a result the complaint was ultimately closed without enforcement action. I was advised that the matter may assist in identifying a pattern if similar conduct was reported in relation to the provider by other clients in the future.

This experience raised broader concerns about accountability and regulatory enforcement within the aged care sector. Effective oversight is critical to maintaining confidence in the system. Where older Australians and their families are required to identify, challenge, and pursue potential non-compliance themselves, confidence in the integrity of the system is undermined.

12. State and Federal Policy in conflict and failing to provide life-preserving essential breathing equipment

Enable NSW say they can't assist to fund a BiPAP (Bilevel Positive Airway Pressure) machine when people are in receipt of a Federal Government Aged Care Package.

I asked the Care Partner to reimburse the cost of the machine because Enable NSW was unable to assist. Our Care Partner declined saying:

"Unfortunately, this item cannot be covered under the Support at Home funding, as it is excluded due to alternative government programs being available to fund this type of equipment. I have reviewed suitable options and identified the Home Respiratory Program (HRP) through Enable NSW, which provides equipment for long-term respiratory support. I have attached further information for your reference, along with the application link below: https://www.enable.health.nsw.gov.au/about/publications/fact-sheets/home-respiratory-program

Additionally, under the Assistive Technology guidelines, respirators are listed as excluded items (page 17). As the BiPAP does not meet oxygen-related criteria, it is also not eligible to be funded under nursing consumables.

I have attached the relevant documents for your reference. I apologise that we are unable to support the BiPAP request. I have had both my Team Leader and clinical team review this to ensure accuracy."

I rang Enable NSW again and said that as the item isn't eligible under the aged care package and AT-HM scheme funding, and their website states *"not be eligible to receive assistive technology through any other government-funded program",* I would put in an application and provide that information from the Care Partner confirming my Mum is not eligible for assistance from another government-funded program.

The representative from Enable NSW told me that it would be rejected as their internal Policy states that are to reject anyone applying who is in receipt of an aged care package. Seemingly even when the package isn't providing very much, let alone for life saving medical equipment.

I bought my mother the lifesaving BiPAP equipment she requires for $4,600. We received no assistance to purchase this machine. I lodged another complaint with the Commonwealth Ombudsman and the Aged Care Quality Complaints Commission about being unable to access funding through both the federally funded aged care package administered by our Care Partner and the State body, Enable NSW.

13. Conclusion and recommendations

The Support at Home program does not adequately respond to progressive neurological disease such as MND and is otherwise causing foreseeable harm to older people experiencing natural ageing.

Key reforms required include:

- Prioritisation pathways for MND and similar conditions

- Predictive assessment models
- Regulation of provider pricing
- Removal of co-pay barriers for essential care
- Immediate access to assistive technology
- Culturally safe First Nations care navigation
- Reform of funding transitions
- Investment in regional service access
- Automatic escalation pathways for progressive neurological conditions where clinical evidence demonstrates ongoing functional decline.
- Presumptive approval of higher support levels where a person has a diagnosed terminal neurological condition and treating practitioners agree that progression is expected.
- Independent review of assessment tools and weighting criteria to ensure urgency is not primarily determined by factors such as homelessness or cognitive decline where those factors are unrelated to the diagnosed condition.
- Time-limited review processes for people with progressive neurological disease, including mandatory determination of reassessment requests within 30 days.
- Realistic alignment between what funding is required and levels of funding offered.

MND Clinics should be funded by the Government and care at home should not depend on administrative timing, geographic location, or personal wealth to access funding that is only available on the other side of paying co-contributions. The harm caused by the 1 November Aged Care reforms is an indictment on this Government.

Throughout this process I have repeatedly been reminded that aged care funding is not "my Mum's money" and that package funds must be viewed as a limited public resource. Yet many of the people responsible for designing and administering these systems will retire with pension arrangements and entitlements that provide a level of certainty and dignity not available to the older Australians subject to their decisions.

It is difficult to reconcile constant warnings about the affordability of showers, respite, physiotherapy, and assistive technology with a political culture that has historically been very comfortable funding its own long-term security.

If fiscal restraint is the justification for denying timely support to older Australians, then that restraint should be applied consistently. Older people living with disability should not be expected to accept lower standards of dignity, security, and support than those afforded to the people making decisions about their lives.

The impact of these reforms on our family has been severe, unnecessary, and entirely foreseeable. We deserve so much more, but in the absence of timely, proactive responses and basic humanity within these systems, we simply wish to spend whatever time we have together in peace, free from government incompetence, negligence, and bureaucracy.

Yours sincerely,

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