Submission from MND Australia in support of the Senate Inquiry into

The Transition of the Commonwealth Home Support Program to the Support at Home Program

Called by the Community Affairs References Committee

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Further Information

MND Australia welcomes the opportunity to provide further information in addition to the information contained in this submission. Please contact Clare Sullivan, CEO of MND Australia, on clare.sullivan@mndaustralia.org.au or 0415 265 262.

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About MND Australia

MND Australia is the national peak body of MND State Associations that support those living with, and impacted by, motor neurone disease (MND). Since 1993, we have been the voice for the MND community. MND Australia, together with the MND State Associations, form the only national network focussed on improving the lives of all Australians living with MND. Through strong national and international partnerships, we advocate for the needs of those impacted by MND and promote greater understanding of the disease. Our State Associations are:

- MND Western Australia
- MND Victoria/Tasmania
- MND Queensland
- MND New South Wales/Northern Territory/Australian Capital Territory
- MND South Australia

There are no effective treatments for MND and there is no cure. There are no remissions and progression of MND is usually rapid and relentless, creating high levels of life-limiting disability, regardless of the age at onset. People living with MND have complex, constantly changing needs, which require a wide range of changing supports. Average life expectancy following diagnosis is a scant 27 months.

MND Australia has four key priorities, these are:

> **Advocacy** - We advocate for improvements in treatments and care to ensure people living with MND have the best quality of life possible. We seek to improve the lives of those affected by MND through improvements to federally-funded care, enhanced data infrastructure, access to new treatments and genetic testing, and investment in research.
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> **Information** - We provide resources, information and service linkage for people living with MND, their carers and family, as well as for the health professionals and service providers who support them to live well.
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> **Research** – We invest millions of dollars annually through our research grants program which supports high-quality research to discover the causes, improve care and find treatments and ultimately a cure for MND.
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> **Connection** – We are the nexus between research, services support and lived experience engagement. Our members, the State and Territory MND Associations, provide services and support to the vast majority of people with MND in Australia. Our National MND Lived Experience Network of 165 people living with or impacted by MND provide critical insights to researchers, service professionals and government, facilitating informed policy, practice and care. We are also the custodians of the MiNDAUS Registry, open to all people diagnosed with MND in Australia and with 12 participating clinics.

What is motor neurone disease (MND)?

Each day in Australia two people are diagnosed with MND and each day two people with MND die.

There is no known cure.

Disease progression is often rapid and relentless, creating a wide range of changing needs and supports.

There are approximately 2,752 Australians living with motor neurone disease (MND) today [1].

Every day in Australia, two people are diagnosed with MND and two people die from the disease.

MND is the name given to a group of neurological diseases in which motor neurons – the nerve cells that control the movement of voluntary muscles – progressively weaken and die.

With no nerves to activate muscles, people with MND lose their ability to walk, speak, swallow and ultimately breathe. MND affects each person differently. Initial symptoms, rate and pattern of progression and survival time can all vary widely.

The lifetime risk of MND is about 1 in 300 people by the age of 85.

In 2025, it was estimated that 63% of people living with MND were diagnosed aged 65 and over [1].

There is no single medical test that can confirm diagnosis. The average time from the onset of symptoms to confirmation of diagnosis is 13 months in Australia [1]. Access to a specialised neurologist is key to timely, accurate diagnoses.

Average life expectancy for people living with MND is 27 months from diagnosis. A third of those die within one year and more than half die within two years of diagnosis. In 2023, 781 people with MND died in Australia [2]. In 2025, this number was estimated at 867 Australians [1].

In 2026, there are three pharmaceutical treatments available in Australia for MND. These treatments can slow disease progression, delay functional decline and extend survival times, but currently only two of these treatments are listed on the PBS. None of these treatments are a cure for MND.

Up to 15% of MND cases have a known genetic basis through a well-established family history. However, as we continue to better understand the complex nature of MND, it is becoming clear that genetic changes are a factor in a much higher percentage of cases.

Living with MND

People living with MND can experience a variety of changes in the early stages, such as stumbling or falling, changes in dexterity, slurred speech, trouble swallowing, muscle twitching, or cognitive and behavioural changes. As MND is a degenerative condition, these symptoms will worsen over time. The support and equipment needs of someone living with MND will therefore change, often rapidly.

People living with MND benefit greatly from coordinated, multidisciplinary care, as well as assistive technology [3]. This care team may include a neurologist, care coordinator, occupational therapist, physiotherapist, orthotist, respiratory specialist, speech pathologist, dietitian, nurse, social worker, psychologist or counsellor, palliative care expertise, an MND association advisor, NDIS support coordinator, and community service providers. Evidence shows that those who attend a multidisciplinary clinic experience extended life expectancy [4].

A large variety of aids and equipment, usually referred to as ‘assistive technology’ (AT) are needed. Common forms of AT include power wheelchairs, hoists, hospital beds, respiratory aides, and/or eye-gaze technology to communicate. Many people also require home modifications, such as ramps or major bathroom modifications.

The MND State Associations provide wrap-around services and coordinated care, access to specialised equipment, assistance with system navigation and psycho-social supports.

Due to the length of time to receive an MND diagnosis, people living with MND will often have significant disability at the point of diagnosis and require immediate supports. This access to immediate supports is critical.

> MND Australia strongly advocates for more equitable solutions that benefit all people living with MND in Australia. We are concerned about inadequate government funding and support for people diagnosed with MND who are aged 65 and over, as well as broader inequities related to access to specialist healthcare, geographic location, cultural and linguistic diversity, and varying levels of health literacy and capacity among people living with MND, their families and carers.

Overview

MND Australia applauds the Inquiry into the Transition of the Commonwealth Home Support Program to the Support at Home Program and appreciates the opportunity to provide feedback based on the experience and observations of the MND State Associations and those of people living with MND.

In summary, our **key concerns** with the transition to the Support at Home Program are as follows:

1. Several people supported by MND State Associations are worse off under the new packages.
2. People diagnosed with MND are inconsistently treated regarding urgency and funding, with little hope for a timely reassessment.
3. The assessment algorithm is not sensitive to the realities of MND.
4. Prices charged by aged care providers have skyrocketed.
5. The co-pay for the 'Independence' category of expenses is inappropriate.
6. Accessing assistive technology, particularly communications devices and respiratory equipment, is problematic.

Our **key recommendations** for immediate action are as follows:

1. The value of Home Care packages should be transferred over to the Support at Home packages.
2. MND should be automatically assessed as urgent priority and at levels of funding that anticipate rapidly-changing needs.
3. The reassessment process should immediately review and rectify inappropriate assessments.
4. Any algorithm used in the assessment process should be adjusted to:
   a. Provide transparency about how criteria are applied in the assessment process;
   b. Recognise MND and other degenerative diseases as a rapidly progressing disease that requires predictive needs assessment; and
   c. Provide a recommendation that can be adjusted by a human assessor.
5. The fees charged by aged care providers should be regulated.
6. The purchasing power of Support at Home packages should be tracked and adjusted as needed.

7. The co-pay framework should be analysed to understand the financial burden it may be placing on individuals and households.
8. ‘Independence’ support services should not have a co-pay.
9. AT-HM funding should be available to people who have been unable to secure an aged care provider.
10. AT funding should explicitly cover respiratory equipment and text-to-speech aides.

1. Several people supported by MND State Associations are worse off under the new packages.

State associations report that many people have been automatically moved onto the same level number as they were under the Home Care Package program. For example, if they were receiving funding at Level 2 under Home Care Packages, they are receiving Level 2 funding under the Support at Home packages, while Level 3 Home Care Packages have moved over to a Level 3 Support at Home Package. This reflects a net drop in the value of their packages, as the amounts associated with each level number have changed. In the case of people receiving Level 2 funding, for example, there is a drop in the annual package amount of approximately $2,500; for people receiving Level 3 funding, the drop is $18,500 (see Table 1). This drop in funding is keenly felt, as the lower-level packages were already much too low to cover the intensive support needs required by a person living with MND.

Table 1: *Estimated value of financial packages from the defunct Home Care Package and the new Support at Home, emphasis on Level 2 and Level 3 comparability*

Home Care Package		Support at Home	
Level	Approx. Amount	Level	Approx. Amount
1	$10,500	1	$10,000
		2	$16,000
2	$18,500	3	$22,000
		4	$29,500
3	$40,500	5	$39,500
		6	$48,000
4	$61,500	7	$58,000
		8	$78,000

The fact sheet provided by the Department of Health, Disability and Ageing entitled “Support at Home program – classifications and budgets” clearly states, “When Support at Home starts, HCP care recipients will move to a transitional Support at home classification and **continue to receive the same funding level as they do with their HCP”** (emphasis added) [5, p. 2].

This has been a highly distressing situation for older people living with MND who are in this predicament. State Association staff have attempted to mediate and rectify this situation with My Aged Care representatives but have been told that the system is automatic and cannot be overridden; an issue discussed in point 4.

Older people living with MND who were already on an aged care support package were not expecting a drop in funding, and the difficulty to achieve a resolution is highly distressing. MND Australia requests that it becomes a matter of priority to rectify what appears to be an automated error.

Recommendation 1: The value of Home Care packages should be transferred over to the Support at Home packages.

2. People diagnosed with MND are inconsistently treated regarding urgency and funding, with little hope for a timely reassessment.

MND State Association staff report that many people with MND are being processed with ‘medium’ priority (8 – 9 month anticipated wait time [6]), and assessments are coming back anywhere from Level 1 to Level 8, with no logic or consistency as to why older Australians with the same degenerative condition are not being assessed consistently.

MND frequently leads to rapid deterioration, and older age corresponds to faster progression of the disease [7]. While the average lifespan from diagnosis is 27 months, for most older people the timeframe is shorter. Every case is urgent, and nearly every case requires high levels of funding to be adequately managed. It would be very rare for the disease to progress slowly enough to accommodate the lower levels of funding for any extended period of time.

Case study: Level 1 package funding in an urgent situation

A 72-year-old Victorian woman who is diagnosed with bipolar disorder and hyperthyroidism in addition to MND lives alone in a 2-story house. Motor neurone disease is having a progressive impact on her functional ability and overall health, with alarming weight loss of over 30 kilograms. Excessive fatigue is diminishing her ability to maintain independence as she struggles to look after her own personal care, shopping and meal preparation, and mobility.

She has sustained multiple falls in the past 12 months due to the progression of MND, including two falls that were serious enough for hospitalisation. While her son looks in on her, she has no dependable community support.

Her Support at Home package has been approved for Level 1 funding, equalling $10,000 per year. Her priority rating is Standard, with a listed wait time of 10 to 11 months. While she has had home modifications approved, again her priority for this funding is Standard. She is in urgent need of rails and ramp to allow her to enter and exit her home safely. She has not had any assistive technology approved; her assessor explained that only an occupational therapist can make that recommendation.

MND Australia has raised the issue of the urgency for adequate, timely funding for older Australians who are diagnosed with MND many times [8 - 13]. It is a relentless disease. Care cannot wait.

Recommendation 2: MND should be automatically assessed as urgent priority and at levels of funding that anticipate rapidly-changing needs.

While there is a reassessment process to address incorrect or inappropriate package or urgency levels, it is too slow to respond to the rapid progression of MND, in which significant degeneration can happen in the course of weeks or even days. An assessment cannot be lodged and processed until the assigned care package, however inappropriate, has been received. This can be a wait of 9 months or even longer. Such lengthy delays are finding older people living with MND with no support for their rapidly compromised health except for hospital.

Our State Associations tell us that reassessments can be fast-tracked but only with a letter from a medical doctor. This process creates an undue administrative pressure on doctors who are often unable to attend to such requests.

MND Australia strongly advocates for a reassessment process that recognises these lengthy wait times which are due to a poor initial assessment should not create a health emergency for older people living with MND or other rapid-progression diseases that compromise health and independence.

Recommendation 3: The reassessment process should immediately review and rectify inappropriate assessments.

3. The assessment algorithm is not sensitive to the realities of MND.

The State Associations are reporting that the algorithm is to blame for much of the inappropriate priority and funding decisions that have been experienced with the transition to the Support at Home program. Specifically, they report two primary issues.

There is never a point in time when a client is asked whether they have been diagnosed with MND or any other degenerative neurological disease. This means that assessments are conducted on the clients' state of health and independence at the time of assessment. A responsive assessment process should recognise MND as a specific category that includes the need to plan for both rapid progression and intensive clinical and non-clinical needs. Specifically, all older people living with MND will need allied health support (e.g., respiratory specialist, orthotist, physiotherapist, occupational therapist), assistive technology (e.g., respiratory aides, lifts, power wheelchairs, hospital beds, eye gaze technology), and home modifications (e.g., ramps, bars, bathrooms, widened doorways). Forward planning is critical to effectively managing MND and its quickly changing needs, but the algorithm does not recognise future states of need, even if they are just around the corner.

The algorithm cannot be overridden. Once the algorithm has delivered an assessment, there is no recourse for adjustment. Assessors have informed clients and State Association staff that they are unable to adjust or change the assessment that the algorithm provides. The only recourse is to await the package arrival and then apply for a reassessment.

Case study: Algorithm cannot be overridden or challenged

A 68-year-old woman in New South Wales was initially placed on a Home Care Package Level 2 (value = $18,500) while waiting for a Home Care Package Level 3 (value = $40,500), for which she had originally been assessed – a 9-month wait. She was allocated a Level 3 Support at Home Package (value = $22,000) which is inadequate for her needs. The client requested and received a reassessment; the Assessor informed the client that the algorithm had indicated her needs had not changed and that there was no way of changing that outcome.

The client and her daughter submitted a dispute and copied in local MPs. They were referred to the MND New South Wales State Association, who have provided a letter of support to the Assessor, providing more evidence for her needs. Due to the escalation of her case, the letter supported a reassessment to a Level 7 package.

With the introduction of a rights-based framework for My Aged Care, it is critical that older Australians are not reliant on an opaque algorithm to determine their level of support, with no pathway for adjustments or human oversight. The aged care system must take responsibility for the algorithm and ensure it does not inflict harm or make assessments that are unjustifiable. Automated decision-making by government departments needs to be clearly explained and described to the people who are impacted by the decision outcomes [14]. Further, there needs to be a reasonable, timely ability to review and correct poor or inappropriate decisions.

Recommendation 4: Any algorithm used in the assessment process should be adjusted to:

a. Provide transparency about how criteria are applied in the assessment process;
b. Recognise MND and other degenerative diseases as a rapidly progressing disease that requires predictive needs assessment; and
c. Provide a recommendation that can be adjusted by a human assessor.

4. Prices charged by Aged Care providers have skyrocketed.

There is much concern that the prices that aged care providers are charging is negating any increases in package values. The newly-required co-pay for some service categories is also impacted by price increases, moving some critical services out of reach.

MND State Associations report that aged care providers are charging much higher prices since the transfer to Support at Home took place in November 2025, at times exceeding NDIS cost structures. To ascertain whether the prices had risen significantly, MND Australia obtained the cost sheets for BlueCare, a major aged care provider in Queensland and northern New South Wales. Pricing sheets were obtained for December 2024 [15] and November 2025 [16]. We also obtained a pricing sheet for the NDIS for 2025/26 [17].

We provide a simple cost comparison in Table 2. With seven selected items, we have compared five items for cost increases by BlueCare from December 2024 to November 2025, and five items are compared with BlueCare November 2025 and NDIS 2025/26. To ensure the comparison is like for like, we have only compared items that are described in the same manner and with the same cost structure. All compared costs are for weekday services provided in the home and charged by the hour.

Comparing BlueCare pricing from December 2024 to November 2025, the five items that are compared have all risen between 31 – 84%. Personal care rose the least, with an increase of 31%, rising from $103 to $135 per hour. The cost of an allied health assistant rose the most, at 84%, from $106 to $195. In-home nursing rose 43% ($157 to $224), and respite in home and domestic assistance both rose 52% ($89 to $135). This random sampling of services which may be utilised by people living with MND indicates that BlueCare has increased their costs significantly within a one-year time span.

Comparing BlueCare pricing to NDIS pricing, the price gaps are even greater, ranging from 49 – 129% higher prices than the NDIS. Occupational therapy has the smallest gap, with BlueCare charging 49% more ($290/hour) than the NDIS ($189/hour). Domestic assistance has the greatest gap, with BlueCare charging 129% more ($135/hour) than the NDIS ($59/hour). The difference in cost for in-home nursing is similar, with BlueCare charging 124% more ($224/hour) than the NDIS ($100/hour). A dietitian costs 51% more from BlueCare ($285/hour) than from the NDIS ($189/hour), while personal care is 92% higher from BlueCare ($135/hour) than from the NDIS ($70). In sum, BlueCare is exceeding the cost structure employed by the NDIS in all five of the domains that are examined here.

This assessment is not intended to single out BlueCare in any way; rather it was chosen as a large and established provider which likely reflects trends across the aged care sector. A more comprehensive review would reveal how representative this simple analysis may be. Nor do we wish to imply that the costs charged are inappropriate; such a value judgement is outside the scope of this analysis. Our point is that the purchasing power of the packages has decreased as a result of price increases.

Table 2: *Comparison of BlueCare costs from 2024 to 2025 and with NDIS prices, 2025/26.*

Item (day, in home, by the hour)	BlueCare, Dec 24	BlueCare, Nov 25	% difference	NDIS, 2025/26	% difference
In-home nursing	$157	$224	+43%	$99.88	+124%
Allied Health Assistant	$105.75	$195	+84%	--	
Personal care	$102.75	$135	+31%	$70.23	+92%
Respite in home	$88.75	$135	+52%	--	
Domestic assistance	$89.25	$135	+52%	$59.06	+129%
Dietetics/dietician	--	$285		$189	+51%
Occupational therapy	--	$290		$193.99	+49%

The increase in costs has placed a lot of stress on people living with MND who are reliant on My Aged Care. First, it is devaluing the Support at Home package amounts even in instances where the amounts may have increased for individuals. Second, the co-pay requirements are harder for people living with MND to meet, meaning some of them are reducing the amount of support services they receive.

Case study: Higher prices from aged care providers means reduction in services

A Victorian man is on the transitional Level 4 Home Care Package (value = $63,758). He is awaiting a review to be placed on Level 8 Support at Home package (value = $78,106). Prior to the change to Support at Home on November 1, 2025 he was accessing 12 hours per week of in-home support from Uniting Agewell. Since the change-over, those hours have been reduced to 9 per week. Uniting Agewell said that their prices have increased due to the introduction of Support at Home. The client cannot afford the co-pay with these higher prices in place, and therefore the hours of support he receives has now dropped.

Older Australians, especially those with high clinical and support needs, must be able to afford the care they require on the Support at Home packages they receive. There is concern that these unaffordable prices will lead to people either doing without services, or arranging to receive services from unregistered individuals (which may lead to sub-standard service without accountability or recourse). MND Australia advocates for a review of aged care providers' fees structures; a comprehensive pricing structure which is similar, or ideally identical, to that used for the NDIS; and an alignment between package amounts and the cost of services. Furthermore, the co-pay process should be reviewed to understand how much older Australians are out of pocket for necessary services and the financial implications for individuals and households.

Recommendation 5: The fees charged by aged care providers should be regulated.

Recommendation 6: The purchasing power of Support at Home packages should be tracked and adjusted as needed.

Recommendation 7: The co-pay framework should be analysed to understand the financial burden it may be placing on individuals and households.

5. The co-pay for the ‘Independence’ category of expenses is inappropriate.

The co-pay funding structure for Support at Home is divided into three service categories [18]:

Clinical supports, such as nursing care, occupational therapy, and podiatry

Independence, such as help with showering, taking medications, transport, and respite care

Everyday living, such as cleaning, gardening, shopping, or meal preparation

The co-pay framework is organised based on an increasing co-pay from clinical supports (no co-pay) to independence supports (a sliding co-pay of between 5 – 50%) to the highest co-pay for everyday living supports (between 17.5 – 80% co-pay); see Table 3. MND Australia very much appreciates that all services categorised as clinical supports have no co-pay for anyone. We further accept that the everyday living category co-pay, which is quite high, is understandable given these services can also be independently sourced external to an aged care provider, often at a lower rate. However, there is great concern about the co-pay amount attached to the independence category.

As outlined on the My Aged Care website, this category includes such items as showering, taking medications, transport and respite care. It also includes assistance with toileting use. As already outlined in Point 4 above, the skyrocketing fees charged by aged care providers is making it difficult for people living with MND to retain services they had access to under the previous system, and many people have had to cut back on the hours of support they receive in the home. It is those services that are included in the independence category that is causing concern and distress.

Table 3: *Outline of participant contribution rates. Reproduced from My Aged Care [19]*

Income and assets assessment outcome	Service category – clinical supports	Service category – independence	Service category – everyday living
Full pensioner	0%	5%	17.5%
Part pensioner and self-funded CSHC holder	0%	Between 5% and 50%*	Between 17.5% and 80%*
Self-funded non-CSHC holder and means not disclosed	0%	50%	80%

Such services as showering, toileting and taking medications are all clinical-related and directly impact on health and wellbeing as well as the ability for many older Australians with MND to remain in their homes. Many clients are dependent on assistance to shower, use the toilet, or take medication, and reduced hours of support and high co-pays are already having a direct health impact, in addition to eroding the ability to live with dignity. These support activities are not optional. MND Australia strongly advocates that the Independence category of services be provided without a co-pay.

Recommendation 8: ‘Independence’ support services should not have a co-pay.

6. Accessing assistive technology, particularly communications devices and respiratory equipment, is problematic.

The two one-off payments, valued at a maximum of $15,000 each, for home modifications and assistive technology (AT) is very welcomed, as is the acknowledgement that MND and similar degenerative diseases has changing AT-HM needs, and is therefore provided with extended time for expending the funding. The State Associations are working with My Aged Care representatives to ensure the AT payment is both timely and adequate.

However, some people living with MND are finding it difficult to access the technology they need. This is due to:

a. Inability to access services.
b. Exclusions.

Inability to access services

The state associations report that some clients are having difficulty accessing the AT-HM funding because the funding is tied to an aged care provider. This is potentially impacting all people living with MND, whether urban or rural, as providers are declining to take on new clients until their Support at Home package is received, and this can take many months. There are also some clients who, due to being in rural, regional or remote areas, are unable to access a provider. Finally, some providers decline applicants because they have MND and the support they require is intensive and complex.

Case study: No local provider means no assistive technology

> An 87 -year-old woman in South Australia lives on her own in a regional town. She has weakness in her lower limbs, arms and head/neck, with no functional hand use. She is unable to stand without support. The family had created a caring roster to support her in the home, providing domestic and personal care support. However, as her needs have intensified they have been unable to continue to support her in the home, as it now requires two people to care adequately for her needs. One daughter works nights and was supporting her mother in the daytime, leaving her no time to rest; this is an unsustainable scenario. The client has therefore had to enter hospital.
>
> The client was approved for a Level 8 package, and also high-level AT-HM funding has been approved. However, she has been unable to sign up with an aged care provider due to lack of providers in her area. While MND South Australia has provided her with some of the equipment she needs, they are unable to claim the cost of the hire fees or delivery because the funding must flow through a provider.

MND Australia has raised concerns about the market consolidation of aged care providers before [20]. The inability to sign up with a provider is particularly problematic if it means funding cannot be accessed by people who desperately need it. We therefore request that funding be made available via another channel, particularly for the AT-HM packages (e.g., through Centrelink).

Recommendation 9: AT-HM funding should be available to people who have been unable to secure an aged care provider.

Exclusions

It is extremely concerning the respiratory equipment has an exclusion from AT funding [21, p. 26]. The reason given for exclusion is because it is “Currently funded by others” [Ibid.] MND Australia is unaware of where someone reliant on My Aged Care would access other funding for respiratory equipment.

Such equipment is critical for people living with MND. The muscles involved in breathing are weakened by MND, which leads to difficulties in speaking, swallowing and coughing; regular breathing also becomes disrupted, leading to very shallow breathing. Such changes lead to less oxygen absorbed into the bloodstream and more difficulty exhaling carbon dioxide; these two physiological changes have profound impacts on overall health and functioning. During sleep these problems are exacerbated, when breathing becomes extremely shallow and disrupted [22].

Many people living with MND choose to utilise non-invasive ventilation (NIV), most often using a bi-level positive airway pressure (bi-PAP) machine. A bi-PAP machine is often initially utilised at night but this can progress to using breathing assistance around the clock. This involves wearing a mask over the nose and/or mouth that is connected to a pump that provides breathing assistance. This is far less invasive than a tracheotomy and also much safer from complications such as infection. The use of NIV/bi-PAP is associated with a significant extension of life for people living with MND, with better outcomes associated with earlier adoption. Researchers reported that bi-PAP users live on average 21 months, compared to 13.8 months for people who did not use a bi-PAP machine, and using a bi-PAP machine for more than 8 hours/day is associated with even better outcomes. Life expectancy was longer using the bi-PAP machine when compared to the use of Riluzole, one of a few pharmaceutical treatments for MND that is available in Australia [23].

This simple intervention can be life-changing for people living with MND and their families. In addition to extended life expectancy, the bi-PAP machine helps with better sleep, increased energy levels, fewer headaches, better cough and speech capability, and overall improved quality of life [24].

We urge My Aged Care to include ventilation in the list of approved AT. It is the single-most effective intervention available to people living with MND that is medially non-invasive, low-risk, and provides extensive benefits for health, wellbeing and improved life expectancy.

MND Australia is also concerned about the wording regarding assistive technology for communication. We note that “text to speech devices and software” are allowed by prescription [21, p. 21]. However, there are exclusions for “voice generation” and “speech flow devices” [21, p. 31]. Many people living with MND are dependent on text to speech devices to communicate in the latter stages of disease progression. MND Australia would like to see clearer wording concerning the funding of such devices to ensure ease of access for clients.

Recommendation 10: AT funding should explicitly cover respiratory equipment and text-to-speech aides.

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