



Advancing care, advocacy and research in support of those living
with motor neurone disease (MND)

Submission to the Department of Health and Aged Care Consultation on the new Aged Care Act

16 February 2024

Clare Sullivan, CEO MND Australia
PO Box 117, Deakin West, ACT 2600
T: 02 8287 4980
ABN: 52 650 269 176
mndaustralia.org.au
info@mndaustralia.org.au

About MND

Motor neurone 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 their muscles, people with MND lose their ability to walk, to speak, to swallow and to breathe.

MND affects each person differently with respect to initial symptoms, rate and pattern of progression and survival time. Average life expectancy is just 27 months from diagnosis, with more than half dying within two years' of diagnosis.

There are no known causes for MND, apart from the 10 per cent of cases which have a genetic basis. There are no effective treatments and there is no cure. There are no remissions and progression of MND is usually rapid and relentless, creating high levels of disability and a consequent need for a wide range of changing supports based on the person's complex needs.

Executive Summary

MND Australia welcomes the opportunity to provide feedback on the new draft exposure Aged Care Act. MND Australia broadly supports the proposed legislation and the Government's ongoing commitment to aged care reform.

The commitment to a "rights" based legislative framework is opportune and in line with the Disability Royal Commission's final report. However, it is noted that not all the recommendations of the Royal Commission into Aged Care have been incorporated into the new Act, nor is disability explicitly stated in the new Act.

The reform process has been lengthy with the Royal Commission into Aged Care having tabled its final report in October 2020. Since this time, numerous people with MND have passed away without access to appropriate and timely supports and services.

More than 55% of people diagnosed with MND are over the age of 65 at the time of diagnosis and are thus ineligible for access to the NDIS. Currently, the maximum aged care package is \$59,593.55 which requires a co-contribution and requires a fund manager who can take up to 20% of this amount in fees.

This level of funding equates to less than two hours a day of supports and services. This is far from comparable to the disability supports and services available on the NDIS for a person diagnosed with MND who may be able to access funding for 24/7 support with no co-contribution. The average package for a person with MND under the NDIS in 2021 was \$242,000.¹

“With a third of people dying within one year and more than half within two years of diagnosis, people with MND do not have time to wait for services and supports.”

¹ NDIS report into Participants with a neurodegenerative condition in the NDIS dated 31 March 2021.

**MND is a debilitating, often fast moving and disabling condition.
MND Australia proposes the following recommendations:**

1. The new Act must clearly state that older people over 65 will receive supports and services comparable to the NDIS under the aged care system and that these supports and services are timely.
2. The new Act needs to give greater clarity to how assessments will be made and that these assessments will specifically take into consideration the changing needs of people with complex conditions such as MND.
3. The Act should state clearly that the uses of all computer-based decisions such as access assessments, including those generated by AI, are monitored and audited, and the findings published publicly in annual reports on the operations of the aged care system.
4. The new Act must articulate clearly how fees and charges will be set and how review of access decisions will be managed.

“With a third of people dying within one year and more than half within two years’ of diagnosis, people with MND do not have time to wait for services and supports.”

Recommendation 1: The new Act must clearly state that older people over 65 will receive supports and services equitable to those available through the NDIS under the aged care system and that these supports and services are timely.

Equity of supports and services

For the 55% of people who are diagnosed with MND when aged 65 or older, the current home based aged care system does not adequately address their complex and changing disability support needs. Consequently, the health and wellbeing of family and carers is negatively impacted and unnecessary or untimely admission to residential aged care often occurs.

Currently, the maximum funding available through a Home Care Level 4 Package is \$59,593.55² per annum. In contrast, a report published by the NDIS, *Participants with a neuro-degenerative condition in the NDIS*³ (31 March 2021) reported the average annualised committed supports for the 2020-2021 financial year was \$242,000 for participants with MND.

It is a fundamental human right^{4,5} that every person with a disability must have equity of access to services and support to facilitate quality of life, independence, safety and community participation⁶. It must also be noted that Aged Care Home Care packages fall into bands, are means tested and capped, the NDIS is neither means tested nor capped.

This is even more critical for people with a life limiting, rapidly progressing, degenerative and complex disability like MND. A diagnosis of MND is devastating for the person with MND and their family no matter the person's age. Further, *The National Strategic Action Plan for Rare Diseases*⁷ outlines action and policy for conditions such as MND to ensure equity of access. The Action Plan is predicated on an integrated, person-centred approach which is responsive to changing needs.

Section 22(3) of the new Act states that the Commonwealth aged care system supports individuals to: (a) be able to reside at the individual's home (if the individual so chooses) or, if that is not possible, in a setting that is appropriate given the individual's circumstances and preferences.

MND Australia seeks clarification on how these supports will be accommodated for people with high disability needs if they choose to reside at home, as many people with MND do.

Additionally, section 22(11) of the Act states that the aged care system is not to be used to fill gaps in other sectors. The NDIS Independent Review's recommendations include that foundational supports for people over 65 with disability will be met through the aged care system. It is imperative that older people with disability have access to appropriate supports and services if they are not eligible for the NDIS, and that these supports and services be comparable in value to those available through the NDIS.

² [My Aged Care](#)

³ National Disability Insurance Scheme, *Participants with a neurodegenerative condition in the NDIS*, 31 March 2021

⁴ [Convention on the Rights of Persons with Disabilities](#), United Nations, articles 25 and 26

⁵ International Alliance of ALS/MND Associations [Fundamental Rights of People Living with ALS/MND](#), April 2021

⁶ UNCRPD 2008

⁷ [National Strategic Action Plan for Rare Diseases](#), February 2020

Furthermore, equitable supports and services must be delivered in a timely manner. MND causes progressive disability and access to appropriate supports and services must occur in a timely manner. People with MND cannot be left waiting for the vital supports and services they need for daily living.

MND Australia supports OPAN and COTA's Key Issues Paper⁸ on the draft Aged Care Act and endorses their call for an explanatory memorandum to the Act that clearly explains the Act's intention and purpose for older people requiring disability supports; and that disability supports are explicitly referenced in the Act.

"It's very unjust. The needs of every person with MND are similar, regardless of how old you are when you're diagnosed. The person over 65 has to self-fund a lot of that."

Recommendation 2: The new Act needs to give greater clarity to how assessments will be made and that these assessments will specifically take into consideration the changing needs of people with complex conditions such as MND

Assessments

The new Act does not make specific mention of disability outside of section 49 which refers to "long term impairment". MND is a permanent impairment that is progressive and debilitating.

Assessments to access aged care services for people with complex long term impairments like MND need to take into account progressive conditions. Reassessments as needs change are time consuming and traumatising for the person with MND. To keep having to explain the likely progression in their decline or loss of function can be frightening and confronting.

In some cases, over time people are unable to clearly articulate their own condition or their own needs, so the responsibility of explanation falls on family members and carers.

The new Act must ensure that assessments are not continuous but are cognisant of progressively debilitating long term impairments like MND. Additionally, the consultation paper on the draft Act provides an academic study outlining the assessment model but no further detail is given on the computer programme on which it will be based upon.

It is tacitly understood that assessment data will also be drawn from an in person assessment process, however much greater clarity is required as to how the assessment process will be carried out and how algorithms will be used.

⁸ <https://opan.org.au/about-us/news-and-events/consultations-2024/>

Recommendation 3: The Act should state clearly that the uses of all computer-based decisions, including those generated by AI, are monitored and audited, and the findings published publicly in annual reports on the operations of the aged care system

Digital Accountability

The Royal Commission into the Robo-debt Scheme made it starkly clear that automated decision making algorithms (ADMs) are both prevalent across human services and also risky in terms of the human toll.

ADM systems are known to pose serious risks – including entrenching bias, eroding privacy, and the absence of procedural fairness, transparency and contestability in decision-making.⁹ The risks of ADMs must be expressly managed and identified in the new legislation as the new Act under section 7 refers to powers of the System Governor to use a computer program to automatically determine decisions relating to the classification of individuals.

Further, to ensure transparency and accountability, the use of ADMs and other technology such as AI must be monitored and audited and the results published publicly in the annual report on the operations of the aged care system.

Recommendation 4: The new Act must articulate clearly how fees and charges will be set and how review of access decisions will be managed

Fees and charges

There is a lack of clarity around fees and charges in the new Act. The Royal Commission into Aged Care was specific in its recommendations around fees and charges in aged care including the following recommendation on respite.

Recommendation 126: Individuals receiving respite care under the new Act should only be required to contribute to the costs of the services that they receive associated with ordinary costs of living up to a maximum of 85% of the single basic age pension, and any additional services they choose to receive. They should not be required to contribute to the costs of the accommodation and care services that they receive.

Older people with disability, including people with MND, need assurances around fees and charges for aged care supports and services. Older people diagnosed with MND over the age of 64 often face onerous personal expenses just to cover equipment they require to live on a daily basis. Older people with MND often have to rely on family to subsidise supports and services.

“Our daughter took out an extra part of her mortgage to get that (equipment) for us.”

As noted above, Aged Care is a means tested and capped system, this means that older people accessing the system, including older people with disability, are often left with considerable out of pocket expenses. These include co-contributions to Home Care packages and having to self-fund or seek alternative funding for home modifications. This is vastly unjust for older Australians, including for people with MND.

Access Reviews

The current draft bill does not appear to have adequately articulated a Review Process. A Review Process provides due process to an applicant should their access request be denied. A Review Process must be specifically stated in legislation in order for the Administrative Appeals Tribunal (AAT) and its next iteration to be able to review any decisions.

Aged Care does not currently fall under the current schedule of areas the AAT can Review.⁹ This leaves older people, including older people with disability, without any access to due process should their access application be denied. This is a clear breach of the human rights of older people with disability.

The Convention on the Rights of Persons with Disabilities (CRPD) sets out the legal obligations of States to promote and protect the rights of persons with disabilities, including older people with disability. This new Act purports to be “rights” based, however, without due process regarding Reviews being clearly articulated within the Act, the Act itself cannot be said to be upholding the rights of older people with disability. CRPD Article 12:¹⁰

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

The consultation paper on the new Act from the Department emphasises the existence of a power to correct incorrect classification decisions and the availability of tribunal appeal. The new Act must clearly articulate how incorrect decisions may be corrected and to which tribunal appeals may be made.

Conclusion

The new Aged Care Act is a much needed legislative reform, however despite the draft Act citing “rights” there are almost no enforceable human rights within the new legislation. Additionally, disability is not explicitly addressed in the Act and this leaves older people with disability in a tenuous position as to the exact nature of the supports and services they will receive within the aged care system.

People with MND diagnosed over the age of 64 need clear assurance within the new legislation that they will be able to access supports and services that are comparable to the NDIS. Further, these supports and services must be timely.

⁹ <https://www.aat.gov.au/about-the-aat>

¹⁰ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html>

People with MND do not have time and they have a right to quality supports and services. Additionally, MND is a progressive condition and assessments to enter aged care must take this into serious consideration.

Older people with disability, including people with MND, need to be confident that if they need to access the aged care system, that it will offer them the supports and services they require and that these supports and services uphold their human rights.

About MND Australia

MND Australia is the national peak body of state organisations that support those living with and impacted by motor neurone disease (MND). Since 1993, we have been the voice for the MND community. Our national and international networks help increase understanding of the disease and advocate for the needs of those affected.

The six state MND associations provide direct support and services to people living with MND, their carers and families, and the health professionals and service providers involved in their care in all states and territories.

Together we are committed to ensuring people living with MND, their carers and family have timely access to:

- care and support to meet their individual needs to enable them to live better, for longer, no matter their age or postcode
- diagnosis, clinical trials, technologies and therapies.