
Submission to the Royal Commission into Aged Care Quality and Safety

Submitted by:
MND Australia

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ABOUT MND AUSTRALIA

MND Australia is the national peak advocate for motor neurone disease (MND). Together with state MND Association members and our research arm, the MND Research Institute of Australia (MNDRIA) we advance, promote and influence MND care and research with a vision to achieving a world without MND.

The six state MND associations provide direct support and services to people living with MND in all states and territories.

ABOUT MND

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

With no nerves to activate them, the muscles of movement, speech, swallowing and breathing gradually weaken and waste, and paralysis ensues. MND affects each person differently with respect to initial symptoms, rate and pattern of progression, and survival time.

Average life expectancy is 2 to 3 years from diagnosis.

There is no known cause for MND (except in a very small number of genetic cases), no effective treatments and 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 progressively changing supports.

THE CHALLENGES

The social and emotional impact of MND is amplified by its complex nature, the speed of its progression and the spiraling series of losses that pose:

1. huge problems of adjustment for people who have MND;
2. an escalating and stressful burden on carers and families
3. a challenge to health professionals, disability services, community care, and aged care providers involved in meeting the variable, progressing and complex care needs, particularly in regional, rural and remote areas; and
4. the need for a coordinated response that addresses the person's disability rather than age

Timely early intervention and access to expert multidisciplinary care, assistive technology (aids and equipment), specialist planning and assessment, home care services and coordination of support, including a proactive framework for decision-making, play vital roles in maintaining quality of life and independence. It also helps people to plan ahead and prevent crisis and avoidable hospital/residential aged care admissions.

Although early intervention will not slow down the disease process in MND, it will strengthen the informal supports available to the person, including supporting the primary carer to maintain the caring role and their own health and wellbeing.

SUBMISSION:

MND Australia is pleased to provide a submission to the Royal Commission into Aged Care Quality and Safety. The focus of the comments provided in this submission are on the key areas as outlined in the terms of reference that impact on people living with motor neurone disease (MND) in Australia.

We believe that people affected by a progressive neurological condition such as MND should be able to access whichever support system best meets their needs, whether it be the National Disability Insurance Scheme (NDIS) or My Aged Care.

Currently there is inequity in Government support of people living with these conditions. People under the age of 65 diagnosed with a progressive neurological condition, eligible for the NDIS, will access supports to meet their individual needs. People aged 65 and older (over 60% of all people diagnosed with MND) must rely on the aged care system which, unlike the NDIS, is capped, means tested and designed to address ageing, not disability.

With an average life expectancy of just two to three years from diagnosis most people with MND prefer to remain at home for as long as possible. However, increasing inequity and long waiting times is causing many people to be pushed into financial hardship or residential aged care earlier than they wish or need. As at 30 June 2019 there were 213 people with MND living in a residential aged care facility.

The Deloitte Access Economics report¹, commissioned by MND Australia states that the total cost of MND in Australia was \$2.37 billion in 2015, comprising \$430.9 million in economic costs and \$1.94 billion in burden of disease costs. The enormity of these costs is akin to the brutality of MND.

Under the national disability insurance scheme (NDIS) people living with MND who are diagnosed when under 65 are entitled and funded to access **reasonable and necessary** supports to meet their individual needs. Many people aged 64 or younger with MND are now receiving NDIS plans that are having a positive and life changing impact.

Approximately 40% of the 2,000 Australians living with MND are diagnosed when under the age of 65 and over 60% at age 65 or older. MND Australia has consistently advocated for access to the NDIS for all people with rapidly progressing neurological conditions no matter how old they are when diagnosed.

Currently people diagnosed with MND under the age of 65 and accessing the NDIS are able to continue receiving NDIS supports as they age. In the past, those aged 65 years and over who were assessed as being ineligible for the NDIS at the time the NDIS began rolling out in their region and who were an existing client of state-administered specialist disability services were eligible to receive ongoing disability support from the Commonwealth Continuity of Support (CoS) Programme². Those

¹ Deloitte Access Economics 2015, [Economic analysis of motor neurone disease in Australia](#), report for Motor Neurone Disease Australia, Deloitte Access Economics, Canberra, November

² <https://agedcare.health.gov.au/programs/commonwealth-continuity-of-support-programme/eligibility-for-cos>

diagnosed when aged 65 years and older who were not eligible for either CoS or the NDIS must seek disability supports funded by the aged care system.

The complex needs of people living with rapidly progressive neurological diseases, such as motor neurone disease (MND), cannot be met by existing or traditional aged care services or facilities which are designed to address needs related to ageing not disability. There are major gaps with respect to timely access to support at home, choice and range of assistive technology and the level and hours of service available. Understanding of MND within the aged care sector is limited further compounding distress for the person with MND and their family.

The Australian Government has implemented a range of aged care reforms to give older people more choice and control. These reforms also include enhanced access to four levels of home care packages covering basic through to higher level home care support.

However, the focus remains on addressing needs related to ageing and the highest Level 4 package, which aims to support people with high-level care needs, has a means tested, subsidy amount limit of \$49,500³ in contrast to NDIS support which is not means tested and has no amount limit.

The Australian Government has recently introduced a national prioritisation queue, but to date this does not seem to have impacted on the waiting times for access to Level 3 and 4 Home Care Packages for people with MND. Recent figures indicate that there are over 120,000 people currently waiting for their allocated package⁴. Waiting in a queue is not tenable in the face of progressing loss of function, speech and swallowing, loss of ability to breathe unassisted and a limited life expectancy.

The crucial issue remains that people with a disability over the pension age are not able to access the full range of reasonable and necessary disability supports to meet individual needs. As the NDIS rolls out nationally the gap between the services available to people with MND based on their age will continue to widen and lead to further discrimination.

People with rapidly progressive neurological disease have changing and complex care needs which are often not well understood by aged care staff. Anecdotal evidence indicates that the introduction of My Aged Care as the gateway to aged care services has slowed down access to specialised assessment. Needs based support hinges on timely access to specialised assessment undertaken by professionals who understand the complex and progressing nature of MND.

Under current aged care assessment processes consideration of whether a person would benefit from a specialist disability service such as complex support coordination, flexible respite, assistive technology, specialised therapy and communication aids rarely occurs.

³ My Aged Care - <https://www.myagedcare.gov.au/help-home/home-care-packages/about-home-care-packages>

⁴ Home care packages program data report 1 January – 31 March 2019, Department of Health, released June 2019.

SUMMARY OF RECOMMENDATIONS

1. The NDIS should be broadened to include all people with disability, regardless of age.
2. Funding to be made available for assistive technology in addition and separate to Home Care Package funding to ensure that older people diagnosed with MND who are living at home can access the assistive technology they need when they need it to maintain their independence, quality of life, communication and community access and to support carer health and well-being.
3. An immediate investment in additional home care packages to address the current urgent needs of those on the national prioritisation queue
4. The introduction of a formal 'fast track' process for automatic access to Level 4 Home Care Packages for people living with terminal, complex and progressive conditions
5. Assessments for any level of support (CHSP or Home Care Package) for people with progressive neurological and neuromuscular conditions should be undertaken by a health professional (e.g. Nurse; Occupational Therapist) with appropriate training and/or understanding of these conditions.
6. Integration of assessment services and easier transfer between CHSP and Home Care Packages to reduce long wait periods for support to commence
7. Investment in disease-specific training packages for the aged care sector workforce that address the needs of older Australians living with MND
8. State and Federal Governments must come together to develop and implement a sustainable solution to the equitable and timely provision of assistive technology to all Australians.
9. If Aged Care is unable to meet the disability needs of older people, the NDIS should develop a safety net model that provides for top-up funding through the NDIS to address needs not met by Aged Care;
10. Effective interfaces with allied sectors, particularly health, aged and palliative care, must be developed to ensure a coordinated inter- and multidisciplinary approach to care, specifically the need for better links between aged care providers and primary health/Aged Care Assessment Teams
11. The development of National Guidelines for the management of people with progressive neurological conditions.

Terms of reference

The terms of reference (ToR) for the Royal Commission into Aged Care Quality and Safety are:

- a. the quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response;
- b. how best to deliver aged care services to:
 - i. people with disabilities residing in aged care facilities, including younger people; and
 - ii. the increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services;
- c. the future challenges and opportunities for delivering accessible, affordable and high quality aged care services in Australia, including:
 - i. in the context of changing demographics and preferences, in particular people's desire to remain living at home as they age; and
 - ii. in remote, rural and regional Australia;
- d. what the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe;
- e. how to ensure that aged care services are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters;
- f. how best to deliver aged care services in a sustainable way, including through innovative models of care, increased use of technology, and investment in the aged care workforce and capital infrastructure;
- g. any matter reasonably incidental to a matter referred to in paragraphs (a) to (f) or that [the Commissioners] believe is reasonably relevant to the inquiry.

1. Help people to stay at home for as long as possible (ToR c. i.)

MND Australia seeks to ensure that people are adequately supported to stay at home for as long as they wish and are only recommended for residential care when every other possible avenue of care and support has been exhausted. This will require a change in the Aged Care Assessment Team processes to ensure a person is accurately assessed and appropriate recommendations made for their care and support.

This also necessitates investment in additional home care packages to alleviate long waiting lists. People living with MND run the risk of being admitted to residential aged care facilities earlier than necessary due to the complexity of their disability and long waiting times with some dying before a Home Care Package becomes available.

MND Australia supports the Council on the Ageing (COTA) recommendation for at least 30,000 additional packages to ensure older Australians never have to wait longer than three months⁵.

Further MND Australia seeks a 'fast track' process for people assessed as having complex and rapidly progressing disability needs.

Case study: John was living with Motor Neurone Disease (MND), cared for by his wife.

In March 2016, John was initially assessed by a Regional Assessment Service (RAS) after a MND Association Advisor submitted an on-line referral for Occupational Therapy (OT) and Physiotherapy. No other supports were requested by John at this time.

In May 2017, the Community Health OT organised an Aged Care Assessment Team (ACAT) assessment which was completed in June 2017. John was placed on the national queue with a High Priority for a level 4 Home Care Package (HCP).

By late September 2017, (three months after assessment), no package of care had been received. John and his wife were very frustrated. They contacted the former Federal Assistant Minister for Health, David Gillespie requesting assistance. Within two days an ACAT representative contacted John's wife and explained that they could only advise that an urgent level 4 package still has a 1-3 month waiting period. John's wife responded, pointing out that it was now 4 months since John's assessment. Understandably, John's wife did not feel supported from this conversation. Prior to this conversation, John had chosen to pay for some private personal care support.

Throughout October 2017, John and his wife reported that they were just managing. They said they are doing OK but wanted reassurance that a HCP was going to be available soon. They continued to pay for private personal care support for John for three mornings per week.

In late November 2017, five months after assessment, John's condition had deteriorated further and he was admitted to hospital. During this time he was informed that his HCP had been approved, John was never discharged home from hospital and died before they could accept the package.

This is a typical scenario for people living with MND. People are waiting many, many months for Home Care Packages and often dying before they get one.

⁵ COTA Australia, Position Paper, Keep Fixing Australia's aged care system, September 2018, p 8

What to consider when making an assessment

Eligibility for home care packages is assessed by Aged Care Assessment Teams/services.

Often, if it is determined a person is managing, they will have an assessment for Commonwealth Home Support, rather than a home care plan. The Regional Assessment Service (RAS) assessor may not have a health-related qualification. This can lead to inadequate understanding and assessment of someone who has a complex progressive neurological condition. When there are more complex health needs identified, longer wait times ensue as the person waits for an appropriate assessment regarding their needs, before any funding, or package, becomes available.

There needs to be a better interface between Commonwealth Home Support Program (CHSP) and Home Care Packages (HCP). Some people making the transition, which is the reality for many people with progressive neurological and neuromuscular conditions, are left waiting longer than 18 months for services to commence (after waiting months for an assessment). This leads to further declines in function and out of date recommendations for supports. With an average life expectancy of just two to three years by the time a HCP becomes available death may be imminent.

MND NSW has recently surveyed its older members regarding access to HCP and has received 23 responses to date.

Of those:

- Six have achieved a level 4 package but at least one of those notes it took nearly 3 years for them to achieve.
- Four are currently on a level 3 package
- Ten are still waiting for a package with one waiting for an upgrade to a level 4
- Three respondents are currently on a level 1 or 2 package

The length of time people are waiting varies with a spread of two months to three years. Of those who are still waiting:

- One waiting less than 6 months – has just started the process
- Five waiting less than 12 months
- Two waiting less than 18 months
- Two waiting in excess of 2 years

Most respondents were noting they were still waiting around the 10-11 month period with no indication that the package was any closer. Responses also indicate that respondents do not understand whether or not they have been placed in a queue.

Frequent comments:

- I will be dead before I receive a package
- The costs are punitive and leave little for direct care delivery
- Have to keep pushing for access

There is a need to mandate the appropriate, adequate and expert assessment of a person's disability needs, including the application of an understanding of progressive

neurological conditions⁶, and other special needs that a person may have, and to ensure adequate funding to meet assessed needs.

Here are some examples of needs:

- Flexible respite options (for the person with the condition and their carer(s))
- Appropriate and timely allied health assessment and access to aids and equipment
- Appropriate therapy/health service supports with a level of hours of support adequate to ensure a person can remain at home
- Support for the primary carer and family to return to their own personal pursuits and roles
- Understanding of the variability and significance of symptoms (including, but not limited to fatigue, weakness, pain, speech and swallowing difficulties, strength, cognitive changes) that affect someone's need for support, and caregivers' capacity to contribute to this support

Recommendations:

- I. The NDIS should be broadened to include all people with disability, regardless of age.*
- II. An immediate investment in additional home care packages to address the current urgent needs of those on the national queue*
- III. The introduction of a formal 'fast track' process for automatic access to Level 4 Home Care Packages for people living with terminal, complex and progressive conditions*
- IV. Assessments for any level of support (CHSP or Home Care Package) for people with progressive neurological and neuromuscular conditions should be undertaken by a health professional (e.g. Nurse; Occupational Therapist) with appropriate training and/or understanding of these conditions.*
- V. Integration of assessment services and easier transfer between CHSP and Home Care Packages to reduce long wait periods for support to commence*

2. Lack of aged care sector workforce knowledge (ToR f.)

MND Australia is concerned that there is a lack of aged care sector workforce knowledge regarding people living with motor neurone disease and in recognising, treating and addressing their symptoms. A solution is for the sector to invest in training packages for the aged care sector workforce. This training could take the form of short on-line modules that lead to professional development accreditation, and could draw on, or be modelled on, the disease "snapshots" currently under development by the National Disability Insurance Agency (NDIA) for internal use by NDIA staff.

In addition the information and training available from specialist organisations such as MND Associations should be actively sought and funded appropriately.

⁶ For example, an understanding that some people have little or no insight into their condition and will insist they are fine and do not need support, when objective clinical evidence shows the opposite to be true.

Case study: Bob was almost 69 when he was diagnosed with motor neurone disease (MND).

From then on everything changed. Bob had to leave his job, and plans to travel with his wife, Julie, during their retirement were cancelled. *Bob said: "Your retirement is completely changed. Where instead of being able to do some travelling etc., that's been cut out for both of us.*

A lot of the money we had earmarked for that we have we spent on house modifications and equipment around the place. We did receive some under MASS (medical aids subsidy scheme) but the rest has been up to us really."

Bob and Julie applied for Aged Care support not long after Bob was diagnosed and were initially awarded a level 1/2 package in 2013 but despite Bob's needs increasing, it was just over a year ago when they were finally given the higher level package.

Julie said: "The service providers couldn't give us the help we wanted and they said 'oh no, it's a good idea to bank your money, you'll need it later on.' And then we kept on saying 'we need more help, we need more help' and they kept saying 'we don't have the staff, we don't have the staff' so we actually changed ships to another group and some of that banked money we are now using because we need more care than what we can afford through the Level Four package. But I don't know how long that will last, that's the problem now.

Moving from the lower to the higher level care package wasn't without its problems either.

Bob and Julie said: "We've only been assessed once and that was not long after diagnosis and I think it was fairly confronting because the whole thing was new and raw. And then about two years ago they wanted to reassess Bob and I said 'no, there's need to, don't you know what his diagnosis is?' and the two people that rang me from ACAT had no idea what MND was! And then finally a woman rang me and I said 'Look, this is ridiculous! Reassessing when the needs are just escalating. It's Motor Neurone Disease, surely you don't have to spell out the obvious!' She said 'I know exactly what it is, and I'll push everything through.' And I think that's when we went onto the Level Four. But they wanted to send someone to the house to reassess you. Silly things like that.

There was a person who came out and we assumed that she knew about MND but by the time you got talking to her a little bit, you found out that she did not know anything about MND. She only tried to push across that she did. Once we found out you felt like saying 'look, you'd better go because this is just useless!' We even had to pay for that person to come out."

Despite being on the high package now, Bob and Julie are still not receiving the level of care and support Bob needs, and have been forced to spend their savings and superannuation on housing adaptations and equipment, which can be extremely costly.

Julie and Bob said: "We bought our own hospital bed and manual chair and shower chair and ramps, a lot of those Tyrex ramps we put in ourselves around the house. And an internal ramp and an external ramp to the carport. We've done all of that.

We do use taxi vouchers a bit. But also we do use the mechanical wheelchair, you know, go out in that, and that means that Julie has got to lift it in and out of the vehicle, which works pretty well but does get a bit tiring for Julie.

Once I can't transfer Bob in and out of the car, we'll be using taxis all the time with the powered chair. But we can't afford to change cars. We're more restricted going out and spend more time at home."

Julie added: "So the Level Four Package... It would be nice to have some psychological support with it, but everything they say 'you've got to pay out of your package', but we need the package for care time rather than anything else.

And from six o'clock in the evening until six o'clock in the morning, or seven o'clock, you don't get anything. That's totally Julie. It would be nice to have some additional care during those hours."

Recommendation:

- 1. Investment in disease-specific training packages for the aged care sector workforce that address the needs of older Australians living with progressive neurological and neuromuscular conditions.*

3. Equal access to assistive technology⁷ (ToR f.)

The current system

The National Disability Insurance Scheme (NDIS) provides support for people with disabilities, their families and carers. Rollout of the scheme commenced in 2013. In the aged care sector, My Aged Care is the portal to the aged care system, providing a central access point to aged care funding and services. Home care funding for older people living independently in their own home has been consolidated into two main programs: the Commonwealth Home Support Programme (CHSP) and Home Care Packages (HCP) Programme. Under this new funding structure, it is unclear where responsibility lies for addressing the assistive technology needs of older people with a disability, people acquiring a disability because of the ageing process and/or people experiencing frailty.

Access to disability services for people aged 65 and older is restricted as they are required to fit into a "frail aged" service paradigm. This is a major problem for many people with disabilities including neuro-degenerative diseases. It is ageist and discriminatory and tends to deny access to a range of services to address identified needs.

Funding and access to assistive technology for people 65 and older in Australia is inequitable and confusing. Programs for older people are spread across multiple departments at both the Commonwealth and State level. There is limited coverage under some private health insurance and condition-specific not-for-profit organisations such as the state based MND Associations. Despite the spread of funding streams, many people are sacrificing their limited income to self-purchase and waiting longer periods before seeking further assistive technology, which may result in accelerated functional decline, loss of independence and a negative impact on the health and safety of their carer.

⁷ Assistive technology: any item, piece of equipment or product that is used to increase, maintain, or improve the functional capabilities of people living with a disability.

The lack of clarity about what will happen to the Commonwealth Government's Continuity of Support Program after July 1st 2019 makes access to assistive technology all the more precarious.

Short term solutions

Federal and State Disability Ministers to:

1. Confirm funding arrangements after 1 July 2019 and provide clear information to the sector about where older Australians with a disability will go to receive their assistive technology services.
2. Confirm that they will honour their legislative obligations to provide support and services to all Australians living with a disability, by continuing to subsidise the purchase or hiring of assistive technology through state-funded assistive technology programs (such as SWEPE in Victoria), until such time as an equitable program is developed for older Australians with a disability.
3. Ensure sufficient funding for assistive technology requirements is available to older Australians.

Case Study:

Listen to Graham's story;

<https://www.mndaction.org.au/Make-Aged-Care-Fair>

Recommendations:

- I. The NDIS should be broadened to include all people with disability, regardless of age.*
- II. State and Federal Governments must come together to develop and implement a sustainable solution to the equitable and timely provision of assistive technology to all Australians.*
- III. Funding made available for assistive technology in addition and separate to Home Care Package funding to ensure that older people diagnosed with MND who are living at home can access the assistive technology they need when they need it to maintain their independence, quality of life, communication and community access and to support carer health and well-being.*

4. Interface with other sectors to meet disability needs of older Australians (relates to all ToR)

Everyone living with a progressive neurological condition such as MND should have access to the right care, in the right place at the right time.

Articulated pathways of care and support, with an emphasis on consumer-directed care, recognising that families and carers can only do so much, are long overdue. The majority of disease-specific organisations have clinical guidelines and training packages available for health professionals working in aged care to have the necessary understanding of how to work with people with progressive neurological and neuromuscular conditions.

The introduction of policies to bring about mandated integration between the aged care, health care and disability care systems will ensure people with a disability have their needs met, regardless of which system they access. This approach will also bring about efficiencies in the NDIS, through the streamlining of services and support.

Case Study: Dianne was 65 when diagnosed with MND. She is living at home with her husband.

Yes I have a MAC package, only because after ringing them and making enquires I received an email to rate my experience and benefits of MAC short version - I told them they were absolutely useless and had done nothing at all to help me stay in my home or help with equipment, we paid for it all and to be on a national waiting list is a waste of time as my approval would probably come through on the day of my funeral. So my opinion of MAC, it's a pathetic cruel joke played on people like me. Five weeks later a level 3 package was approved and 5 weeks after that a level 4 came through.

To the Government.

My Aged Care was designed for frail elderly people to enable them to stay in their own homes longer. You assume people 65 and over, dying of Motor Neurone Disease, don't suffer the same as 64 and younger people do, so you decided we don't need the same respect, support and care because you think we are too old and a waste of money. You conveniently swept us under the MAC mat and you have no idea how many of us there are as there are no statistics kept on ANY older disabled people because to you we don't exist as we are now only considered as "old".

Speaking for MND, your blatant discrimination has disadvantaged us enormously, the pathetic weekly allowance is woefully inadequate for our needs and to add insult to injury, unlike NDIS which is not means tested for anyone - under MAC, pensioners and part pensioners have to pay for their package.

The bottom line for my huge level 4 package, with my payment less admin fees for provider is 112.74 per day.....how far do you think that goes for disability care???

So if you can justify your discrimination, lack of care and support, I have added my email address as I would be interested to hear it.

Recommendations:

- i. The NDIS should be broadened to include all people with disability, regardless of age.
- ii. *If Aged Care is unable to meet the disability needs of older people, the NDIS should develop a safety net model that provides for top-up funding through the NDIS to address needs not met by Aged Care.*
- iii. *Effective interfaces with allied sectors, particularly health, aged and palliative care, must be developed to ensure a coordinated inter- and multidisciplinary*

approach to care, specifically the need for better links between aged care providers and primary health/Aged Care Assessment Teams.

- iv. *The development of National Guidelines for the management of people with progressive neurological conditions.*

5. Provider costs and management of funds (ToR g.)

Inequity in Government support of people under the age of 65 diagnosed with a progressive neurological condition compared to older Australians is growing. Those who acquire a disability under the pension age are entitled to access fully funded reasonable and necessary supports to meet their individual needs through the NDIS.

People aged 65 and older must rely on the aged care system which, unlike the NDIS, is capped, means tested and designed to address ageing, not disability. In addition provider costs must be taken out of the amount allocated for supports further eroding the amount of funds available for vital personal care services.

Means testing and co-payments leads to older people being forced to use their life savings and superannuation to enable them to remain at home and avoid residential aged care. In turn following the death of the person with MND their partner may have to rely on the aged pension to survive rather than their superannuation as planned.

Case study: Peter aged 67 when he was diagnosed in 2012 was asked ‘What two things would you tell our Government if you had the opportunity, about your experiences with the My Aged Care System?’.

It is ill designed to cater for those with MND. It would seem that the Government has a cure for MND, your 65th birthday. Prior to your 65th birthday you are recognised as to be suffering from a physical disability thus eligible to receive NDIS support, but after turning 65 you are cured of MND and now suffer from restrictions due to your age.

My experience with the National My Home Care system, supposedly designed to allow aged persons to remain living in their own home instead of moving into aged facilities and nursing homes. I am a victim of Motor Neurone Disease and fortunately receive strong support from family, friends and neighbours, but life is becoming more difficult every day for me and those around me to the stage where I find the need to sell my home, purchase a new house (Makes me liable to pay stamp duty) and relocate to a more suitable residence with no stairs or other mobility restrictions.

I was assessed for Home Care assistance in 2016 as a grade 3 – 4. I received no further communication until nearly twelve months later where I was informed that I had been allocated a Grade 2 package and to seek out an approved provider.

X Provider was the preferred provider selected and the services that commenced November 2017 were as follows:

Initial support services to be managed by *X Provider* were fortnightly garden and lawn care at \$30 a visit (\$60 a month). Fortnightly house cleaning and domestic duties for 2 hour each visit at approximately \$46 per hour (\$180 per month).

Approximate total cost per month for assisting services being \$240

Fees applied and payable to *X Provider* were

Basic daily fee \$10.17 per day, even on days where no services were received.

Income tested care fee \$11.62 per day, even on days where no services were received.

My *X Provider* monthly invoice for November required a payment of \$584.36 over and above My Home Care contribution

The same support services applied for December where I received an invoice from *X Provider* required payment for \$646.97 over and above My Aged Care contribution.

Needless to say I had to discontinue support services from *X Provider* as I could not afford to maintain monthly payments of the above amounts of \$584.36 and \$646.97 for services that cost in total per month approximately \$240 per month

From my perspective of My Aged Care scheme is that the only winner is the provider, *X Provider*. To me the Providers were given a licence to print money at the Governments expense and to the detriment of those needing care assistance.

Maybe if the daily supplement fees applied only to the days that support services were provided the system would be more fairer and affordable to those requiring assistance.

An alternative approach would be cutting the Middle man out completely and the person requiring assistance organise and manage their own needs as is an option in NDIS. This would cost the Government no more and possibly less than currently costing.

Can it be explained how this scheme works for me and to encourage and allow aged people requiring care and assistance to remain in their own home rather than going into a nursing home?

Recommendations:

- I. The NDIS should be broadened to include all people with disability, regardless of age.*
- II. If Aged Care is unable to meet the disability needs of older people, the NDIS should develop a safety net model that provides for top-up funding through the NDIS to address needs not met by Aged Care.*

6. Impact on families and the community (ToR g).

Daughters, sons, grandchildren and friends may also become carers of, and advocates for, older people diagnosed with MND. This impacts on productivity and cost to the Australian community.

The Deloitte Access Economics report ⁸, commissioned by MND Australia in 2015 highlighted that the costs of MND comprise both economic costs as well as burden of disease costs. The total cost of MND was estimated to be \$1.13 million per person with MND in 2015 with a total cost of MND in Australia of \$2.37 billion dwarfing the cost of all other similar conditions. The cost to the Australian economy alone was estimated to be \$430.9 million with productivity costs comprising 38% of these costs.

Key findings of the report related to productivity and carer costs:

- The productivity loss in individuals with MND is \$162.8 million in 2015, or \$77,776 per person with MND. Individuals (\$101.8 million) and government (\$57.7 million) bear most of these costs. The productivity cost is largely due to losses as a result of premature death (\$128.1 million).
- The productivity loss due to informal care was \$68.5 million in 2015, or \$32,728 per person. Individuals bear most of these costs (\$44.0 million), with government bearing the rest (\$24.5 million).
- Each informal carer is estimated to provide 7.5 hours of care per day to people with MND.

Case study: Cariona's Story

When Cariona's mum, Lorraine, was diagnosed with motor neurone disease in September 2016, a lot of things changed for the whole family. Cariona and her teenage daughter decided to move in with Lorraine to help care for her as her symptoms progressed.

Being diagnosed at age 74 meant that Lorraine had to rely on Aged Care services for care and support, rather than the National Disability Insurance Scheme which is restricted to those under the age of 65. The waiting list of over 100,000 for Aged Care meant that Cariona's mum only received her package several weeks after she passed away.

Cariona said: "Mum was fairly self-sufficient until around March 2017, she deteriorated pretty quickly. She was diagnosed with Bulbar Onset MND so she lost her ability to speak and swallow first, and although she was still mobile, we were really worried she would have a fall and not be able to call for help. We got her a personal alarm, but it would take too long for me to get back from work to help her and if anyone else came she wasn't able to communicate with them."

"Me and my teenage daughter decided to move in with mum so I could care for her properly, and I was lucky to have a really supportive employer which enabled me to work from home. If it wasn't for that, I don't know how we would have managed."

"We applied for My Aged Care at the beginning January 2017 just a few months after mum was diagnosed but we weren't given an assessment until late March. That's a long time for someone that has MND."

⁸ Deloitte Access Economics 2015, [Economic analysis of motor neurone disease in Australia](#), report for Motor Neurone Disease Australia, Deloitte Access Economics, Canberra, November

“When we finally got an appointment the person that came to see us was an administrator, with no knowledge of MND or the care required. I spent the better part of 2 hours trying to explain what MND is because all the questions for the assessment began with ‘Up until this point have you.....’, which didn’t matter because mum would never be as well as she was that day.”

“Eventually, Mum was approved for a level 4 package but there would be a 12+ month wait for it to be assigned. When I said that Mum could well be gone by then, the woman said that was just how the system worked.”

“Each time mum had a major progression and I called My Aged Care to get an update on the waiting list and each time I was advised to just wait. No one could give me any information despite the fact that mum was considered high priority.”

“We were given a level 2 and then 3 care package until the level 4 became available, which only provided two hours of domestic services per week (level 2) and then one carer for 2.5 hours, two days a week for personal care (level 3). When the support workers did come some of them weren’t qualified to use the equipment she required such as a hoist, so they had to leave.”

“We were lucky to have such strong family ties and support. I stopped working fulltime so I could care for mum with the help of my teenage daughter. We were able to get equipment provided free of charge by the MND Association of NSW and my brother and boss made modifications to mum’s home to meet her access needs. We were really lucky in that respect.”

Cariona’s mum died in September 2017, one year after her diagnosis. Six weeks later My Aged Care informed Cariona that they had been given access to a level 4 package.

Recommendations:

- I. The NDIS should be broadened to include all people with disability, regardless of age.*
- II. If Aged Care is unable to meet the disability needs of older people, the NDIS should develop a safety net model that provides for top-up funding through the NDIS to address needs not met by Aged Care.*

MND Australia would like to thank the Federal Government for the Royal Commission into Aged Care Quality and Safety and for the opportunity to raise issues related to access to support for older Australians diagnosed with motor neurone disease.

We would be pleased to provide further information or present to the Royal Commission if required.

Carol Birks
CEO, MND Australia