

---

# Submission to A New Program for In-Home Aged Care Discussion Paper

24 November 2022

---



## Background

Muscular Dystrophy Foundation Australia (MDF) is the national peak body for Australians living with neuromuscular conditions. We are committed to advocating on behalf of our community to influence improved health, social and economic outcomes for all Australians living with neuromuscular conditions. MDF's members are state and territory-based organisations which provide specialised support and services for their neuromuscular communities.

With rapidly evolving diagnostic techniques and the unravelling of the human genome, science is yet to uncover the actual incidence rates of the more than 75 known neuromuscular conditions. We do know that the prevalence of neuromuscular diseases is at least as high as Parkinson's disease worldwide (100 - 300 people for every 100,000) and twice that of Multiple Sclerosis in Europe (800 people for every 100,000)<sup>1</sup>. Based on Australia's current population of 25.88 million people we estimate that 41,408 Australians currently live with one or more of these conditions.

Some neuromuscular conditions can be clinically diagnosed at birth and in others symptoms do not appear until toddlerhood; childhood; adolescence; early or late adulthood. Many conditions are equally distributed amongst genders, while some, such as Duchenne muscular dystrophy appear mostly in males and others, such as Myasthenia Gravis, occurs twice as often in women.

All neuromuscular conditions result in a complex, progressive profile of disability over the lifetime of the person living with a condition. Each condition has a set of features unique to that diagnosis, but they almost always include a severe impact upon functional capability, caused by:

- progressive muscle weakness in all muscles of the body, mostly leading to profound physical disability
- significant and fluctuating fatigue and pain which progress with the condition, and
- in many cases, reduced life expectancy.

Whilst individuals under the age of 65 years when diagnosed with a neuromuscular disorder will be able to access supports to meet their individual needs via the NDIS, many people aged over the age of 65 years need to rely on the aged care system, which, unlike the NDIS, is capped, means tested and not designed to address disability.

## Submission

MDF acknowledges that the *A New Program for In-Home Aged Care Discussion Paper* does not specifically go into detail on 'the level of support available to people in aged care, including for people who would otherwise be eligible for the NDIS but for the age criteria', and is in particular seeking views on how support providers could be more innovative for funding for goods, equipment and assistive technologies, however, it is vital that any innovative practices and models are underpinned by principles of equity. MDF is supportive of innovation and new technologies that will assist older Australian's living with neuromuscular conditions to remain independent at home, but any grants program on delivery model must ensure equity of access to services and support comparable to the funding and support provided under the NDIS.

The Australian Government has committed to transforming aged care so that it meets the needs of older Australians and their families, now and in the future. In response to the final report of the Royal Commission into Aged Care Quality and Safety (Royal Commission), the Government committed to deliver a \$17.7 billion package of support and a once in a generation reform to agreed care to deliver respect, care and dignity to our senior Australians.

---

<sup>1</sup> (PDF) [The Epidemiology of Neuromuscular Disorders: A Comprehensive Overview of the Literature \(researchgate.net\)](#)

Under the Home Care Pillar Response to the recommendations of the Royal Commission, the Government announced the establishment of a new support at home program. The Government announced that this reform would deliver *‘on a number of the Royal Commission’s recommendations and will better support senior Australians to stay at home in line with their wishes’*.

Further, the preparatory work being undertaken by the Department of Health and Aged Care was to include the consideration of people with higher levels of need than are currently supported, including those with a disability who are ineligible for the NDIS.

People with neuromuscular conditions who were aged over 65 when the NDIS came to their area are unable to access an NDIS plan regardless of the severity of their disability. Instead, they must rely on the aged care system – an alternative which is frequently inadequate in practice.

Any funding and implemented improvements of the Aged Care system must be comparable to the funding and supports that are available under the NDIS. Additionally, any funding program established for assistive technologies (AT) must be fully funded and equal to the NDIS, needs based, and with no requirement for people with neuromuscular conditions to contribute to the cost or purchase or maintenance of the AT. The National Strategic Action Plan for Rare Diseases<sup>2</sup> outlined the action and policy for diseases including neuromuscular diseases to ensure equity of access.

The case studies presented below demonstrate why there must be equity for people living with neuromuscular conditions that is not simply based on age at diagnosis. They also demonstrate why it is important that new programs include understanding and knowledge of rare conditions and why a generalist approach, or one size fits all model will not be suitable.

Any new grants program or delivery model that is designed must:

1. Ensure equity of access to service and support for older Australians with neuromuscular conditions irrespective of age or location.
2. Ensure service providers have an understanding and knowledge of the nature of degenerative conditions and not simply apply a generalist approach that overlooks those who are unable to improve independence or function.
3. Include capacity to anticipate and respond to the high likelihood that people will have increasing needs over time as their condition progresses.

### Case Study 1

James is a 74-year-old man with severe physical disability as a result of Becker muscular dystrophy. He is ineligible for an NDIS plan because he was aged over 65 when the NDIS came to his area. Instead, James has a level 4 home care package of \$52,000 p.a. After his aged care supplier deducts its administration fee – he is left with approximately \$47,800 each year.

Bruce is 55 years old with the same diagnosis and a similar level of disability. Because he is under 65, Bruce receives support via the NDIS. His NDIS plan value is \$127,000 p.a. Both James and Bruce live at home and have a similar level of need.

In the past 12 months, both men have experienced progressions in their conditions, leading to reduced functional independence.

---

<sup>2</sup> [national-strategic-action-plan-for-rare-diseases.pdf \(health.gov.au\)](#)

Life for James	Life for Bruce
<ul style="list-style-type: none"> <li>• Support worker 2 hrs per day to assist with personal care</li> <li>• Unable to afford to purchase equipment including a new chair @ \$40,000+</li> </ul>	<p>Bruce has the following supports funded through his NDIS Plan:</p> <ul style="list-style-type: none"> <li>• Support workers for 9-12 hrs per day including for community access twice per week, plus awake overnight shifts, three times per week.</li> <li>• All allied health services that he needs as well as 6 weekly podiatry treatments.</li> <li>• All equipment, including loans whilst he waits for equipment to be supplied.</li> </ul>

The men in the above case study have similar needs for support workers, therapy, socialisation, community access and equipment. However, the disparity in their standard of living is driven by their age and the current lack of equity between funding available under the NDIS and the Aged Care program.

### Case Study 2

Jan is a 68-year-old lady, living with Facioscapulohumeral muscular dystrophy (FSHD).

Jan lives with her daughter for support and assistance in her daily living. Her daughter works fulltime but provides assistance in the morning and afternoon/evening. This support will increase, beyond her ability in coming years as Jan's FSHD deteriorates.

Jan has a significant aged care package, and her service provider, has been requesting that she use her funding or risk losing it.

Recently Jan had a fall and found that she could no longer get herself up. She lay on the ground for several hours waiting for her daughter to get home. Her daughter struggled to get Jan off the floor and is concerned she may end up hurting herself and not being able to care for Jan.

An occupational therapist (OT) undertook a review of Jan's situation considering this fall. Her review and report recommended that Jan, trial a Mangar Carmel lift (self-inflating equipment which retails for about \$4,000) to assist her in regaining her footing when she fell again. Both Jan and her daughter were happy with this recommendation.

Unfortunately, the service provider overruled the OT's recommendation – stating "this is not the best use of the client's package". And provided the following recommendations as better alternatives.

1. Falls alarm
2. Physiotherapy to improve muscle strength and balance, including how to get off the floor using a chair
3. Contact a neighbour to help get her off the floor
4. Call an ambulance to assist getting her off the floor

The first recommendation will alert people to Jan falling, but not allow her to get up off the floor herself. Jan is not opposed to trialling this but still would like to trial the lift. The second

recommendation demonstrates the services providers lack of understanding of FSHD which prevents Jan's muscles from regaining strength. Jan is not comfortable calling a neighbour, for assistance and is concerned for her dignity. Jan is desperate to maintain her independence within the parameters of her disability.

Jan requested another review, which occurred with the same provider and was again turned down. Jan's package remains untouched.

Further demonstrating the lack of understanding during the process, is the fact that at no point during this process did the service provider discuss ways to prevent Jan from falling in the first place.

This case study highlights that current aged care service providers do not understand the complexities of an older Australia with a degenerative disability.

## Conclusion

Currently access to, and funding for the NDIS and the Aged Care systems are not equitable. MDFA supports recommendations 35, 36 and 72 of the Report of the Royal Commission into Aged Care Quality and Safety with regards to equity for people with a disability receiving aged care to those that would be available under the National Disability Insurance Scheme (NDIS). MDFA supports the Government's work to reform the support at home program for people in aged care, but it must ensure both equity for people with disability receiving aged care and entitlement to care at home is appropriate to individual needs.

## Recommendations

1. Ensure equity of access to service and support for older Australians with neuromuscular conditions irrespective of age or location.
2. Ensure service providers undertake improved or compulsory training to gain an understanding and knowledge of the nature of degenerative conditions and not simply apply a generalist approach that overlooks those who are unable to improve independence or function.
3. Ensure the new program includes the capacity to anticipate and respond to the high likelihood that people will have increasing needs over time as their conditions progress.