



Pre-Budget Submission 2023-24

January 2023



Key recommendations

As part of the 2023-24 Budget, Muscular Dystrophy Foundation Australia is asking the Government to:

- **Provide funding to ensure the continued development and sustainability of ‘The Loop: Neuromuscular Digital Resource’.** This recommendation aligns with Action 1.1.1.3 from the National Strategic Action Plan for Rare Diseases to address urgent funding gaps for rare disease organisations to enable them to sustain and expand upon current awareness and education activities.¹
- **Establish a national neuromuscular helpline to ensure people living with a neuromuscular condition have a pathway to access knowledge and information enabling them to be active participants in their rare disease journey regardless of location.** This recommendation aligns with Priorities 1.2 and 2.5 from the National Strategic Action Plan for Rare Diseases.²
- **Immediately increase NDIS price limits for Level 2 and Level 3 Support Coordination, Plan Management and Therapy Supports in line with inflation (7.3 per cent in 2022) to reflect wage pressures and changes.** This recommendation will ensure patients with neuromuscular conditions, will continue to receive the level of support they need from specialist service providers who have the expertise and condition based knowledge to provide for complex support needs.

A summary of these measures and their need, including indicative costings are provided below. We welcome the opportunity to discuss these proposals in detail with government.

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¹ Australian Government Department of Health, 2020. ‘National Strategic Action Plan for Rare Diseases’ <<https://www.health.gov.au/sites/default/files/documents/2020/03/national-strategic-action-plan-for-rare-diseases.pdf>>

² Ibid.

About Muscular Dystrophy Foundation Australia

Neuromuscular Conditions in Australia

Muscular Dystrophy is an umbrella term that refers to a group of rare, complex genetic conditions within a wider group of more than 75 conditions collectively referred to as neuromuscular conditions. Neuromuscular conditions cause progressive deterioration of muscle strength and function and commonly result in profound disability. Neuromuscular conditions are rare diseases, that bring complex and multi-system challenges that the health and disability systems are not traditionally geared to focus on.

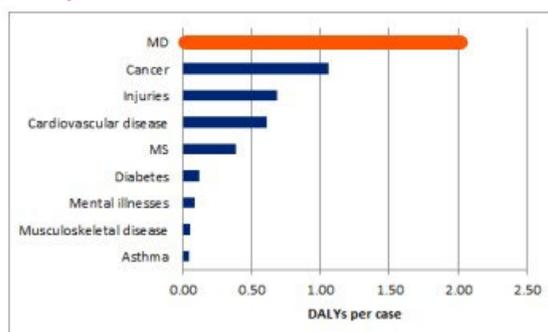
A Rare Disease Survey of 771 people by the McKell Institute recently found that over **seven in 10 people with a rare disease report not having their health and disability care needs meet.**³



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 conditions 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)⁴. 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.**

Compared to other health conditions such as cancer, cardiovascular disease, and diabetes, for a person with a neuromuscular condition, more than two disability adjusted life years (DALYs) are lost each year, indicating a substantial loss of wellbeing.⁵

Comparison of case burden, Australia⁶



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

³ The McKell Institute, 2019. 'Disability & Rare Disease: Towards person centre care for Australians with rare diseases.

⁴ Deenan et al, 2015. 'The Epidemiology of Neuromuscular Disorders: A Comprehensive Overview of the Literature', *Journal of Neuromuscular Diseases*, 2(1), 73-85.

⁵ Deloitte Access Economics, 2013, *Economic Study of Muscular Dystrophy*, Report for Muscular Dystrophy Association Inc.

⁶ Deloitte Access Economics, 2013, *Economic Study of Muscular Dystrophy*, Report for Muscular Dystrophy Association Inc.

and others, such as Myasthenia Gravis, occurs twice as often in women.

All neuromuscular conditions result in a complex, progressive profile of disability and deteriorating health 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.

About us

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 that work to support and empower people living with a neuromuscular condition, their families and support network. MDF's operating activities are supported by a voluntary Board of Directors and is inclusive of members living with neuromuscular conditions. As a registered charity MDF relies on support from donors, both individual and philanthropic and currently receives no support from the Federal Government.

Recommendation 1

The Government provides funding to ensure the continued development and sustainability of 'The Loop: Neuromuscular Digital Resource'. This recommendation aligns with Priority 1.1 and Action 1.1.1.3 from the National Strategic Action Plan for Rare Diseases to address urgent funding gaps for rare disease organisations to enable them to sustain and expand upon current awareness and education activities.⁷

The Issue

In 2020, a two-year project entitled 'The Loop – Your Neuromuscular Resource Hub' was completed and launched (The Loop). The Loop is a digital resource that has been developed for the neuromuscular community, by the neuromuscular community. The Loop, funded under a NDIA ILC grant (2018-2020), is an online integrated, accessible and multi-language support system designed to build the capacity and skills of people living with neuromuscular conditions, their families and carers, regardless of nationality (<https://theloopcommunity.org>).



A key focus of the online resource is to ensure people living with neuromuscular conditions are more integrated with specialist and mainstream service provision and support networks in their local area. Continuity of The Loop would ensure the community is able to continue to share their lived experience, as well as helping the community remain connected with others who are traveling similar journeys. The resource also includes tailored condition guides and a forum to chat and interact with others.

Through The Loop, MDF can influence the achievement of broader Commonwealth health policies such as the National Medicines Policy. The Loop provides a place for the neuromuscular community, their families and carers to participate in the health sector and find evidence based information, particularly for those who may experience inequity of access.⁸

Additionally, continued development and sustainability of The Loop aligns with Priority 1.1 and Action 1.1.1.3 from the National Strategic Action Plan for Rare Diseases which calls for urgent funding to expand upon current awareness and education activities.⁹

⁷ Australian Government Department of Health, 2020. 'National Strategic Action Plan for Rare Diseases' <<https://www.health.gov.au/sites/default/files/documents/2020/03/national-strategic-action-plan-for-rare-diseases.pdf>>

⁸ Australian Government Department of Health and Aged Care, 2022. 'National Medicines Policy' < <https://www.health.gov.au/sites/default/files.2022-12/national-medicines-policy.pdf>>

⁹ Australian Government Department of Health, 2020. 'National Strategic Action Plan for Rare Diseases' <<https://www.health.gov.au/sites/default/files/documents/2020/03/national-strategic-action-plan-for-rare-diseases.pdf>>

The resource was created following extensive consultation with the neuromuscular community which found that many people living with neuromuscular conditions were experiencing feelings of isolation and struggling to find reliable, trustworthy neuromuscular information.

More than 350 participants across Australia took part in the overall consultation process. Findings from the qualitative and quantitative data also showed that the ability to communicate needs can be a challenge, leading to a lack of independence and lack of clarity around what the future holds. Thus, The Loop was built to focus on the overarching themes of ‘life beyond diagnoses, and ‘practical and achievable independence’.

Community Consultation Report¹⁰

	Strongly disagree	Disagree	Agree	Strongly agree	Not applicable	Total
I would like to have contact with people with neuromuscular conditions via an online resource as it would make me happier and feel more connected.	1.45% 3	19.81% 41	51.21% 106	17.39% 36	10.14% 21	207
I am well served by existing information about my neuromuscular condition and do not see the need for a new resource.	16.43% 34	60.87% 126	14.98% 31	3.86% 8	3.86% 8	207

Feedback from users has been resoundingly positive with users sharing the following comments:

“It has put together in one place a range of information and experiences about BMD¹¹ that had found difficult to find on my own”

“Great to have all relevant info, contacts, stories etc. in the one place. Long overdue so thank you!”

“The Loop’s simplicity and ease of looking for things – all at the simple click of a button. Also, the life experiences shared so far are very encouraging”

The Loop has been successful in meeting community need; however, funds are now required to ensure the resource continues to be developed in a collaborative, innovative and sustainable way with the capacity to respond to the current and future needs of the neuromuscular community.

This includes hosting and licencing costs, maintaining the technology that drives The Loop, maintenance of current content, creation of new content (condition specific resources, living life resources and user generated resources), management of AI analysis, collaboration with relevant patient representative groups and moderation of the chat forum.

The Loop was born out of a challenge to restore hope despite diagnosis and build independence, dignity, and wellbeing. Through continued funding to support operational costs and ongoing development, The Loop can continue to empower the neuromuscular community.

¹⁰ Muscular Dystrophy Foundation Australia, 2019, *Neuromuscular Digital Resource Project – Community Consultation Report*.

¹¹ Becker Muscular Dystrophy (BMD)

Action required

We recommend funding over the forward estimates, with a review in two years. The cost per annum of providing the service would be approximately **\$250k per annum** indexed at 3.0 per cent per annum. (Year one allows for a start date of 1 October 2023 – see below).

	2023-24	2024-25	2025-26	2026-27	Total
	\$	\$	\$	\$	\$
Content development/forum management/moderation & delivery	\$155,584	\$215,765	\$208,762	\$209,785	\$789,895
Operating expenses	36,940	\$33,245	\$34,182	\$35,148	\$139,515
Review			\$50,000		\$50,000
Total Funding	\$192,524	\$249,010	\$292,944	\$244,933	\$979,410

Recommendation 2

The government funds a national neuromuscular helpline to ensure people living with a neuromuscular condition have a pathway to access knowledge and information enabling them to be active participants in their rare disease journey regardless of location. This recommendation aligns with Priorities 1.2 and 2.5 from the National Strategic Action Plan for Rare Diseases.

The Issue

It has been widely recognised that organisations such as MDF play a critical role both in raising awareness of neuromuscular conditions and in providing person-centred information to those living with neuromuscular conditions. Further, the vital role that organisations such as MDF play filling gaps in the health and disability systems across the many spheres of awareness and education, care and support, and research, has been well documented.¹²

In July 2020, a survey was conducted to identify the impact of COVID-19 on people with neuromuscular conditions, their families and carers.¹³ The results suggested that while people with neuromuscular conditions faced similar emotional and isolation challenges to that of the general public, there was a greater impact in relation to overall mental health. Feedback indicated the need for improved communication, regular updates and the ability of service organisations to use a variety of communication tools to provide support or promote services. Over 70% did not or could not access mental health services and approximately 36% indicated that their health and wellbeing deteriorated during this time. When asked what neuromuscular organisations could do to provide support, one of the most important factors was the ability to be able to promote existing services to people to support their health journey.

When someone is first diagnosed with a neuromuscular condition, it affects every facet of their life. From diagnosis on, there is a need to be able to navigate care and support across education, employment and mental and physical health.

Access to a helpline that is staffed by a trained professional with expertise in neuromuscular conditions would assist people living with neuromuscular conditions, and those caring for them to navigate their way through the health and disability systems and provide a level of care and support that is currently not available.

The national neuromuscular helpline model would be based on a triaged service offering and include:

- Trained clinical staff with expertise in neuromuscular conditions to answer calls and provide information about services available and how to navigate them (including connection with existing information and resources)
- Referral to supports, carer services and other organisations that may be of assistance (linkage to existing services and supports)
- Emotional support drawing on clinical expertise to assist with support and understanding of each callers unique experience
- Pathways to access knowledge, information regardless of location

¹² Australian Government Department of Health, 2020. 'National Strategic Action Plan for Rare Diseases' <<https://www.health.gov.au/sites/default/files/documents/2020/03/national-strategic-action-plan-for-rare-diseases.pdf>>

¹³ Muscular Dystrophy Foundation Australia, 2020. 'Covid 19 and its impact on people with neuromuscular conditions', <'COVID-19 and its impact on people with neuromuscular conditions' Survey Report - The Loop - Your Neuromuscular Resource Hub (theloopcommunity.org)>

- Facilitation of support and connection for people with neuromuscular conditions, their carers, family and friends
- First point of call from diagnosis through to transition pathways to ensure continuity of care throughout health and disability journey
- Initial point of contact in what may be a lifelong relationship of education and support from their specialist neuromuscular community service providers

The helpline would provide a person-centred approach that empowered people living with neuromuscular conditions, their carers and families to better self-manage their condition. Funding would enable:

- Improved ability to self-manage care
- Improved quality of life
- Improved health literacy relating to neuromuscular conditions and the management of neuromuscular conditions
- Reduction in unplanned hospital admissions and reduction in visits to emergency departments

Action required

We recommend funding over the forward estimates, with a review in two years. The cost per annum of providing the service would be approximately **\$600k per annum** indexed at 3.0 per cent per annum. (Year one allows for a start date of 1 October 2023 and initial set up costs).

	2023-24	2024-25	2025-26	2026-27	Total
	\$	\$	\$	\$	\$
Helpline Development & delivery costs	\$537,677	\$618,543	\$568,072	\$579,799	\$2,304,091
Operating expenses	\$46,940	\$35,305	\$36,304	\$37,333	\$155,882
Review			\$50,000		\$50,000
Total Funding	\$584,617	\$653,848	\$654,376	\$617,132	\$2,509,973

Recommendation 3

The Government immediately increase NDIS price limits for Level 2 and Level 3 Support Coordination, Plan Management and Therapy Supports in line with inflation (7.3 per cent in 2022) to reflect wage pressures and changes. This recommendation will ensure patients with neuromuscular conditions, will continue to receive the level of support they need from specialist service providers who have the expertise and condition based knowledge to provide for complex support needs.

Issue

In June 2022, indexation was frozen on NDIS Pricing Arrangements and Price Limits for Level 2 and Level 3 Support Coordination, Plan Management and Therapy supports.

The Social, Community, Home Care and Disability Services Industry Award (SCHADS) increased by 4.6% from 1 July 2022. Combined with the impact of the loss of income and expense of COVID, investments in quality and safeguards, and the increase in the Superannuation Guarantee, the ability to effectively deliver supports by organisations that service people with neuromuscular conditions has been negatively impacted.

At the same time, the indexation was frozen, other price limits for providers of disability support work increased by 9 per cent to address and take into account the changes to costs described above, that is, the SCHADS increase, COVID, and Superannuation Guarantee. While this was a much-needed uplift, the failure to not index price limits for Level 2 and level 3 Support Coordinators, Plan Managers and Therapy providers does not recognise the challenge of cost increases or the specialisations required for NDIS practitioners. The cost model needs to be continually reviewed to reflect cost pressures and changes.

Small specialist organisations that have the expertise and condition based knowledge to provide services for people with rare and progressive conditions are a valuable asset to the Government. The loss of such organisations would result in the loss of income that is injected into the disability sector via fundraising, a loss of diversity within NDIS providers, a loss of choice for patients, and a loss of social capital.

It is vital that prices keep pace with the market to enable participant choice and control and ensure the best possible outcomes. Many people with neuromuscular conditions have complex needs and require complex support. The current situation is likely to leave some people without the level of support they require.