

## Public Submission Cover Sheet

Please complete this sheet and submit with any attachments to the Sustainable Health Review Secretariat

### Your Personal Details

*This information will be used only for contacting you in relation to this submission*

<b>Title</b>	Mr <input checked="" type="checkbox"/> Miss <input type="checkbox"/> Mrs <input type="checkbox"/> Ms <input type="checkbox"/> Dr <input type="checkbox"/> Other <input type="checkbox"/>
<b>Organisation</b>	The Motor Neurone Disease Association of WA Inc.
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### Publication of Submissions

*Please note all Public Submissions will be published unless otherwise selected below*

- I do not want my submission published
- I would like my submission to be published but remain anonymous

### Submission Guidance

**You are encouraged to address the following question:**

**In the context of the Sustainable Health Review Terms of Reference listed below, what is needed to develop a more sustainable, patient centred health system in WA?**

- Leveraging existing investment in Primary, Secondary and Tertiary healthcare, as well as new initiatives to improve patient centred service delivery, pathways and transition;
- The mix of services provided across the system, including gaps in service provision, sub-acute, step-down, community and other out-of-hospital services across WA to deliver care in the most appropriate setting and to maximise health outcomes and value to the public;
- Ways to encourage and drive digital innovation, the use of new technology, research and data to support patient centred care and improved performance;
- Opportunities to drive partnerships across sectors and all levels of government to reduce duplication and to deliver integrated and coordinated care;
- Ways to drive improvements in safety and quality for patients, value and financial sustainability, including cost drivers, allocative and technical efficiencies;
- The key enablers of new efficiencies and change, including, research, productivity, teaching and training, culture, leadership development, procurement and improved performance monitoring;
- Any further opportunities concerning patient centred service delivery and the sustainability of the WA health system.

## Submissions Response Field

*Please type your response into the field below. Alternatively you may provide your submissions as a separate attachment (Suggested Maximum 5 pages).*

Motor Neurone Disease (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. There is no known cause for MND (except for a small portion of cases having a genetic link), no effective treatment and no cure. The condition presents itself and affects each individual differently with the average life expectancy from diagnosis being 2-3 years. There are no remissions and the progression of the disease is often rapid, resulting in high levels of disability which require a timely response to the constant changing needs of the patient.

The Sustainable Health Review has identified five key areas to a sustainable future for health; patient first, value for money, healthy lifestyles, partnerships across sectors and technology and innovation. These are addressed below to ensure the highest level of sustainable care and support is available for people living with Motor Neurone Disease (plwMND) in Western Australia.

### **Patient centred service delivery (patient first)**

There are more than 2000 Australians living with MND and approximately 170 plwMND in Western Australia (WA). Around 58% of people diagnosed with the condition will be under the age of 65 and 42% will be aged 65 and older. MND Australia, the national peak advocacy body for MND, commissioned a Deloitte Access Economics report (2015) which 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. The per person cost of MND in 2015 was \$1.1 million dwarfing the cost of many other chronic health conditions (Deloitte Access Economics 2015). The enormity of these costs are parallel to the horrific and cruel effects of MND.

From the findings of the Deloitte Access Economics report, MND Australia developed a National Action Framework which outlines two crucial needs of people impacted by MND: **1. Research** - to find effective therapies to stop MND, and **2. Care** - to meet identified needs from diagnosis through to bereavement. Furthermore, it addresses the five key commitments needed from the government and our politicians to ensure plwMND have equitable and timely access to health services. These include;

1. Increased investment in research
2. Development of National MND Guidelines
3. Improvements of aged and disability care
4. Timely access to a full range of assistive technology
5. A specific commitment to fund specialist MND multidisciplinary clinic coordinators

(Motor Neurone Disease Australia, National Action Framework, 2015).

For plwMND access to the right care, services and accurate, up to date information at the right time is vital to allow individuals to make informed decisions about their own future care. Coupled with this, it is essential that service providers better understand the complex and progressive nature of MND and the unique needs and support required by each individual living with the condition.

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The Motor Neurone Disease Association of WA (MNDAWA) is the pre-eminent specialist care and support organisation for people living with MND, their carers and families in WA. With over 33 year's experience in delivering the core MND Advisory Service, the Association provides patient centred service delivery including specialist planning and assessment, care coordination and emotional support to individuals living with the condition. This crucial and proactive approach in the care and support of plwMND assists families in planning ahead, enabling them to make informed decisions and choose their own care pathway. By having the correct support services in place at the right time it prevents crises and avoidable hospital and/or residential aged care admissions.

MNDAWA undertakes satisfaction surveys each year to identify the support needs of plwMND and their family carers. This provides us with a greater understanding of their experiences with the overall service provision from the Association, with a primary focus on the MND Advisory service. The importance of the Association's specialised services to plwMND and their families was clearly highlighted with 84.3% of plwMND and 90.7% of carers agreeing/strongly agreeing that they felt more supported and cared for as a result of the supports provided by the Association (from those who responded to the survey). A remarkable 90% of patients and family carers find the MND Advisory Service of high value, both practically and emotionally, in particular valuing the aspects of the personal contact and the time dedicated to home visits, and 86-88% stated that the service has met their expectations. The majority (80%) stated that this service could not be provided by any other current service providers in the sector. It is worth noting that there are two unique features to this service that are not provided by other services to the same extent: The emotional benefit to the clients (in addition to the practical benefit) and the particular focus on the needs of the family carers as well. (Aoun 2017).

It is imperative that specialised organisations such as MNDAWA who understand the acute and critical needs of plwMND, are supported by the State Government and Department of Health. This will not only prevent crises and avoidable hospital and/or residential aged care admissions but enable plwMND to make informed and personal decisions about their health care, including palliative care, end of life decisions; as well as, provide a clear and coordinated pathway for service delivery across all services.

#### **Value for money and health lifestyles**

The Deloitte Access Economic report (2015) highlights that MND is the highest cost to the NDIS of the progressive neurological group. The MND Australia National Action Framework explains the importance for governments to work strategically and collaboratively with MND Associations to minimise cost and maximise quality of life. As the specialist organisation for plwMND in WA, MNDAWA provides expert guidance, information and support to plwMND and service providers to ensure the right care is accessible at the right time.

Care provision for plwMND crosses traditional funding streams with a combination of both federal and state funding across disability, equipment, respite, chronic disease and aged and palliative care (MND Australia National Action Framework, 2015). This system is a major barrier to efficient use of services, timely referrals and equitable access to quality needs-based care. This is heightened in WA with the lack of decision making around the NDIS and whether the federal or state model will be adopted.

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Another finding the satisfaction survey highlighted is that patients over 65 years are more satisfied than those under 65. The proportion of plwMND over 65 years agreeing/strongly agreeing that they feel more supported and cared for was 87.9%, compared to 77.8% of those who were 65 years and under. This may point to the better integrated and responsive service that MNDAWA is providing to the over 65 in terms of information, education, equipment, and the MND community nurse, compared to the fragmented service the under 65 are receiving from the Neurodegenerative Conditions Coordinated Care Program (NCCCP), funded by the Health Department and delivered by a different service provider. A collaborative Sustainable Health Review submission between MNDAWA and the Neurological Council of WA discusses this further.

MND Australia and MND State Associations are working together to review service provision and structures to prepare for a sustainable health future in Australia. The MND Associations of Victoria and NSW reported, from the NDIS trial sites, that NDIS staff have found the complex and progressive nature of MND challenging. It was identified that their understanding of the range and number of services that need to be organised and coordinated to support a person with MND and their family is limited. They struggle to adapt plans to fund both the present and future needs of the plwMND due to the often rapid and progressive nature of MND.

MND Associations in Victoria and NSW have advocated strongly for accurate and timely care provision for plwMND in the NDIS trial sites and are now reporting positive and cost effective outcomes related to fast track planning and 'MND starter packs'. Regardless of which model the WA government choose to roll out, NDIS or NDIS WA, MNDAWA will advocate to be involved in the planning process for plwMND. The MND Advisors' experience and expert guidance will ensure that plans created for plwMND have provision for both current and future needs, utilising cost effective planning resources provided by MND Australia, which have been adapted from MND NSW and Victoria Associations experiences with the NDIS.

MND Australia identify in the National Action Framework that the needs of people living with rapidly progressive neurological diseases such as MND cannot be met by existing or traditional aged care services or facilities. People diagnosed with MND aged 65 years and older access support services through the aged care system. This system presents major gaps for the care provision of a person living with MND, with waiting lists, an inadequate level of services available and limited hours of support. MND is not acquired as part of the natural aging process and as the disease progresses so does the individual's care needs. This is not supported by the current aged care system. Many residential facilities or aged care homes will not have the understanding or expertise to care for someone with MND. MNDAWA provides education workshops and delivers education at residential facilities to ensure plwMND have access to the right care at the right time. United with MND Australia, we ask that aged care reforms make for a fair health care system for plwMND and highlight the importance for the Department of Health to work collaboratively with the Association to ensure plwMND have an equitable access and equitable outcome of services.

The Association currently receives funding support from the Department of Health, Subacute Community and Aged Care Directorate. These funds are vital to maintain the provision of care and support services for plwMND in WA. The MND Advisory Service is a patient-centric service model, delivering specialist planning, care coordination and emotional support to plwMND that is not duplicated by any other service provider in the sector. By linking in plwMND to the services they require, the MND Advisory Service provides an integrated and coordinated care

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pathway.

There are still gaps to the care and services available to plwMND. One such example which has been identified by the clinical neurology leaders in MND and the Association is the lack of clinical nursing service provision to plwMND aged 65 years and over in WA. In response to this lack of care provision, MNDAWA have funded a full time clinical MND Community Nurse position. This is discussed in more detail further in the report under partnerships. Additional support services provided by the Association, which are completely self-funded through fundraising include; mobility equipment, communication aids and technology, non-invasive ventilation (costing thousands per person and discussed in more detail under technology and innovation), accessible transport, additional support groups and education.

We remain dedicated and committed to plwMND, their carers and families and will continue to advocate and ensure they receive the right care at the right time. In order for this to be possible it is vital that MNDAWA and the WA Department of Health work together.

#### **Partnerships across sectors**

Based at the Centre for Neurological Support in Nedlands, MNDAWA works collaboratively with other neurological organisations located in the building and is part of the Centre for Neurological Support Collaborative Steering Committee. This includes the Neurological Council of WA (NCWA), Neurocare, Parkinson's WA, Huntington's WA, Muscular Dystrophy WA and the Stroke Foundation. The Centre for Neurological Support is an integrated support centre which provides specialised support and care for all people living with neurological conditions. The creation of this steering committee highlights the importance these neurological support organisations have placed on a collaborative approach to a centralised location, reduction in service duplication and working partnerships for the neurological community.

An example of MNDAWA's willingness to work collaboratively with other organisations in the sector is the successful partnership created with NCWA to employ a MND Community Nurse. Funded by MNDAWA, this full time position was created as a result of a gap in service provision being identified for plwMND 65 years and over. A partnership with NCWA was created using a shared governance model approach, allowing NCWA to add their clinical governance and neurological nursing leadership and expertise to support this valuable resource for plwMND. This approach aligns well with a coordinated integrated neurological community model and was delivered as a successful partnership at a 2016 WA Health Department Community Neurological Collaboration event. The position is the only dedicated nursing resource to support plwMND 65 years and over in Australia.

MNDAWA proactively engage with the MND clinical neurology leaders in WA (as demonstrated with the creation of the nurse position). The Association recently launched a project aimed towards local WA Neurologists highlighting the support and services provided by MNDAWA and encouraging them to refer people to the Association at the time of diagnosis and optimise early provision of services. To support this initiative, MNDAWA consulted with the clinical neurology leaders and developed a comprehensive Motor Neurone Disease brochure. This has been designed for Neurologists to use at the time of diagnosis and assist in answering some of the many questions patients have at that difficult time. This brochure is also a very useful educational tool for allied health professionals to assist them in understanding the disease, the unique and varying rate of progression in each

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individual and to gain a further understanding of the multidisciplinary care pathway.

### **Technology and Innovation**

The Deloitte Access Economics report (2015) highlights that communication aids, assistive technology and equipment comprise one of the highest per person costs for plwMND at \$31,598 per person in 2015. Due to the often rapid rate of progression of the condition it is vital that plwMND have timely access to equipment as soon as the need arises to ensure they maintain their independence, communication and mobility for as long as possible. MNDAWA's equipment pool is funded through grants from organisations and fundraising projects. Without the Association's efforts to maintain an equipment pool (ongoing maintenance costs and consumables, circa \$40,000 per annum), plwMND would not have access to assistive communication tools and mobility aids. Nor would plwMND have access to vital equipment such as non-invasive ventilation (approximately \$10,000 per machine), which according to Berlowitz et al (2016) is reported to improve an individual's survival rate, on average, by 13 months.

One area highlighted for improvement in the annual satisfaction surveys (July 2017) was the lack of access to support services in rural areas, one respondent commented: "We live in the country - so too isolated to access many of MND services, but we really value the phone calls, the support, and the willingness to help when asked". In response to this, MNDAWA have launched project iPad Connect, to find funding to purchase more iPads (our existing iPads are used as communication devices for people with Bulbar Palsy MND) and the relevant software to enable face time support and access to telehealth services, assisting them to be more connected in rural areas.

### **Summary**

In summary, to ensure a sustainable, patient centred health system for plwMND in WA it is imperative that the Department of Health continue to support specialised care and support organisations such as MNDAWA and the collaboration of the Centre for Neurological Support. With expert knowledge on MND, the Association provides patient-centric planning and assessment, care coordination and emotional support to individuals' living with the condition. This crucial and proactive care model assists families in planning ahead, enabling them to make informed decisions and choose their own care pathway and by having the correct support services in place at the right time it prevents crisis and avoidable hospital and/or residential aged care admissions.

### **References:**

Deloitte Access Economics (2015), 'Economic analysis of motor neurone disease in Australia', on behalf of MND Australia.

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