

# Response to the Annual Price Review

NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

Submitted by:

**MND Australia**

On: 2 February 2020



## **Background**

MND Australia is the national peak advocate for motor neurone disease (MND). Together with the state MND associations 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 communities; and
4. the need for a coordinated response that addresses the person's disability

Timely early intervention and access to expert multidisciplinary care, assistive technology (aids and equipment), specialist planning and assessment 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 to 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**

### **Coordination of Support:**

It is estimated that there are currently 2,000 people living with MND and around 50% of these people were diagnosed when under the age of 65. All those living with MND under the age of 65 are eligible for the NDIS, however, the range and level of reasonable and necessary supports needed vary greatly. Some of these people will be recently diagnosed and may not need to draw on supports for some months whilst others will be very disabled and require a wide range of assistive technology, services and support on entering the scheme. Approximately 300 to 400 people will be eligible to enter the scheme per annum. Each year the same number will likely die and therefore leave the scheme.

The crucial issue is to recognise that MND is a rapidly progressing condition resulting in complex and changing needs which requires a rapid and responsive approach from diagnosis onwards. Coordination of Supports is vital throughout the disease trajectory due to complex and progressing disability needs and to ensure a person's plan is enacted effectively. Coordination of Support plays an important role in helping people with disability implement their plan in the most comprehensive manner possible.

For people with rapidly progressing and complex diseases, like motor neurone disease, Coordination of Support is a priority as people diagnosed with MND will, in most cases, have no prior experience of disability and disability support services. It is essential that the service is delivered by someone who has an in depth understanding of the disease. For this reason, the State MND Associations seek individuals with health qualifications and experience to fill the roles. In order for this strategy to be successful, the salary needs to be comparable to other Health related employment opportunities which is considerably higher than a standard Coordination of Supports salary. Therefore, a third tier of Support Coordination is required that fits between Specialist Support Coordination (\$186.58/hour) and Coordination of Supports (\$98.06/hour). This third tier would reflect the increased complexity of the service being provided whilst differentiating from the supports required through Specialist Support Coordination.

The state MND Associations employ Coordination of Support staff under the SCHADS modern award. This award is subject to the Equal Remuneration Order which is due to finish in December 2020. Annual wage growth under the SCHADS award through CPI and the ERO has seen an increase of over 5% each year and in 2019/2020 the increase was 4.6%.

Coordination of Supports under the NDIS price guide increased by 2.08% in 2019/2020. This discrepancy has occurred each year since the implementation of the NDIS and, as evidence would suggest, is creating a high turnover of Coordinators of Support and driving organisations away from delivering Coordination of Supports to the detriment of participants on the NDIS.

**MND Australia recommends a pay point between Specialist Support Coordination and Coordination of Support of \$120-130/hour for support coordination for people with complex ,rapidly progressing and ongoing support needs.**

**Carol Birks**, CEO, MND Australia