



National Disability Insurance Scheme

POSITION STATEMENT

Background:

The national disability insurance scheme (NDIS) will transform the lives of people living with motor neurone disease (MND) who are diagnosed when under the pension age.

The NDIS recognises the need for:

- early intervention for people with progressive degenerative disease including MND
- a planning process that can anticipate changing need
- effective protocols for timely and smooth referrals to and from the different sectors

Commencing July 2013 trial sites have been rolled out in various regions nationally with some focussing on a specific age range. The MND associations in Victoria and NSW are working closely with the NDIA in Barwon and the Hunter to support people with MND, particularly in the planning process. The small number of MND clients in these sites affords a unique opportunity to review and analyse the processes undertaken and their impact on people with MND.

The first half yearly report on the NDIS indicates that people with neurological conditions are receiving the highest average packages. While people living with MND are only a small proportion of them, rapid progression of the disease, high and complex needs and the short life expectancy mean that they have potential to be a significant impact on the Scheme.

MND Associations are working together nationally to review their current service provision and structure to prepare for the future. The experiences in trial sites to date have identified that NDIA staff find the complex and progressive nature of MND challenging. In addition, 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 fail to recognise or accept that the progressive degenerative nature of MND means that services need to be planned and funded for future needs, as well as the present. It is imperative that the skills, expertise and knowledge of MND association family support staff are effectively utilised to enhance the impact of the NDIS on people with MND and their carers.

To date generic government equipment services have been unable to meet the needs of people living with MND in a timely manner. MND Associations play a vital role in providing aids and equipment and assisting the person with MND to plan ahead for their equipment needs.

A rapid response to service provision from a range of providers with an understanding of MND, timely access to aids and equipment, coordination and regular review is imperative in meeting the individual needs of a person living with MND.

MND Australia believes:

- MND association regional advisors should be involved in the planning process and undertake complex support coordination for people living with MND to streamline early intervention, coordination and access to necessary supports, reduce the time needed for initial planning and facilitate timely review plans when needs change
 - their expertise would ensure cost effective services could be built into the plan, resulting in significant savings for the scheme. It would also ensure that support from volunteers and MND education for service providers become an integral part of the plan
- MND association equipment service should provide aids and equipment loan to people living with rapidly progressive neurological disease
- MND associations should provide specialist MND information and education to NDIA staff and registered service providers

MND Australia calls for:

- The NDIA to provide a minimum basic package for people diagnosed with MND on entry to the scheme that includes complex support coordination, home assessment/therapy, respite and equipment
- The NDIA to support MND associations to be involved in and/or undertake the planning process for people living with MND
- The NDIA to support MND associations to undertake complex support coordination for people living with MND if that is their choice
- The NDIA to support access to the MND Association equipment loan service for people living with rapidly progressing neurological disease
- Continued bipartisan government support and commitment to funding the NDIS so that this significant social change can be rolled out and implemented nationally as planned

On behalf of the MND Australia board and state MND Association's

Signed: David Ali (President)

Dated: 26 June 2014