To: The Secretary
Senate Community Affairs References Committee
PO Box 6100
Parliament House
Canberra ACT 2600

From: Alex Malley
National Executive Director
Motor Neurone Disease Association of Australia
Building 4, Old Gladesville Hospital, Gladesville NSW 2111
Telephone: +612 88770999
Email: ned@mndaust.asn.au

Submission to the Inquiry into the funding and operation of the Commonwealth State/Territory Disability Agreement by the Motor Neurone Disease Association of Australia (MNDAA)

Submission approved by the President and Board of MNDAA

Lodgement Date 3 August 2006 by email

Signed hard copy mailed 4 August 2006

Five pages including this cover page

Signature: Alex Malley…………………………………

Background to Motor Neurone Disease (MND)

MND results in the death of more than one Australian every day of the year.

MND affects people across a range of ages, more commonly between the ages of 40-70 years.

MND is a progressive degenerative neurological disease that causes rapidly increasing levels of disability, and death. The average life expectancy is between 2-3 years. The rapid progression of MND creates high levels of disability and consequent needs for support — feeding, communication, movement, transferring, toileting, day activities etc. MND has a comprehensive impact on all aspects of living.

The key feature of the disease is the speed of progression, which poses huge problems of adjustment for people who have MND, an escalating burden on carers and families, and a challenge to those who are involved in providing the highly variable and complex care.

Community services should be accessed by people with MND on the basis of essential need. However, service types and delivery options have traditionally been based on age, and in many cases bear little relationship to the needs of the individual.

Carer stress is a significant cause of patient hospitalisation, facility-based care/respite and movement to residential aged care facilities. With increasing numbers of people living with MND demand for residential aged care services will continue to grow as community and respite care needs remain substantially unmet. Many people do not have family carers and have no option other than to seek supported accommodation sooner than later.

These services are accessed by people with MND on the basis of essential need. However, service types and delivery options have traditionally been based on age, and in many cases bear little relationship to the needs of the individual.

Residential aged care services may have the skills to meet the needs of people with MND, but usually do not have the time, resources, knowledge or commitment to support them in a manner which reflects their support needs.

Residential aged care service staff need to recognise that while people with MND have a progressive disability, and in most cases difficulties with their speech, they have no cognitive deficit, and are aware of themselves and their surroundings at all times.

In terms of accommodation services, they need support that recognises the lost ability to communicate, or to use call button systems. The environment and management must be able to cope with PEG feeding (gastrostomy) non invasive ventilation and in a minority of cases tracheostomy and full ventilation.

And despite severity of the disability, people with MND, especially younger people require interaction and communication with people.

Realities for people living with MND

In relation to residential care;

Staff Training –staff are trained in respect to managing frail aged and aged people with dementia, but do not have the skills, training or experience to appropriately support, in a caring environment, people living with MND

Dementia focussed services – increasingly, residential aged care facilities have become focussed on dementia care. Those with advanced MND who access aged care facilities are often younger people, do not suffer from dementia, are aware of their surroundings, can hear and understand all that is going on around them, but are trapped in an increasingly unable body. They require the "nursing" component of the aged care facility due to their disability as they do not receive sufficient support to remain at home.

Risks for people with MND – Some people with MND require ventilatory support, while many have PEG feeding tubes. People with MND living in residential aged care facilities with severe physical disability may face the risk of assault or disruption to life support equipment by other residents who are physically able but suffering from dementia. In addition people living with MND are at a psychological risk due to isolation and vulnerability.

Aids and Equipment – while residential aged care facilities are required to provide appropriate aids and equipment, most residential services do not have the funds available to provide equipment that is necessary for people living with MND. This is complicated by the State Government aids and equipment program (A&EP) which specifically exclude people living in residential aged care facilities.

There needs to be a national standard in relation to the provision of Aids and Equipment in each State to take into account the rapid nature of MND progression.

Why should one State have a means test and another not? MND families face the biggest hurdles of anyone with a disability because of the rapid and debilitating nature of the disease. Finding the resources to quickly cater for the necessary aids and equipment, after often relinquishing two salaries is often impossible.

The time delays in the current systems across Australia are too long to cater for MND patients. The eligibility criteria for aids and equipment also vary greatly from state to state.

Communication – residential aged care facilities are required to have call facilities to enable residents to call for attention. However, the emergency call systems are generally structured around a push button system. People with MND requiring residential aged care support have generally lost the capacity to use their hands and are unable to use a call bell system using the traditional push button switch.

Inability to call for assistance is potentially dangerous and creates a high risk for people living with MND and highlights the need for provision for allied health professionals to review the needs of people with MND in residential care on a regular basis.

Time – significance of needs created by MND is reflected in the time required to assist or support someone with the disease. This is particularly true of those who live in residential aged care facilities. Time is required for positioning and repositioning to reduce pressure areas or to optimise comfort or reduce discomfort, time for communication, feeding, transferring from bed to chair and return etc.

Yet the time to do these things is not available in residential aged care facilities.

In relation to home and community care;

Adequacy of support and assessment –current resourcing levels of home and community care services are inadequate for existing demand and significant delays exist in assessment.

Issues for consideration by Senate Community Affairs References Committee

We request that the Committee in examining the funding and operation of the Commonwealth-State/Territory Disability Agreement consider the following issues;

- Services for people with disabilities must be provided to address needs created by the disease, not only address needs created by ageing
- Some people under the age of 65 require levels of support that are currently only provided in residential aged care facilities
- Some people over the age of 65 need services that are only currently provided through state based disability services for people under the age of 65
- End the discrimination at age 65 regarding access to services to support people with particular needs arising from disability and ageing
- Services must be holistic and effectively address the needs of people with MND and their carer
- Move to a model of flexible service that is tailored to the needs of the individual with basic components which all people require and enhanced components that only some people will require
- Where people move from one service provider to another due to the progression of MND this must be seamless in provision of equipment and support services
- Ensure that people living with MND are able to access services that meet their needs to help them live **better** for **longer**
- Provision of realistic alternatives to residential care for people living with MND such as long term hospice beds, 24 hour care in the home

- Provision of and access to timely, flexible, regular respite for those living with MND to enable the family carer to have regular breaks from caring

- Timely and affordable access to adequate levels of personal care in the home to maintain independence, quality of life and health and well being of the carer

- Equitable national access to optimal respiratory assessment and regular review and the recommended respiratory equipment to maintain quality of life

- Greater Government investment in research and engagement of community based stakeholders in the development of research agenda