Submission
No 54

INQUIRY INTO SERVICES PROVIDED OR FUNDED BY THE DEPARTMENT OF AGEING, DISABILITY AND HOME CARE

Organisation:	Motor Neurone Disease Association of NSW
Name:	Mr Graham Opie
Date received:	6/08/2010

---

mnd
New South Wales

5 August 2010

The Director
Social Issues
Legislative Council
Parliament House
Macquarie St
Sydney NSW 2000

Lodged electronically

Inquiry into services provided or funded by the Department of Ageing, Disability and Home Care

The Motor Neurone Disease Association of NSW (MND NSW) represents people living with motor neurone disease (MND), their families and carers across NSW. MND NSW provides ongoing support, information, education and equipment for people with MND as soon as the need arises wherever possible. Our Regional Advisors help clients navigate the health and disability system and make referrals to the relevant services.

MND NSW currently has 415 people with MND registered. Throughout 2009/2010 580 people with MND were registered with the Association and 147 members died from MND. The median life expectancy for our members is 27 months from diagnosis to death.[1]

MND is a rapidly progressive degenerative neurological disease that causes increasing and complex levels of disability leading to death, usually within three years from diagnosis. People living with MND and their carers face a spiralling series of losses – loss of speech, swallowing, mobility and breathing – with severe impact on physical, emotional, psychosocial and financial well-being. Rapid progression and the complex care needs in MND are currently poorly met for many people. In most cases people rely entirely on their families for care and in some cases the person has young children.

At present there is no known cause and no known cure for motor neurone disease. 90% of cases are sporadic and the other 10% of cases are familial.

MND NSW currently provides over $1.5 million dollars worth of equipment per annum to people with MND. The equipment is loaned free of charge and all maintenance and shipping is paid for by MND NSW.

Historically MND and other neurological diseases have not had the attention of ADHC and, until recently MND NSW has only received NSW Government funding through the Department of Health.

---

[1] MND NSW client database

Motor Neurone Disease Association of New South Wales Inc.
Building 4, Gladesville Hospital Victoria Road Gladesville NSW 2111
Locked Bag 5005 Gladesville NSW 1675
Phone: 02 8877 0999 Freecall: 1800 777 175 Fax: 02 9816 2077
admin@mndnsw.asn.au www.mndnsw.asn.au
ABN 12 387 503 221 CFN 11154

Over the past 4 years this has changed dramatically with:

- Flexible respite funding
- Rapid response case management packages made available during periods of rapid degeneration and prior to assessment,
- Increased access to High Needs Pool and Attendant Care Packages for those at risk of rapid degeneration,
- Greater regional and remote focus and
- Top up equipment funding to enable people to be cared for at home.

Many of these enhancements have been the result of non recurrent funding.

The rapid degenerative nature of MND requires that assessment and service delivery happens as quickly as possible. ADHC has worked with MND NSW to decrease waiting time through High Needs Pool and Attendant Care Packages and funding through Community Options to provide packages for rapidly degenerative neurological disease.

Through MND NSW's work with consortiums that include Muscular Dystrophy NSW and Multiple Sclerosis Australia – ACT/NSW/Vic we have developed flexible respite funding models that are based on and driven by the carers and families needs.

Over the next 5 years MND NSW plans to enhance our client focussed services through consortiums and collaboration with organisations such as Muscular Dystrophy NSW, Multiple Sclerosis Australia – ACT/NSW/Vic, Alzheimer's Australia NSW, Parkinson's NSW and the Australian Huntington's Disease Assoc. NSW. This can only happen with support from ADHC and the NSW Department of Health.

MND NSW welcomes the opportunity to comment on the quality, effectiveness and delivery of services provided or funded by ADHC and believes that the advances in services to people with neurological disease may be enhanced by:

1. Timely, client focussed service delivery - depending, to a large extent on the expertise of community based organisations, particularly where rapid degeneration occurs

2. Recurrent funding should be implemented to ensure the advances in service delivery and support are not only maintained but enhanced

3. The management of the Commonwealth/State funding divide for aged care services should be carefully considered as this has the potential to hinder rather than help support a lifespan approach to people with disability. People with degenerative disease no matter what age require access to high level disability services and their families and carers have no interest in where support comes from.

Sincerely

Graham Opie
Chief Executive Officer