

**Submission  
No 18**

## **THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)**

**Organisation:** Motor Neurone Disease Association of NSW  
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**Position:** Chief Executive Officer  
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The Director  
General Purpose Standing Committee No. 2  
Parliament House  
Macquarie St  
Sydney NSW 2000

### **Inquiry into the Program of Appliances for Disabled People (PADP)**

The Motor Neurone Disease Association of NSW (MNDNSW) represents people living with motor neurone disease (MND), their families and carers across NSW. MNDNSW 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.

MNDNSW currently has 346 people with MND registered. In 2007/2008 170 new members joined the Association and 157 members died from MND during that period. The median life expectancy for our members is 27 months from diagnosis to death.<sup>1</sup>

The disease is terminal leading to progressive paralysis of limbs and increasing difficulties with speech and swallowing. Generally the person remains astute and mentally alert, however eventually people with MND are unable to breathe without assistance. In most cases people rely entirely on their families for care and in many 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.

MNDNSW currently provides over \$1million 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 MNDNSW.

PADP, in its current form is unable to cater for people with rapidly degenerative disease. The assessment process is drawn out and often leaves a person with a disease such as MND without a means of communication or mobility for extended periods. In the past regional differences in the administration of PADP has also played a role in making it more difficult for people with MND getting equipment.

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<sup>1</sup> MNDA NSW client database

For those people with a more slowly progressive form of MND, MNDNSW requires these people to apply for PADP as an interim coverage, with varying degrees of success.

In a meeting held with the authors of the *Report into the Program of Appliances for Disabled People* undertaken by Price Waterhouse Coopers and released in June 2006, MNSNSW submitted that clarity and consistency of information across all regional PADP suppliers across NSW was essential. A lack of transparency and often differing loan criteria led to confusion and frustration amongst applicants and MNDNSW. At this meeting MNDNSW emphasised the importance of a centralised database of equipment that allowed tracking, recovery and certainty (or not) of availability.

MNDNSW's database and tracking systems were used as an example.

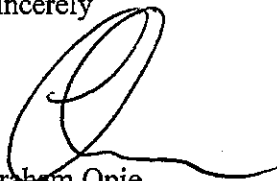
### **Conclusion**

1. Appliances for people with disability are expensive. They require proper tracking, maintenance and recovery.
2. A centralised system offers people with disability transparency and clarity of information, enabling them to know of the equipment currently available and the length of waiting lists.
3. A centralised system of coordination, delivery, maintenance and recovery is essential. Equipment is becoming more technical and expensive, leaving some areas in NSW unable to manage complex devices such as communication.

To date the PADP under the auspice of the Department of Health has been unable to deliver a transparent, cost effective service. The Government's response to the findings of the Price Waterhouse Coopers review whilst promising has had little effect given the complexity and time needed to draw many disparate regional PADP services together.

Whether a centralised service is run by the state or federal governments, not for profit or a for profit organisations there is a need to centralise all facets of the service and keep clear and transparent records of all equipment loaned and in stock. A streamlined assessment process is essential.

Sincerely



Graham Opie  
Chief Executive Officer