



**Senate Standing Committee on Community Affairs
Private Health Insurance Act
January 2007**

Submitted via email

to: Community.Affairs.Sen@aph.gov.au

On: **Thursday 25 January 2007**

MND Australia is the national peak body for MND in Australia. During 2005/06 **445** people newly diagnosed with MND registered with MND Associations across Australia. During that period state/territory Associations were informed of 355 people who had lost their fight with MND. 939 people were registered with State and Territory Associations as of 1/7/06.

MND Australia has recently become aware of the introduction of Broader Health Cover as part of the proposed changes to the Private Health Insurance Act 2006. MND Australia supports the intention of this Act to extend the range of products available through private health insurance. We believe that private health insurance can assist in addressing the unmet needs of people living with MND that can result in inpatient admission and lengthy hospital stays. We see the implementation of this Act as having potential to reduce hospital inpatient admissions due to MND, enhance quality of life and help reduce carer breakdown by making available appropriate services to people with unmet needs. MND Australia welcomes this opportunity to highlight the unique needs of people living with MND and their carers.

Background

1,300 people in Australia today are living with motor neurone disease (MND). Each day at least one Australian dies of MND and a new person is diagnosed with this progressive and inevitably fatal disease.

Although MND was first described nearly 150 years ago there is still no known cause and no known cure

MND is a progressive degenerative neurological disease that causes rapidly increasing levels of disability and death. Average life expectancy from diagnosis is about 27 months (Sach 1995). Average age of onset is 59 years; however, the age range of onset is 20 to 70 years.

The rapid progression of MND creates high levels of disability and consequent needs for support including: feeding, communication, movement, transferring, toileting and all daily activities. MND has a comprehensive impact on all aspects of living. While people of working age can remain at work after diagnosis, this is usually for a very short time, often only weeks or a few months. MND also impacts on the family carers ability to maintain employment.

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

The extension of products available through private health insurers will assist people to live better for longer and carers to care better for longer by accessing services that would otherwise have to be delivered in hospital. This will assist them to either return home or to remain at home. The present

structure of private health insurance does not provide for privately funded services or equipment to support this option. Their health funds are therefore of limited support unless admitted to a private hospital. The proposed expansion of the types of services funded by private health insurance has the potential for people living with MND to access appropriate private services to prevent hospital admission.

Submission

Allied health services are integral to the care management of people living with MND in the community. The limited life expectancy drives urgency for access to services and support. It is imperative that funded benefits from private health insurance encompasses products to support regular review and follow up from allied health providers with regard to the psychological health, equipment, communication, respiratory support and dietary needs of the person with MND.

Timely assessment from the relevant therapist for equipment to assist with daily living and communication is essential. People accessing these services through the public system often face long waiting periods which may necessitate admission to hospital and inpatient support and care.

MND Associations in each State provide for some of the equipment needs of people living with MND following a prescription from an allied health professional. Benefits to cover essential aids and equipment items should be included to support “hospital-substitute treatment” and to address the current untenable waiting times for equipment available through state based equipment schemes. Access to timely provision of equipment at minimal cost is also essential to enable the carer to carry out the role of primary carer safely throughout the disease trajectory. Carer injury often results in the person with MND being admitted to acute care. Some people with MND need assistance to breathe and ventilation equipment may be prescribed by their respiratory physician. It is imperative that provisions are made for private health insurers to provide these products.

Enhancement of private health insurance products must encompass the needs of people living with MND and should include the following key elements to help keep people living with MND out of hospital:

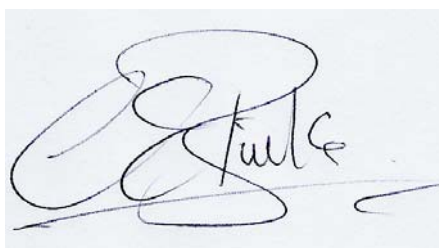
- **Equipment** to support activities of daily living and to assist with breathing must be included as *goods intended to manage MND*
- **Case management** is a key component in helping people remain independent, living at home and preventing inappropriate admission to hospital. State MND Associations provide services as part of a multidisciplinary team to facilitate and coordinate best practice care management. It is therefore also essential that case managers and MND association family support services be specified as eligible services to manage diseases such as MND and to sustain the health of the carer

- **Regular, flexible, tailored respite**, including access to in home overnight respite care, is an essential service to support carers in their caring role and to prevent hospital admissions due to carer burn out
- **Information and education programs** for people living with MND, their carers and health and community care providers are vital and must be included as part of the proposed disease specific management products. MND Australia family support staff, as coordinators of MND management programs, should be identified as eligible health care providers for these programs
- **Broadening the horizons of funded services** beyond the current Medicare schedules to augment overstretched publicly funded services

We look forward to the proposed changes to the Private Health Industry Act.

We anticipate that the development and extension of health cover products will be of benefit to people living with MND and their carers. The key components of disability aids and equipment, case management to reduce hospital admission, respite care to sustain the carer and information/education programs to support individuals and families will be attractive products that will assist people living with MND to live better for longer, and significantly reduce their admission to acute care services and hospitals.

MND Australia would welcome the opportunity to participate in any public hearings.

A handwritten signature in black ink, appearing to read 'Carol Birks', with a horizontal line underneath.

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