

**INQUIRY INTO PROVISIONS OF THE AGEING AND
DISABILITY COMMISSIONER BILL 2019**

Organisation: Motor Neurone Disease Association of NSW
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Inquiry into the provisions of the Ageing and Disability Commissioner Bill 2019

ABOUT MND

MND is the name given to a group of neurological diseases in which motor neurones, the nerve cells that control the movement of voluntary muscles, progressively weaken and die. With no nerves to activate them, the muscles of movement, speech, swallowing and breathing gradually weaken and waste, and paralysis ensues. MND affects each person differently with respect to initial symptoms, rate and pattern of progression, and survival time.

Average life expectancy is 2 to 3 years from diagnosis.

There is no known cause for MND (except in a very small number of genetic cases), no effective treatments and no cure. There are no remissions and progression of MND is usually rapid and relentless creating high levels of disability and a consequent need for a wide range of progressively changing supports.

Approximately 60% of people with MND are aged 65 or older when diagnosed.

THE CHALLENGES

The social and emotional impact of MND is amplified by its complex nature, the speed of its progression and the spiralling series of losses that pose:

1. huge problems of adjustment for people who have MND;
2. an escalating and stressful burden on carers and families
3. a challenge to health professionals, disability services, community care, and aged care providers involved in meeting the variable, progressing and complex care needs, particularly in regional, rural and remote; and
4. the need for a coordinated response that addresses the person's disability

Timely early intervention and access to expert multidisciplinary care, assistive technology (aids and equipment), specialist planning and assessment and coordination of support, including a proactive framework for decision-making, play vital roles in maintaining quality of life and independence. It also helps people to plan ahead to prevent crisis and avoidable hospital/residential aged care admissions.

Although early intervention will not slow down the disease process in MND it will strengthen the informal supports available to the person, including supporting the primary carer to maintain the caring role and their own health and wellbeing.

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SUBMISSION

The Motor Neurone Disease Association of NSW (MND NSW) supports approximately 520 people with MND across NSW. Because of the rapid nature of the disease early support through education, advocacy and provision of assistive technology is essential, enabling a person to be cared for at home and reducing the risk of admission to hospital through falls and, eventually aged care as the family are unable to care for the person.

For those aged under 65 at diagnosis the national Disability Insurance Scheme is now providing packages that truly support a person with rapidly changing needs.

For those aged 65 or older at diagnosis there is a waiting list of approximately 126,000 people for a Level 1 Aged Care Package. To gain access to a Level 3 or 4 package, usually required within the first six months to a year of a diagnosis of MND there is a 12 to 24 month waiting list. Most people with MND die before receiving a Level 3 or 4 package.

When people with rapidly progressive neurological disease enter an aged care facility the facility is, on most occasions not prepared for the rapid nature of the disease nor the degree paralysis. Often leading to neglect.

MND NSW is pleased with the broad terms of the functions of the Commissioner relating to abuse, neglect and exploitation of older adults. The systemic abuse and neglect, partly due to the inequity of services for people with rapidly progressive neurological disease, is an issue that may fall outside the role of the Commissioner. However, it is an underlying factor that creates environments where abuse and neglect flourish and older, vulnerable people living with MND are at substantive risk.

Sincerely

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