



Review of Australia's Future Tax System

**Closing date:
Friday 1 may 2009**

Submitted by MND Australia via email

to:

Review Secretariat

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MND Australia
Review of Australia's Future Tax System
May 2009

Background

MND Associations in Australia were formed during the 1980's to meet the varying and complex support, equipment and information needs of people living with MND their carers and their families. MND Australia was established in 1991 as a national peak body for motor neurone disease (MND). In 2009 the MND Australia network comprises of six MND Associations, representing all states and territories, and the MND Research Institute of Australia (MNDRIA).

MND Australia members work together to advance, promote and influence local and national efforts to achieve the vision of a *World Free from the Impact of MND*.

Motor neurone disease is the name given to a group of rapidly progressive degenerative neurological diseases that cause increasing and complex levels of disability leading to death, usually within five years of diagnosis. The most common form of MND is amyotrophic lateral sclerosis (ALS).

Currently around 1300 Australians are affected by MND and thousands more; family, friends and carers live daily with its effects. Each day at least one Australian dies of this cruel disease and a new person is diagnosed. Although MND was first described nearly 150 years ago there is still no known cause, no known cure and no effective treatment. Average life expectancy from diagnosis is about 27 months (Sach 2003). Average age of onset is 59 years; however, the age range of onset is 18 to 90 years.

The rapid progression of MND results in increasing support needs and reliance on a range of aids and equipment to maintain quality of life and social inclusion. Support needs can include assistance with: feeding, communication, breathing, movement, transferring, toileting and all daily activities. The social impact of MND is amplified by its complex nature, the speed of its progression and the spiralling series of losses, which pose:

- huge problems of adjustment for people who have MND;
- an escalating burden on carers and families; and
- a challenge to health professionals involved in meeting the variable and complex care needs, particularly in regional, rural and remote areas of Australia.

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.

During 2007/08 **493** people newly diagnosed with MND registered with MND Associations across Australia. During that period state Associations were informed of **431** people who had had lost their fight with MND. **989** people were registered with State Associations as of 1/7/08.

The motor neurone disease research institute of Australia (MNDRIA) has awarded \$550,000 for new grants commencing in 2009.

Submission

The Motor Neurone Disease Association welcomes the opportunity to contribute to the review of Australia's Future Tax System.

Each state Motor Neurone Disease Association is incorporated under their respective state Associations Incorporation Act. Motor Neurone Disease Australia (MND Australia) is incorporated under the *Associations Incorporation Act (Victoria)*.

As a consolidated entity the level of per annum funding to all seven Motor Neurone Disease Associations would not exceed \$5million with NSW and Vic raising the majority, approximately \$2million each. Approximately 80% of the total funding is received through gifts, donations, events and bequests thus requiring greater transparency and accountability.

We will respond to relevant Consultation questions as outlined in the Consultation Paper - Summary

Q5.7 At what age should an individual be able to access their superannuation and at what age should they become eligible for the Age Pension?

People diagnosed with MND are usually unable to work and often their family carer also has to leave work to care for them. Therefore, in addition to the cost of care, income reduces drastically compounding financial distress. Access to non assessable superannuation lump sum payments to individuals with a terminal medical condition such as MND has assisted in decreasing financial burden on families.

However, the burden after the superannuation has been expended is generally placed on the spouse and beneficiaries in later life forcing individuals onto the age pension. This demonstrates "*the importance of inter-temporal equity — which considers how the system affects individuals over their entire lifecycle, not just in a particular year*"¹. Eligibility and access to the Age Pension should be reviewed under such circumstances.

Q7.1 What is the appropriate tax treatment for NFP organisations, including compliance obligations?

Recruitment and retention of qualified staff is an ongoing area of uncertainty with non profit organisations. In recent times the tight labour market has seen many organisations unable to meet market expectations for wages which has impacted directly on their ability to deliver services.

The Fringe Benefit Tax exemption and rebate that applies to many non profit organisations has remained static since 2001. An increase in the grossed up amount (to \$40,000) and recurrent indexation would help with equitable employment and retention of essential staff, enabling NFPs to at least maintain some part parity with other employers.

¹ Australia's Future Tax System; Design Principles for the Tax Transfer System
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Q7.2 Given the impact of the tax concessions for NFP organisations on competition, compliance costs and equity, would alternative arrangements (such as the provision of direct funding) be a more efficient way of assisting these organisations to further their philanthropic and community-based activities?

The requirement for NFPs to maintain a “Gift Fund” to separate donated funds from those contributed through grants, fundraising and government funding creates a greater burden on many small NFPs. As all proceeds to NFPs go directly to the specific cause and administration of that cause.

Greater transparency through a national, tiered reporting structure and Act would promote consistency amongst NFPs and allow greater clarity to the general public, government funding bodies and the ATO, decreasing the need for a Gift Fund.

MND Australia would welcome the opportunity to provide further information.

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

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