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Cost of motor neurone disease up to 1000 times greater than other chronic conditions

A new Deloitte Access Economics Report reveals that in Australia, the per person cost of motor neurone disease (MND) in 2015 was \$1.1 million, dwarfing the cost of many other chronic health conditions.

The report, commissioned by MND Australia, will be launched at Parliament House, Canberra on 24 February 2016. It is the first Australian study of the economic impact of MND, a progressive neurological disease that kills two Australians every day, usually within 2.5 years following diagnosis. Full report: [Economic analysis of MND in Australia](#)

The report states that the total cost of MND in Australia was \$2.37 billion in 2015, comprising \$430.9 million in economic costs and \$1.94 billion in burden of disease costs.

“The enormity of the cost is akin to the brutality of MND. People living with MND may rapidly develop physical disabilities often forcing them and their carer to withdraw from work prematurely. This loss of productivity places a great burden on families and the economy,” says Ms Carol Birks, National Executive Director of MND Australia.

While government bears 68% of health system costs there is still a significant gap borne by individuals and other organisations.

MND NSW Board Member, Dr Kirsten Harley was diagnosed with MND three years ago:

“When you receive a diagnosis of MND, money is the last thing on your mind. But along with the relentless physical and emotional effects on yourself and loved ones are the financial costs: early retirement, medical appointments, hospitalisations, treatments, equipment, wheelchair transport, personal care ... There is support from the state MND associations and government, but it all adds up.”

The national network of six state MND associations assist Australians living with MND to get the right care at the right time. Over 75% of Australians living with MND seek care, information and support from their state MND Association.

“The state MND associations currently do an excellent job of ameliorating the shortcomings of the care system and supporting people to remain at home. As we dawn on a new era of care in Australia, we appeal to the government to make MND a health priority and fast-track care and support services for people living with MND.” says Ms Birks.

MND Australia calls on the government to:

- Ensure fast-track access to care and support services to meet the reasonable and necessary support needs of all people living with MND by June 2017
- Fund the full range of assistive technology as part of a person’s NDIS plan and aged care package (p.75), both now and as the NDIS rolls out nationally
- Ensure Information, Linkages and Capacity Building (ILC) funding for state MND associations to provide disease-specific and timely information, referral to the right service at the right time, ongoing support, cross sector collaboration and support for carers to delay the need for individually funded packages
- Subsidise non-invasive ventilation in the management of MND (p.43)
- Include progressive neurological diseases as a National Health Priority by 2017
- Invest at least \$1 million annually to support the employment costs of the MND Multidisciplinary Clinic nurses
- Invest at least \$20 million annually in large research projects until researchers understand the causes of MND and find an effective treatment

Key report points about the economic impact of MND:

- The total cost of MND in Australia was \$2.37 billion in 2015, comprising \$430.9 million in economic costs and \$1.94 billion in burden of disease costs. This equates to \$1.1 million per person.
- Government bears 68% of health system costs, with 18% borne by individuals and the remaining 14% borne by other organisations (e.g. MND associations, private health insurers).
- Productivity loss in individuals with MND is \$162.8 million or \$77,776 per person, largely due to losses associated with premature death.
- Informal care costs of \$68.5 million, or \$32,728 per person with MND.
- The largest component of other financial costs is expenditure on aids, equipment and modifications to the home or vehicle for people with MND. These were estimated to be \$66.2 million, or \$31,598 per person.

Key report points about care and research:

- In any year 88% of people with MND require at least some level of care.
- Informal carers are estimated to provide 7.5 hours a day of care to people with MND.
- The average annual cost of National Disability Insurance Scheme (NDIS) packages for people living with MND was \$64,000, substantially higher than other neurological disease packages (\$46,060).
- The cost of using an MND equipment loan service (\$19,625) is less expensive than the cost of equipment purchase under the NDIS (\$24,030).
- The research expenditure for MND in Australia is estimated to be \$10.6 million in 2015.

MND in Australia:

- Motor neurone disease (MND) is the name given to a group of diseases in which the nerve cells (neurones) controlling the muscles that enable us to move, speak, breathe and swallow undergo degeneration and die.
- 2,094 people are living with MND in Australia, of whom 60% are male and 40% are female.
- Mean time from onset to confirmation of diagnosis is 10 to 18 months
- Prevalence – 8.7 per 100,000 or 1 per 11,434 Australians
- Approximately 58% of people with MND are under the age of 65.

About:

Together with the [state MND associations](#), MND Australia promotes best practice MND information and support, and encourage and promote equitable state-based services to help people with MND and their carers live better.

Instructions:

If you would like to organise an interview or produce a story about the Deloitte Access Economics Report, *Economic analysis of motor neurone disease in Australia*, please contact Rachel Rizk, 0414 219 015 rachelr@mndaust.asn.au; or Alison Mudie, alisonm@mndaust.asn.au

Full report: [Economic analysis of MND in Australia](#)

[MND Background Information Fact Sheet](#), provides further facts about MND.

Social Media:

Please use both of the following two hashtags across any social media posts where character count allows.

#MNDcosts

#MNDaction

Spokespersons available for interview:

Carol Birks, National Executive Director of MND Australia

David Ali, President of MND Australia

Kirsten Harley, Board member of MND NSW and living with MND

Lynne Pezzullo, Partner of Deloitte Access Economics