

MND Australia background information on motor neurone disease 2014

What is motor neurone disease?

Motor neurone disease (MND) is the name given to a group of diseases in which motor neurones progressively die. Motor neurones are nerve cells that control the movement of voluntary muscles, that is, muscles that are under conscious control. These include all the muscles of the arms, legs, back and neck and of speech, swallowing and breathing. With no nerves to activate them, muscles gradually weaken and waste, and paralysis ensues. Weakness is often seen first in the hands or feet, or the first sign may be swallowing difficulty or slurred speech. Muscle twitching and/or cramps may also occur.

MND affects each person differently in respect of initial symptoms, rate and pattern of progression, and survival time. There are no remissions. The key feature of the disease is the speed of progression, which poses huge problems of adjustment for people who have MND, an escalating burden on carers and families, and a challenge to those who are involved in meeting the variable and complex care needs. More information: www.mndaust.asn.au

Key facts

- MND is a rapidly progressive, terminal neurological disease
- There is no known cure and no effective treatment for MND
- Each day in Australia two people die from MND
- Each day in Australia two people are diagnosed with MND
- People with MND progressively lose the use of their limbs and ability to speak, swallow and breathe, whilst their mind and senses usually remain intact
- Average life expectancy is 27 months

MND in Australia

- An estimated 1,900 people are living with MND (based on 2011 population and Australian Institute of Health and Welfare, 2011)
- In 2011, 790 people with MND died compared to 592 people with MND who died in 2001 - (Australian Institute of Health and Welfare, 2011)
- It is estimated that the incidence in Australia is around 3.5 per 100,000 of population per year (Based on the 2011 death rates, Australian Institute of Health and Welfare)
- The six state MND associations provide support in all states and territories
- MND Australia and its research arm, MND Research Institute of Australia (MNDRIA), form one national body that represents both care and research
- During 2012/13 MND associations provided:
 - care, information and support for 1,209 people living with MND
 - support and information for 578 people newly diagnosed with MND
 - support for the families of the 480 people registered with an MND association who died
 - over 3,435 items of equipment to people living with MND at no cost
 - information on MND to over 12,000 people including those living with MND, carers and health professionals and community care providers
 - \$2.6 million for MND specific research through MNDRIA

Summary of needs for people living with MND

- Early diagnosis given by a neurologist expert in MND
- Counselling and support at and following diagnosis
- Early access to MND Associations for information, support and referral to services
- Early access to palliative care services
- Early and timely intervention and access to a range of services based on the needs of the individual and their family
- Coordinated multidisciplinary care from a team of professionals
- Urgent response and regular review - waiting lists are not appropriate
- MND specific information, education and support for people living with MND, their carers and for the health professionals and service providers involved in their care.
- Funding for research to find the cause and a cure for MND and better care for people living with MND

MND WEEK 2014, 4 – 10 May

Right care, right place, right time

MND Week is celebrated nationally in the first full week of May to raise awareness of the needs of people living with MND and their family. It is a time to acknowledge the MND community and people living with MND today and to remember those who have died. More information www.mndaust.asn.au/mndweek14

People living with MND face many challenges but accessing the right care, in the right place, at the right time should not be one of them. During MND Week we will be using the five rights petition as a powerful advocacy tool to defend the rights of all Australians living with MND. More information www.mndaust.asn.au/five-rights

We will be asking people to join the collective voice of the MND community by signing the petition and writing to parliamentarians to tell them that all Australians living with MND must have access to the right care, in the right place, at the right time.

The five rights of people living with MND

1. People with MND have the right to an early diagnosis and information
2. People with MND have the right to access quality care and treatments
3. People with MND have the right to be treated as individuals and with dignity and respect
4. People with MND have the right to maximise their quality of life
5. Carers of people with MND have the right to be valued, respected, listened to and well-supported.

Case studies

MND Australia and the state MND associations have a database of individuals from around Australia who would like to share their story about living with MND. Please contact us to discuss your requirements and organise an interview.

More Information

MND Australia

Phone: +61 2 9816 5322

www.mndaust.asn.au

Email: info@mndaust.asn.au

Facebook: /mndaustralia

Twitter: /mndaustralia

YouTube: /mndaust

State MND associations

To contact the MND Association in your state freecall: 1800 777 175 or visit www.mndaust.asn.au/state-mnd-associations