

**MND Australia**

**Background Information on**

**Motor Neurone Disease**

**April 2020**

To contact the MND Association in your state or territory  
National Freecall: 1800 777 175



# 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.
- MND is also known as Amyotrophic Lateral Sclerosis (ALS) and Lou Gehrig's disease in other parts of the world.
- 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. In most cases the senses are not affected. MND is not contagious
- 50% of people with MND may experience some change in cognition, language, behaviour and personality. Most people experience relatively mild changes. However, a small proportion (5–15%) will show more significant changes and will receive a diagnosis of 'motor neurone disease with frontotemporal dementia' or MND/FTD.
- MND affects each person differently in respect of initial symptoms, rate and pattern of progression, and survival time. There are no remissions.
- Average survival time after diagnosis is 2.5 years\* (Deloitte Access Economics report [Economic analysis of MND in Australia](#), 2015), but a minority of people will survive 5 years or more.
- Progression of MND is rapid, creating high levels of disability and consequent needs for support. People with MND need assistance with feeding, communication, movement, transferring, toileting, and breathing. MND has an impact on all activities of living.
- 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.
- The causes of the majority of cases of MND remain unknown. However about 5 to 10% of cases are inherited (familial) and the genetic fault of about 60% of these cases is now known in Australian families.
- The lifetime risk of developing MND is about 1 in 300 by the age of 85, with the risk increasing steadily with age (Martin S, Al Khleifat A and Al-Chalabi A. [What causes amyotrophic lateral sclerosis?](#) [version 1; peer review: 3 approved]. F1000Research 2017, 6(F1000 Faculty Rev):371).
- Researchers from around the world are studying genetics; toxins; chemicals by which nerve cells are controlled and communicate; the use of stem cells; and the growth, repair and ageing of motor neurons. The provision of better care and the development of more effective treatments are also being investigated.
- The blue cornflower (*Centaurea cyanus*) was adopted by MND Australia as the national symbol of hope for MND, because of its fragile appearance but hardy nature. Like the cornflower, people living with MND show remarkable strength in coping with a devastating disease. It was first adopted by the ALS Society of Canada and is used by a number of countries worldwide including South Africa and New Zealand.

## MND around the world

- MND occurs in all countries of the world. It does not discriminate on the basis of race, ethnicity or demographic.
- Over 420,000 people are living with MND worldwide. Approximately 140,000 cases are diagnosed worldwide each year. That is 384 new cases every day. (*International Alliance of ALS/MND Associations*)
- MND is not a disease of ageing and can affect adults at any age, although the peak age of onset is during the fifties and sixties. Men are affected slightly more often than women.
- Riluzole is the only treatment that has been demonstrated in trials to extend life expectancy in people living with MND and registered in Australia. Riluzole, and its liquid form Teglutik, are included in the PBS.
- Researchers globally are currently developing and trialling many potential therapies. The intravenous therapy, Edaravone, has been approved in the USA and has been available in some countries in Asia for a number of years. It has been shown to slow down disease progression in a sub-set of people with MND. Studies are ongoing and results of these studies will inform whether approval will be sought in Europe and Australia.
- Global Day is marked annually on 21 June as the international day of recognition for ALS/MND.

## In Australia

- More than 2,000 people are living with MND (Deloitte Access Economics report [Economic analysis of MND in Australia](#), 2015)
- In 2018, 755 people with MND died ([Australian Institute of Health and Welfare](#))
- The prevalence of MND was 8.7 per 100,000 people in 2015 or one per 11,434 Australians (Deloitte Access Economics report [Economic analysis of MND in Australia](#), 2015)
- Mean time from onset to confirmation of diagnosis is 10 to 18 months (Deloitte Access Economics report [Economic analysis of MND in Australia](#), 2015)
- The total cost of MND in Australia was \$2.37 billion in 2015. This equates to \$1.1 million per person (Deloitte Access Economics report [Economic analysis of MND in Australia](#), 2015)
- The six State MND Associations provide support in all states and territories
- 60% of the people supported by State MND Associations are aged 65 or older
- MND Australia and its research arm, MND Research Australia, form one national body that represents both care and research

**MND Research Australia awarded over \$3 million** for new MND research projects to commence in 2020. This vital source of funding is only possible thanks to the generous support of State MND Associations, donors and bequestors.

## During 2018/19 State MND Association support services provided:

- information, referral and support to over 2,000 people living with MND
- support and information for 726 people recently diagnosed with MND
- support for the families of the 635 people registered with an MND association who died
- over 5,429 items of equipment to people living with MND
- 4,520 home visits and over 36,000 electronic contacts with people living with MND
- education to over 3,000 health, disability and aged care providers

## Summary of needs for people 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 including:
  - specialist physicians and allied health
  - assistive technology to maintain independence, communication, feeding and breathing
  - flexible and timely respite for carers
  - personal home care and support
  - support from volunteers when appropriate
- Coordinated multidisciplinary care from a team of professionals
- MND specific information and education and ongoing support for carers of people living with MND
- MND specific information, education, support and resources for health, disability and aged care providers
- **Urgent response and regular review – waiting lists are not appropriate**

## Summary of facts

FACT	MND is a rapidly progressive, terminal neurological disease
FACT	There is no known cure and no effective treatments for MND - yet
FACT	Each day in Australia two people die from MND
FACT	Each day in Australia two people are diagnosed with MND
FACT	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
FACT	Average life expectancy is 2.5 years
FACT	More than 2,000 people have MND in Australia and thousands more families and carers live daily with the effects of MND

## Why MND Week?

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. In 2020 MND Week will run from the 3<sup>rd</sup> to 9<sup>th</sup> of May.

This year due to the [COVID-19 pandemic](#) a number of virtual and online campaigns and events will be launched in MND Week. The community can get involved to raise funds to support vital care and research by signing up for the [Australia Moves for MND \(AM4MND\)](#) campaign and by taking action to make [Make Aged Care Fair](#) for older people diagnosed with MND.

## Why Global Day?

Every year the [International Alliance of ALS/MND Associations](#) celebrates 21 June as the global day of recognition of ALS/MND – a disease that affects people in every country of the globe. June 21 is a solstice – a turning point – and each year the ALS/MND community undertake a range of activities to express their hope that this day will be another turning point in the search for treatments and cures.

## Some famous people who are living with or have died from MND

- Percy Cerutti – Australian athletics coach
- Lord Leonard Cheshire – VC
- Ronnie Corbett – comedian
- Neale Daniher – AFL player, coach and mentor
- Peter Doohan, Australian Tennis
- Sean Dorney, ABC Radio Announcer
- Brad Drewitt, Australian Tennis
- Ron Edgeworth – musician
- Jenifer Estess – theatre producer, founding member of Project ALS
- Scott Gale – Balmain rugby league player
- Pro Hart – painter

- Stephen Hawking – mathematician, physicist and author
  
- Stephen Hillenburg – creator of the animated series *Spongebob Squarepants*
- James Kemsley – cartoonist
- Charles Mingus – jazz composer and bassist,
- Richard Morgan – actor
- David Niven – actor
- Morrie Schwartz – American Professor of Sociology, media personality and author, who was the subject of the international best-selling book, “Tuesdays with Morrie”
- Mao Tse Tung – revolutionary leader of China
- Joost van der Westhuizen – South African rugby union player
- Doddie Weir - Scottish rugby union player
- Gary West – Cycling Australia's head track sprint coach

## More about MND Australia and the State MND Associations

MND Australia is the national voice representing all Australians who share the vision of a world without MND. Together, with the State MND Associations and MND Research Australia, we form the only national network focused on improving the lives of all Australians living with motor neurone disease (MND) as well as funding research to move us closer to our collective vision of a world without MND.

The key to quality and length of life for people living with MND lies in access to the best possible, evidence-based care including coordinated multidisciplinary clinics and/or care, riluzole, non-invasive ventilation, nutritional support and support and services from the State MND Associations.

For over 35 years the state MND Associations have provided direct support, education, assistive technology and advocacy to ensure people living with MND have the best quality-of-life possible. Over the last few months MND Associations have adjusted to the impacts of the COVID-19 pandemic to ensure the continued provision of high quality support services and information to people living with MND and their families and carers. MND doesn't stop and neither will we.

The support services provided by the [State MND Associations](#) are dependent on the generous support of Australian donors and may include all or some of the following:

- information
- active assistance to members through home visits and ongoing support
- assistance in accessing MND clinics and local services
- assistance in development of National Disability Insurance Scheme (NDIS) plans and planning
- support coordination
- equipment provision or assistance in accessing equipment from government agencies
- peer support, support groups and information programs
- carer workshops
- information and education for health and community care professionals
- local advocacy and influencing
- volunteers

Research is the only way that we can change the future of MND. **Every dollar** received for research is directed to the research arm of MND Australia, [MND Research Australia](#), and invested in research with the greatest chance of leading to the development of effective treatments and improving the lives of people with MND. We believe that it is only a matter of time, funding and hard work before we unravel MND's mystery.

MND Australia is an active member of [The International Alliance of ALS/MND Associations](#), which represents ALS/MND Associations around the world.

## MND Voices

Please contact MND Australia and the State MND Associations to interview individuals from around Australia who would like to share their story about living with MND.

**More Information:** MND Australia: [www.mndaustralia.org.au](http://www.mndaustralia.org.au)

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