

MND Australia

**BACKGROUND INFORMATION
ON
MOTOR NEURONE DISEASE**

March 2009



MOTOR NEURONE DISEASE

- Motor Neurone Disease (MND) is the name given to a group of diseases in which damage to motor neurones occurs. 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 trunk and limbs, 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
- In most cases the senses, intellect and memory are not affected
- 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 to 3 years or less, some people survive 5 years or more
- Progression of MND is rapid, creating high levels of disability and consequent needs for support. Support needed includes assistance with feeding, communication, movement, transferring, toileting, breathing, daily activities etc. 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 sporadic MND are still unknown. About 5-10 % of cases are familial and the genetic mechanism of about 2% of these cases is understood. MND is not contagious
- Research taking place around the world includes the study of genetic factors, toxic factors, the chemicals by which nerve cells are controlled and communicate, the potential for stem cell therapy, and the growth, repair and ageing of motor neurones
- 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

The World

- Incidence is around 2 per 100,000 of population per year, and prevalence 6 per 100,000 (International Alliance of ALS/MND Associations, 2008)
- MND occurs in all countries of the world, usually in people over the age of forty, but there have been many cases of younger people being affected. Peak ages of onset are the fifties and sixties, and men are affected slightly more often than women
- Riluzole, developed by sanofi aventis, is the only treatment that has demonstrated in trials to extend life expectancy in people living with MND. It is registered in Australia and is included in the Pharmaceutical Benefits Scheme.

In Australia

- Approximately 1,300 people each day are suffering from the devastating effects of MND
- In 2006, 532 people died from MND (Australian Institute of Health and Welfare, 2006)
- The MND Australia network comprises of six MND Associations, representing all states and territories, and the MND Research Institute of Australia (MNDRIA)
- During 2007/08 the MND member network provided:
 - care and support to over 1000 people with MND as well as their family and friends
 - support and information to 493 people newly diagnosed with MND
 - support for the families of the 431 people with MND registered who died
 - over 2,000 items of equipment to people living with MND at no cost
 - education on MND to over 5,000 people including those living with MND, carers and health professionals and community care providers
 - \$370,000 to MND specific research through MNDRIA

Outcomes of MND

- increasing paralysis and dependence on others
- loss of independence, employment, relationships, communication, social life and future plans,
- one carer commented “I feel more paralysed by MND than my husband”
- families, carers and friends live with the impact of MND forever

Needs Arise From

- rapidly changing physical ability of person with MND and decreasing capacity of carer
- increasing levels of support required for the carer and the person living with MND
- emotional demands of caring and being cared for

Summary of Needs

- 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
- accurate information
- early intervention which often reduces overall service needs
- timely access to specialists including neurologists, gastroenterologists, palliative care, respiratory physicians and allied health
- equipment to maintain independence and quality of life, including equipment related to communication, feeding and breathing
- support in accessing services and activities to maintain independence
- flexible and timely respite for carers
- personal home care and support
- coordinated support from a team of professionals – multidisciplinary care teams
- support from volunteers when appropriate
- urgent response and regular review - waiting lists are not appropriate

Care

- Most people with MND remain at home throughout the course of their illness, and in most cases, the person with MND will have been capable of making his/her own decisions
- An extensive network exists within the community of people who will assist in accessing appropriate support services, preserving independence and maintaining quality of life. Such services are important not only for the person with MND, but also for their carers
- MND Associations play a pivotal role in ensuring that people living with MND are linked into support services in their own neighbourhood
- People living with MND are not traditional service users, and have rarely had involvement with the disability or community services sector
- Research by Sach (1995, 1997, 2003) indicates that people living with MND **will not access services** unless they are confident in the knowledge of the provider about MND and its impact
- People living with MND need counselling, needs assessment, referral to appropriate services, multidisciplinary care, equipment, monitoring, reassessment, and ongoing support
- Carers of people living with MND need counselling, flexible respite options, carer specific information and education and ongoing support
- Service providers need training, education, information, support, adequate resources and backup

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

- Mathematician, physicist and author Professor Stephen Hawking
- Actor David Niven
- Painter Pro Hart
- Balmain rugby league player Scott Gale
- Cartoonist James Kemsley
- Actor Richard Morgan
- Lord Leonard Cheshire, VC
- Jazz composer and bassist, Charles Mingus
- Australian athletics coach Percy Cerutti
- Mao Tse Tung Revolutionary leader of China
- Morrie Schwartz American Professor of Sociology, media personality and author, who was the subject of the International best-selling book, "Tuesdays with Morrie."

Why MND Week:

MND Week is celebrated nationally in the first full week of May each year. MND Associations work together during this week to raise awareness of MND to realise our vision of a **world free from the impact of MND**. It is also a time to acknowledge the MND community and people living with MND today and to remember those who have died.

Why Global Day:

Every year since 1997, the International Alliance of ALS/MND Associations has celebrated 21 June as the global day of recognition of ALS/MND – a disease that affects people in every country of the globe. 21 June is a solstice – a turning point - and each year the ALS/MND community undertake activities to express their hope that this day will be another turning point in the search for cause, treatment and cure of this cruel disease.

Summary of Facts:

FACT	<i>MND is a rapidly progressive, terminal neurological disease</i>
FACT	<i>There is no known cure and no effective treatment for MND</i>
FACT	<i>Each day in Australia more than one person dies from MND and another is diagnosed</i>
FACT	<i>People with MND progressively lose the use of their limbs, their ability to speak, swallow and to breathe, whilst their mind and senses usually remain intact</i>
FACT	<i>Average life expectancy is 27 months</i>
FACT	<i>An estimated 1300 people have MND in Australia and thousands more, families and carers, live daily with the effects of MND</i>

National Freecall: 1800 777 175

Contact Details for MND Associations in Australia

[MOTOR NEURONE DISEASE AUSTRALIA INC.](#)

Building 4, Old Gladesville Hospital, Gladesville NSW 2111
(PO Box 785, Gladesville NSW 1675)
Telephone: (02) 9816 5322 Fax: (02) 9816 2077
Internet: www.mndaust.asn.au Email: info@mndaust.asn.au

[MOTOR NEURONE DISEASE NEW SOUTH WALES INC](#)

Building 4, Old Gladesville Hospital, Gladesville NSW 2111
(Locked Bag 5005, Gladesville NSW 1675)
Telephone: (02) 8877 0999 Fax: (02) 9816 2077
Internet: www.mndnsw.asn.au Email: admin@mndnsw.asn.au

[MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND INC](#)

P O Box 259, Corinda Qld 4075
Telephone: (07) 3372 9004 Fax: (07) 3278 9871
Internet: www.mndaq.asn.au Email: mndaq@tpg.com.au

[MOTOR NEURONE DISEASE SOUTH AUSTRALIA INC](#)

302 South Road Hilton SA 5033.
(PO Box 2087, Hilton Plaza SA 5033)
Telephone: (08) 8234 8448 Fax: (08) 8152 0447
Internet: www.mndasa.com.au Email: admin@mndasa.com.au

[MOTOR NEURONE DISEASE TASMANIA INC](#)

PO Box 379, Sandy Bay TAS 7006
Internet: www.mndatas.asn.au Email: info@mndatas.asn.au

[MOTOR NEURONE DISEASE ASSOCIATION OF VICTORIA INC](#)

265 Canterbury Rd, (PO Box 23) Canterbury Vic 3126
Telephone: (03) 9830 2122 Fax: (03) 9830 2228
Internet: www.mnd.asn.au Email: info@mnd.asn.au

[MOTOR NEURONE DISEASE ASSOCIATION OF WESTERN AUSTRALIA INC](#)

Centre for Neurological Support -The Niche, B/11 Aberdare Rd, Nedlands WA 6009
Telephone: (08) 9346 7355 Fax: (08) 9346 7332
Internet: www.mndawa.asn.au Email: admin@mndawa.asn.au

[MOTOR NEURONE DISEASE RESEARCH INSTITUTE OF AUSTRALIA INC](#)

PO Box 990, Gladesville NSW 1675
Telephone: (02) 8877 0990 Fax: (02) 9816 2077
Internet: www.mndresearch.asn.au Email: info@mndresearch.asn.au

Associate Member:

[MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC](#)

Motor Neurone Disease Assoc. of NZ (Inc.)
PO Box 24036, Royal Oak, Auck 1345
14 Erson Ave, Royal Oak, Auckland
Telephone: (09) 624 2148 Fax: (09) 624 2149
Internet: www.mnda.org.nz Email: info@mndanz.org.nz