

MND Australia

**BACKGROUND INFORMATION
ON
MOTOR NEURONE DISEASE**

2011



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 25% 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 1,400 people each day are suffering from the devastating effects of MND
- In 2007, 594 people died from MND (Australian Institute of Health and Welfare, 2009)
 - Deaths from MND in Australia have increased. In 2000, 457 people died from MND
- The MND Australia network comprises of six MND Associations, representing 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 2009/10 MND associations provided:
 - care and support to over 1000 people with MND as well as their family and friends
 - support and information to 533 people newly diagnosed with MND
 - support for the families of the 454 people with MND registered who died
 - over 2,600 items of equipment to people living with MND at no cost
 - information on MND to over 15,000 people including those living with MND, carers and health professionals and community care providers
 - \$1.4 million for 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 will 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
- multidisciplinary care - coordinated support from a team of professionals
- support from volunteers when appropriate
- urgent response and regular review - waiting lists are not appropriate

Care

- people with MND and their carer need access to care and support as soon as a need arises
- most people with MND remain at home throughout the course of their illness, and in most cases, the person with MND will be 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, assessment, referral to appropriate services, multidisciplinary care, equipment, monitoring, reassessment, information 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

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.

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 undertakes 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.

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
- Musician Ron Edgeworth
- Cartoonist James Kemsley
- Actor Richard Morgan
- Lord Leonard Cheshire, VC
- Jazz composer and bassist, Charles Mingus
- Australian athletics coach Percy Cerutty
- 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."

Summary of Facts:

- FACT** *MND is a rapidly progressive, terminal neurological disease*
- FACT** *There is no known cure and no effective treatment for MND*
- FACT** *Each week in Australia more than 10 people die from MND*
- FACT** *Each week in Australia at least 10 people are diagnosed with MND*
- FACT** *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*
- FACT** *Average life expectancy is 27 months*
- FACT** *An estimated 1400 people have MND in Australia and thousands more, families and carers, live daily with the effects of MND*

National freecall: 1800 777 175