MND Australia

Background Information on Motor Neurone Disease

2013

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.

- Intellect and memory are not usually affected but recent research indicates cognitive change occurs in some cases.

- 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, but a minority of people 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.

- MND is not contagious.

- 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.

- 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 is 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
- Incidence is around 2.69 per 100,000 of population per year, and overall prevalence is around 6 - 7 per 100,000 (Based on death rates 2010 - Australian Institute of Health and Welfare)
- 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. It is registered in Australia and is included in the PBS.
- Global Day is marked annually on 21 June as the international day of recognition for ALS/MND

In Australia

- Approximately 1,500 people are experiencing the devastating effects of MND
- In 2010, 648 people died from MND compared with 450 deaths in 2000 - (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 2011/12 MND associations provided:
    - 1,119 people living with MND with care, information and support
    - 567 people newly diagnosed with MND support and information
    - support for the families of the 469 people with MND registered who died
    - over 2,713 items of equipment to people living with MND at no cost
    - information on MND to over 11,000 people including those living with MND, carers and health professionals and community care providers
    - $1.4 million for MND specific research through MNDRIA

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
    - equipment 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

- Urgent response and regular review - waiting lists are not appropriate

- MND specific information and education and ongoing support for carers of people living with MND

- MND specific information and education, support, adequate resources and backup for health professionals and service providers

- Funding for research to find the cause and a cure for MND and better care for people living with 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. MND Week 2013 runs from Sunday 5 to Saturday 11 May.

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 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 27 months***
FACT	***An estimated 1,500 people have MND in Australia and thousands more families and carers live daily with the effects of MND***

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More about MND Australia and the State MND Associations

MND Australia is the national peak body for MND care and research in Australia. The six state Associations, representing all states and territories, are members of MND Australia. The MND Research Institute of Australia (MNDRIA) is the research arm of MND Australia. The MND Association of New Zealand is an associate member.

MND Australia acts as the national voice for people living with MND to promote MND care and research through our advocacy, information and awareness activities. Our aim is to improve outcomes for people living with MND today and in the future as we work towards our ultimate goal of a world free from MND.

Community support has helped to push research funds allocated through our research arm to well over the one million dollar mark for the third consecutive year – a fantastic result for MND research in Australia. We are all working together to achieve our goal of having at least one million dollars available for MND research every year. This year a grand total of $2,613,700 has been allocated for all new grants for MND projects commencing in 2013.

The State MND Associations support around 80% of all people diagnosed with MND in Australia. The state association family support staff and regional advisors aim to provide some or all of the following services:

- information
- active assistance to members
- home visits and ongoing support
- assistance in accessing MND clinics and local services
- 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