



Motor Neurone Disease Week 3 – 9 May 2009

Living Better for Longer

- 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 more than one person dies from MND and another is diagnosed*
FACT *People with MND progressively lose the use of their limbs and 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 1300 people have MND in Australia and thousands more, families and carers, live daily with the effects of MND*

Motor Neurone Disease (MND) is a devastating neurological illness affecting around 1300 people across Australia. It is estimated that there are many more thousands of families, carers and friends who are involved in the day-to-day care of people with this rapidly progressive disease impacting on their lives emotionally, physically and socially.

Sadly, there is no known cure or effective treatment for MND which takes the life of at least one Australian each day. MND Australia and its state-wide associations provide the vital access and links to support, information, coordinated care, respite and equipment once the initial diagnosis is confirmed to assist people to live better for longer.

MND Week, an initiative of MND Australia, will be held from 3 – 9 May 2009 and all Australians and governments are encouraged to donate and commit funds to ensure health professionals, service providers and MND Associations can provide the best possible care and to support vital research to find the causes, effective treatments and hopefully a cure for this cruel disease.

“Motor Neurone Disease progressively attacks the nerves that control the muscles of movement, speech, swallowing and breathing, but the mind is usually left untouched”, says Ralph Warren, President of MND Australia.

Tragically MND usually results in death within 2 – 3 years, though some may live for many years, like Professor Stephen Hawking. While MND can strike at any age, it is most common in people in their 50s and 60s.

“The reality at the moment is that while many people living with MND will have continued access to state of the art care management as well as equipment to assist with activities of daily living, communication, feeding and breathing, unfortunately others cannot access even basic services and interventions to meet their needs” Mr Warren continues. “For example, specifically designed computer technology can enable a person living with MND to keep on communicating with their loved ones and broader community long after their physical condition renders them immobile.”

Tanya Mason, a 23 year-old from NSW who has MND knows the value of these services. “I still manage to live independently with the fantastic support of the MND Association and my health service providers”. My computer allows me to network with all my friends. As I have started to become physically weaker, MND NSW has provided me with all the equipment I need to make my everyday life easier.”

The types of care and support people living with MND and their families need to help them live as well as possible include: **C**o-ordinated support and care; **A**ccess to timely information; **R**espite and research; and **E**arly diagnosis and equipment.

By showing you **CARE** throughout MND Week, you will be ensuring that people with MND **live better for longer** until a possible treatment or even cure is discovered.

Various fundraising or awareness raising events are being held throughout Australia during the week which culminates in Blue Cornflower Day, Friday 8 May. For a list of events visit www.mndaust.asn.au

During MND Week and on Blue Cornflower Day you can make a donation, volunteer or buy a blue cornflower – a symbol of hope – through MND Associations or on-line at: www.mndaust.asn.au/mnd-week/ or phone 1800 777 175.

MND Australia supports the MND Research Institute of Australia (MNDRIA) which allocates research grants to scientists and clinicians throughout Australia to conduct vital research into MND. MNDRIA relies totally on donations for its research programs. See www.mndresearch.asn.au for more information.

For further information or to interview Ralph Warren or Tanya Mason, please contact Helen McDonald or Julie Morgan on (03) 9696 5060 or email: hmcDonald@jmm.com.au