



motor neurone disease

## **MEDIA RELEASE**

**Friday 2 May, 2008.**

**For Immediate Release**

### **MND WEEK 4 to 10 May 2008**

## **LIVING BETTER FOR LONGER**

1300 people are living with this cruel disease that takes the life of at least one Australian every day. Some of these people will receive world class treatment and care but many will not.

MND Associations will this week be raising awareness of the care needs of people living with MND through the launch of a film clip featuring the renowned physicist Professor Stephen Hawking.

Motor neurone disease, or MND, attacks the nerve cells and gradually causes muscles to waste away - usually resulting in death within two to three years. Some people may only live for a few months whilst others, like Professor Hawking, can live for many years.

"MND is a cruel disease because it progressively attacks the nerves that control the muscles of movement, speech, swallowing and breathing leaving the mind intact" Ralph Warren, President of MND Australia said "People with MND need access to early diagnosis, information, coordinated care, ongoing support, respite, and equipment" he continued.

This week people living with MND, their friends and families will be calling on all governments to commit funds and resources to enable health professionals, service providers and MND Associations to provide the best possible care and support

"This would bring us closer to our vision of *A World Free from the Impact of MND*", Mr Warren said "It would ensure that the needs of people with MND are met now and in the future to enable them to **live better for longer** until an effective treatment or a cure is discovered".

During MND Week and especially on Blue Cornflower Day (Friday 9 May) blue cornflowers – a symbol of hope – can be purchased from MND Associations. The proceeds will help MND Associations to continue their essential work.

**MORE 1/-2**

## **News Eds/Chiefs-of-Staff:**

Further information on MND and MND Week activities, the Stephen Hawking film clip and the campaign poster are available for download at the MND Australia website [www.mndaust.asn.au](http://www.mndaust.asn.au)

## **FOR FURTHER INFORMATION OR TO ARRANGE AN INTERVIEW:**

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## **NEWS ENDS 2/-2**

### **Background:**

The MND Australia Living Better for Longer campaign will highlight to governments and the community the types of care and support people living with MND and their families' need - at, during and after diagnosis to help them live as well as possible. Examples include:

- Coordinated support and care
- Access to timely information
- Respite and funding for Research
- Early diagnosis and Equipment

The International Alliance of MND/ALS Associations Statement of Good Practice for the Management of MND lends international support to the campaign and is available for download on the MND Australia web site [www.mndaust.asn.au](http://www.mndaust.asn.au)

### **Supporting research and references:**

Andersen P, Borasio G.D, et al. *The EFNS taskforce on management of Amyotrophic Lateral Sclerosis: guidelines for diagnosing and clinical care of patients and relatives*, European Journal of Neurology 2005, **12**: 921-983

Leigh P N, Abrahams S, Al-Chalabi S, et al. and the King's MND Care Research Team, *THE MANAGEMENT OF MOTOR NEURONE DISEASE*, Journal of Neurology Neurosurgery and Psychiatry 2003;**74**:iv32 – iv 47

Miller R.G. Rosenberg D.F. et al. *Practice Parameter: The care of the patient with amyotrophic lateral sclerosis (an evidence-based review): Report of the Quality Standards Subcommittee of the American Academy of Neurology*, Neurology 1999;**52**:1311

Eng D, *Management guidelines for motor neurone disease patients on non-invasive ventilation at home*, Palliative Medicine, March 1, 2006; **20**(2): 69 - 79

## **Key facts:**

### **MND**

1. MND is a rapidly progressive neurological disease
2. There is no known cure and no effective treatment for MND
3. Care and research must go hand in hand until an effective treatment or cure is found
4. The causes of sporadic MND are still unknown. About 5-10 % of cases are familial and the genetic mechanisms of about 2% of these cases is understood
5. MND is not contagious
6. Each day in Australia more than one person dies from MND and another is diagnosed
7. MND attacks the nerves that control the muscles of the trunk, limbs, speech, swallowing and breathing
8. People with MND become progressively paralysed but, in most cases, their mind and senses remain intact
9. Average life expectancy is 27 months
10. MND can strike anyone but is most common in people aged in their 50's and 60's
11. Motor neurone disease (MND) is also known as Amyotrophic Lateral Sclerosis (ALS) and Lou Gehrig's disease in the USA
12. An estimated 1300 people have MND in Australia and thousands more, families and carers, live daily with the effects of MND

### **MND Associations**

1. The MND Australia network comprises of six state Associations, representing all states and territories, and the MND Research Institute of Australia (MNDRIA)
2. MND Australia members work together to advance, promote and influence local and national efforts to achieve the vision of a ***World Free From the Impact of MND***
3. People diagnosed with MND face a spiraling series of losses and need timely access to high quality information and support
4. MND Associations provide critical support to people with MND and their carers from diagnosis to bereavement
5. MND Associations aim to be at the forefront of providing information, support, equipment, group programs and education for people living with MND, families, carers and health and community care providers
6. MND Associations support research to find the causes, treatments and cure for MND and research to provide evidence for the best way to care for people living with MND
7. MNDRIA allocates research grants to scientists and clinicians throughout Australia to enable them to conduct vital research into MND in Australia
8. Without MND Associations people with MND and their families would be left largely to face the consequences of MND alone

### **Financial Support**

1. MND Associations are dependent on private and business donations, fundraising, philanthropic and government grants to provide their valuable services
2. People living with MND, their families and carers and the health and community care providers involved in their care are given information, support and often equipment totally free of charge
3. MND Associations are charities and rely on the community getting involved in fundraising activities
4. MNDRIA is fully dependent on donations to provide research grants  
[www.mndresearch.asn.au](http://www.mndresearch.asn.au)