



MEDIA RELEASE

Motor Neurone Disease Week - 6 to 12 May 2007

MND WEEK CALL TO ACTION

PEOPLE LIVING WITH MND URGE GOVERNMENTS TO COMMIT EXTRA FUNDS

FOR IMMEDIATE RELEASE
Sydney – 6 May 2007

To mark the commencement of MND Week people living with the disease and their carers will today write to their State and Federal MPs urging them to commit extra funds for disability services to help them to maintain their independence and quality of life.

The unanimous and bipartisan Senate Committee Report on the **Commonwealth State and Territory Disability Agreement (CSTDA)** recommended that all governments jointly commit to **substantial additional** funding to address **identified unmet need** for disability services. These recommendations have so far been ignored.

In Australia approximately 1,400 people are living with MND. *“MND can strike anyone at any time,”* says MND Australia President, Helen Sjardin-Howard. *“It insidiously robs people of their independence, their ability to communicate and to influence their surroundings; in fact of most of the life choices we take for granted”.*

People living with MND and the MND Associations will be raising awareness of the disease this week and calling on all governments to provide additional funding for disability services. *“This would bring us closer to the MND Australia vision of A World Free From the Impact of MND”*, Helen Sjardin-Howard continued *“It would ensure that the needs of people with MND are met now and in the future to enable them to live as well and for as long as possible until an effective treatment or a cure is discovered”.*

Every day in Australia people living with MND continue to face a high level of unmet need related to:

- Assessment
- Respite
- Equipment
- Case management
- Community care

They experience a disparity of services at aged 65 when they are forced to transfer from disability to aged care services. The State/Territory they live in determines the level of support they can access and they battle daily with a confusing and complex service system.

The Federal Government has yet to make a specific funding offer and continues to insist that State/Territory Governments meet conditions that will not necessarily lead to better services. Delays and the continued ‘blame game’ will impact on people living with MND and their carers - unmet needs will increase.

During MND Week and especially on **Blue Cornflower Day** (Friday 11 May) blue cornflowers – a symbol of hope – can be purchased from the MND Association in each State or Territory and a variety of outlets across Australia. The proceeds will help MND Associations to continue their essential work.

news ends



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About Motor Neurone Disease (MND)

Every day in Australia at least one person dies from MND and another person will be diagnosed with this devastating disease. Yet most Australians know little about MND.

Motor Neurone Disease (known as ALS in many other parts of the world, and as Lou Gehrig's disease in the USA), is the name given to a group of diseases in which the motor neurones die. These nerve cells control the movement of voluntary muscles, including the muscles of the trunk, limbs, speech, swallowing and breathing.

With no nerves to activate them, muscles gradually weaken and waste, and paralysis occurs. Weakness is often seen first in the hands or feet, or the first sign may be difficulty with swallowing or slurred speech. In the majority of cases the senses, intellect and memory are not affected. MND has often been described as "deadly, creeping paralysis." 90% of people with MND die within five years of diagnosis. While some live longer, others die within a few months.

MND Australia is the national peak body for MND in Australia representing all State and Territory MND Associations who support people with MND, their families and carers. MND Associations in each State and Territory provide information, equipment and support to people living with MND and their families.

People living with MND and their carers are available for interviews to tell their story of the impact of Motor Neurone Disease on their lives.

Facts:

- FACT** *There is no known cause, 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** *MND is a terminal neurological disease*
- FACT** *People with MND progressively lose the use of their limbs, their ability to speak, swallow and to breathe, whilst their mind and senses 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*

Notes for Media:

Position Statement related to the Call to Action and further information on MND and MND Associations in Australia is available at:

www.mndaust.asn.au

Further information on the Senate Committee Report on the **Commonwealth State and Territory Disability Agreement** (CSTDA) http://www.aph.gov.au/senate/committee/clac_ctte/cstda/report/index.htm



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FOR FURTHER INFORMATION OR TO ARRANGE AN INTERVIEW CONTACT:

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