

Enclosed is my donation of:

___\$30___\$50___\$100___\$200___\$500

or \$_____

Please debit my Mastercard/Visa

Card No. _____

Signature. _____

Expires /

Donations over \$2.00 are Tax Deductible.

Dr/Mr/Mrs/Ms/Miss _____

Address: _____

_____ Postcode: _____

Phone: _____

Email: _____

Please send me more information on:

- Motor neurone disease
- Becoming a member
- Becoming a volunteer
- How my Will can make a difference

***Please return to the MND Association
in your State or Territory***

Privacy statement

Details you supply to us are entered into the MND Association database. MND Associations adhere to the terms and conditions of the Privacy Act 1988 and State Privacy Acts as applicable.

How can MND Associations assist?

MND Associations assist people living with MND to get information, support, aids and equipment and referral to other services when needs change.

Where can I find more information?

Contact the MND Association in your State or Territory for more information on living with MND.

A booklet titled *MND More Facts* provides information about hereditary factors, different forms of MND, as well as answers to a range of frequently asked questions. It is available from the MND Association in your State or Territory.

Financial assistance and advice

There are a number of pensions, allowances and benefits available from the Australian Government for people who are aged or disabled. Financial help is also available for carers. For further information contact the MND Association in your State or Territory.

Reviewed and reprinted
July 2015



Motor Neurone Disease Associations

MND New South Wales

Gladesville Hospital
Victoria Road
Gladesville NSW 2111
(Locked Bag 5005
Gladesville NSW 1675)
Ph: 02 8877 0999
Freecall: 1800 777 175
Fax: 02 9816 2077
www.mndnsw.asn.au
admin@mndnsw.asn.au

MND Queensland

PO Box 1039
Inala East Qld 4077
Ph: 07 3372 9004
Freecall: 1800 777 175
Fax: 07 3278 9871
www.mndaq.org.au
info@mndaq.org.au

MND South Australia

302 South Road
Hilton SA 5033
(PO Box 2087
Hilton Plaza SA 5033)
Ph: 08 8234 8448
Freecall: 1800 777 175
Fax: 08 8152 0447
www.mndasa.com.au
admin@mndasa.com.au

MND Tasmania

PO Box 379
Sandy Bay TAS 7006
Freecall: 1800 777 175 or
1800 806 632
www.mndatas.asn.au
info@mndatas.asn.au

MND Victoria

265 Canterbury Road
Canterbury Vic 3126
(PO Box 23
Canterbury Vic 3126)
Ph: 03 9830 2122
Freecall: 1800 806 632
Fax: 03 9830 2228
www.mnd.asn.au
info@mnd.asn.au

MND Western Australia

Centre for Neurological
Support
The Niche
Suite B/11 Aberdare Rd
Nedlands WA 6009
Ph: 08 9346 7355
Freecall: 1800 777 175
Fax: 08 9346 7332
www.mndawa.asn.au
admin@mndawa.asn.au

**ACT and Northern
Territory contact:**

Locked Bag 5005
Gladesville NSW 1675
Ph: 02 8877 0999
Freecall: 1800 777 175
Fax: 02 9816 2077
www.mndnsw.asn.au
admin@mndnsw.asn.au

MND AUSTRALIA

PO Box 990
Gladesville NSW 1675
Ph: 02 9816 5322
Fax: 02 9816 2077
www.mndaust.asn.au
info@mndaust.asn.au

**Motor
Neurone
Disease**
SOME FACTS

What is motor neurone disease?

Nerve cells (neurones) control the muscles that enable us to move, speak, breathe and swallow. Motor neurone disease (MND) is the name given to a group of diseases in which these neurones fail to work normally. Muscles then gradually weaken and waste.

The effects of MND – initial symptoms, rate and pattern of progression, and survival time after diagnosis – vary significantly. The average life expectancy after diagnosis is two to three years.

MND is known as amyotrophic lateral sclerosis (ALS) in many parts of the world, and also as Lou Gehrig's disease in the USA.

What are the symptoms?

Early symptoms are often mild. They may include stumbling due to weakness of the leg muscles, difficulty holding objects due to weakness of the hand muscles, and slurring of speech or swallowing difficulties due to weakness of the tongue and throat muscles.

How is MND diagnosed?

Diagnosis requires an expert neurological opinion. Many other conditions can mimic MND early in the disease. A series of detailed investigations is usually made before the diagnosis is reasonably certain, including some tests which can eliminate other conditions. Commonly, an electromyography (EMG), which is a diagnostic procedure that measures muscle electrical activity through the insertion of a needle into various muscles, assists with both diagnosis and prognosis.

What remains unaffected?

Sight, hearing, taste, smell and touch are usually not affected by MND.

Bladder and bowel

The bladder is not usually directly affected; however, some people experience changes to bladder control. Constipation can occur, especially when people become less mobile or change their diet.

Cognitive and behaviour change

About 50% of people with MND may experience some change in cognition, language, behaviour or personality. Most people experience relatively mild changes. However, 5–15% will show more significant changes and will receive a diagnosis of 'motor neurone disease with frontotemporal dementia' or MND/FTD.

Is there a cure for MND?

Although there is no cure for MND yet, research has shown some interventions can help people living with MND to live better for longer.

Sometimes, costly and unproven therapies for MND are recommended by well-meaning people or advertised on the internet. People with MND are encouraged to discuss any therapies they hear about with their neurologist, general practitioner or care team. This is because these therapies can be harmful or may already have been shown to have no effect on the progression of MND.

Living better for longer with MND

There is one medication approved for treatment of MND in Australia – riluzole (Rilutek™ or APO-Riluzole). Riluzole probably prolongs median survival by two to three months. Riluzole may keep people with MND in the milder stages of the disease for longer, if they start taking it early in the disease progression.

Other interventions such as getting multidisciplinary care, good nutrition and using non-invasive ventilation have all been shown to help people living with MND to live better for longer. Also, the way that people manage their earlier symptoms of MND can affect how later symptoms can be managed. Early discussion about symptom management helps people with MND to plan ahead.

What is multidisciplinary care?

Multidisciplinary care involves a range of health and community care professionals working together to care for an individual.

A multidisciplinary care team for a person with MND usually includes a doctor, allied health professionals (such as a dietitian, occupational therapist, physiotherapist, social worker and speech pathologist), nurses and local palliative and community care workers. Other team members who have particular expertise are involved as needed, such as a respiratory specialist. In many areas of Australia, the MND advisor from the MND Association liaises with the team, providing MND specific information and education.

You can join our work to support people living with MND in your State or Territory by:

Giving donations

MND Associations in your State or Territory rely upon the generosity of many members of the community to develop and maintain their work and to support research into MND.

Giving through your Will

Bequests are a way of providing for the future, ensuring that the MND Association in your State or Territory can continue their work. A bequest can be a cash sum, a percentage, or the residue of your estate.

Giving in memory of a relative or friend

Gifts can be made in memory of a person to support the work of the MND Association in your State and Territory or to support MND research.

Giving your time

Many people volunteer their time to MND Associations. For more information contact the MND Association in your State or Territory.