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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.

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### 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 more detailed information as well as answers to a range of frequently asked questions. It is available from the MND Association in your State or Territory.

### Government assistance and support

Government financial assistance and programs to assist people living with MND at home vary and depend on individual circumstances. Assistance may also be available for carers.

The **National Disability Insurance Scheme (NDIS)** is designed to provide reasonable and necessary supports for people aged under 65 years who have a permanent disability, including people living with MND.

**My Aged Care** is the entry point to services for people aged 65 years and older in Australia. Costs of these services depends on the individual's financial situation.

For further information contact the MND Association in your State or Territory.

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# Motor Neurone Disease

## SOME FACTS

mnd   
Australia

## 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?

The diagnosis of MND is often clinically difficult, and sometimes it is necessary to review a person for some time before the diagnosis can be confirmed.

A general practitioner may suspect a neurological problem and organise referral to a neurologist (a doctor who specialises in disorders of the nervous system). Several other neurological conditions resemble MND, especially in the early stages, and need careful exclusion. The diagnosis can be assisted through a range of tests, including some which eliminate other conditions.

## 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 and may slow progression. People started on riluzole soon after diagnosis show the greatest benefits.

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, orthotist, 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.

## Getting involved

There are many ways you can participate in fundraising efforts to support the work of MND associations and the global fight for a world without MND.

- > Join in a walk; run, swim or ride for the cause
- > Get involved with MND Week in May each year
- > Join in events for MND Global Day on 21st June