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**Please send me more information on:**

- Motor Neurone Disease
- Becoming a member
- Becoming a volunteer
- Remembering people with MND in my Will
- Establishing a Memorial Fund

***Please return to the MND Association  
in your state or territory***

## Where can I find further information?

A booklet with information about hereditary factors, different forms of MND, as well as answers to a range of frequently asked questions, is available from the Motor Neurone Disease Association in your state, or from your neurologist.

### ACKNOWLEDGMENTS

Motor Neurone Disease Assn. of Vic.  
What is Motor Neurone Disease?  
Living with Motor Neurone Disease.  
Maintenance of Independence.

Reviewed and reprinted  
October 2010



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**Motor  
Neurone  
Disease**

**SOME FACTS**

## What is Motor Neurone Disease?

Nerve cells (neurones) control the muscles that enable us to move around, speak, breathe and swallow. Motor neurone disease 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 motor neurone disease - initial symptoms, rate and pattern of progression, and survival time after diagnosis - vary significantly.

## 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?

Many other conditions can mimic motor neurone disease early in the disease. Diagnosis requires an expert neurological opinion and often a series of detailed investigations. Diagnosis may take some time to be established, although diagnosis may be confirmed rapidly by a neurologist.

The diagnosis can be assisted through a range of tests, including some which eliminate other conditions. Often an electromyograph (EMG) is used, in which a needle is inserted into various muscles to measure their electrical activity. This can assist with both diagnosis and prognosis.

## What remains unaffected?

Until recently it was thought that the memory and intellect remained unaffected by motor neurone disease. However, in the past few years, fronto-temporal cognitive change (a type of dementia) has been associated with motor neurone disease and it is now thought that one in five people with motor neurone disease may experience these changes. Researchers have also found that about one in three people with motor neurone disease may have very mild changes in cognitive skills and processes.

The bowels and bladder are not affected by the disease, although nutrition should be carefully monitored. Sight, hearing, taste, smell and touch are usually not affected by motor neurone disease.

## Is there a cure for MND?

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

Sometimes, costly therapies for motor neurone disease are recommended by well-meaning people or promoted on the television or internet.

People with motor neurone disease 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 motor neurone disease.

## Living better for longer with MND

There is one medication approved for treatment of motor neurone disease in Australia - riluzole (Rilutek). Riluzole prolongs median survival by two to three months. Riluzole also keeps people with motor neurone disease 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 motor neurone disease to live better for longer. Also, the way that people manage their earlier symptoms of motor neurone disease can affect how later symptoms can be managed. Early discussion about symptom management helps people with motor neurone disease to plan ahead.

## What is multidisciplinary care?

A multidisciplinary care team for people with motor neurone disease usually includes a doctor, allied health professionals (such as a dietitian, occupational therapist, physiotherapist, social worker and speech pathologist) 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 regional/care advisor from the MND Association liaises with the team, providing information and education.

The MND Association assists people living with motor neurone disease to get information, support and referral to other services when needs change.

You can join our work for people living with motor neurone disease by:

### ***Giving donations***

MND Associations 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 Associations 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 who may have used an Association's service or to support ongoing research work. A special memorial fund can be established at your request.

### ***Giving your time***

Many people volunteer their time to help run Associations or join one of the many support groups. All these services rely upon people giving their time to help others. For more information please ring or write to your local Association.