

My response to the needs of people who have Motor Neurone Disease

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Donations over \$2.00 are Tax Deductible.

Please fill in your name and address

Dr/Mr/Mrs/Ms/Miss _____

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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.

*The content of this leaflet
has been approved by
the Council of the Australian Association
of Neurologists.*

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MOTOR
NEURONE
DISEASE

SOME FACTS

mnd 
Australia

People who receive a diagnosis of any serious illness, and those close to them, are very likely to have feelings of shock, anger and despair. This is especially true when people who are fit, well and active, develop very early signs of motor neurone disease (MND) such as weakness in one hand.

The shock experienced when hearing the diagnosis frequently means that people do not remember very much of what their neurologist has explained to them. The questions they most frequently ask and their answers are:

What is Motor Neurone Disease?

Motor neurone disease is the name given to a group of diseases in which the nerve cells - neurones - controlling the muscles that enable us to move around, speak, breathe and swallow, fail to work normally.

With no nerves to activate them, muscles gradually weaken and waste. The patterns of weakness vary from person to person.

What are the symptoms?

Early symptoms are mild, and include stumbling due to weakness of the leg muscles, difficulty holding objects due to weakness of the hand muscles, slurring of speech or swallowing difficulties due to weakness of the tongue and throat muscles. The effects of MND - initial symptoms, rate and pattern of progression, and survival time after diagnosis - vary significantly from person to person.

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?

In the majority of cases the intellect and memory are not affected, nor are the senses of sight, hearing, taste, smell and touch. The bowels and bladder are not affected by the disease, although diet and exercise should be carefully monitored.

Is there a cure or treatment for MND?

At present there is no cure, but co-ordinated research is being carried out across the world and encouraging progress is being made.

In clinical trials riluzole (Rilutek) has been demonstrated to show a modest extension of life expectancy for people diagnosed with MND. It is available on the Pharmaceutical Benefits Scheme for patients who meet defined selection criteria.

Costly and unproven therapies are sometimes recommended by well meaning people. People should seek professional advice before embarking on unproven therapies.

You may hear through television or other media of new advances. You should always check with your neurologist, general practitioner or care team before trying these.

What can be done?

Support people include family, friends, general practitioners, neurologists, occupational therapists, physiotherapists, speech pathologists, psychologists, dietitians, home care nurses, social workers, palliative care workers, community care services and MND Associations in each state and territory.

Most MND Associations employ professional staff. They work with people living with MND and their carers. They provide information about resources, equipment and support, based on a wide understanding of the issues associated with each stage of the disease.

Information about the support available in your area can be obtained from the Motor Neurone Disease Association in your state or territory. Contact numbers are printed overleaf.

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.