

What is MND?

About Motor Neurone Disease



What is Motor Neurone Disease (MND)?

Motor Neurone Disease (MND) refers to a group of diseases in which nerve cells that control muscles get sick and die. As the nerve cells die, the muscles they support weaken and waste away over time. This results in changes in movement, speaking, breathing and swallowing.

The early signs of MND vary from person to person. So does the rate and pattern of progress, and length of life after diagnosis. For many people with MND, it progresses fast. The average life expectancy after a doctor tells someone they have MND is 2.5 years. A minority of people will live for 5 years or more.

MND is not contagious. About 10% of MND is 'familial'. Familial MND means that there is or has been more than one person in a family affected by MND.

Amyotrophic Lateral Sclerosis (ALS) is the name for the most common form of MND. In the USA it is referred to as Lou Gehrig's disease.

MND impacts people of all races and ethnicities.

The lifetime risk of developing MND is about 1 in 300 by the age of 85.

What are the signs of MND?

Early problems from MND include:

- stumbling due to weakness of the leg muscles
- difficulty holding cups and other objects due to weakness of the hand muscles
- slurring of speech or trouble swallowing due to weakness of the muscles of mouth and throat
- twitching or cramping muscles.

Over time MND can create high levels of disability that requires a wide range of support for daily living.

How does a doctor test for MND?

Deciding if someone has MND is often difficult for doctors.

A general practitioner (family doctor) may suspect a nervous system problem. They would then ask the patient to see a neurologist. A neurologist is a doctor who is an expert on the nervous system and the brain. Other nervous system issues can look like MND in the early stages. Doctors will need to conduct a number of tests and watch a person for some time before they can definitely say they have MND. A neurologist is the only doctor who can diagnose MND.

What remains the same with MND?

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

Thinking and behaviour change

About 50% of people with MND may experience some changes in thinking, language, behaviour or personality. Most people will have relatively mild changes. Sometimes people with MND may feel apathetic. This is a lack of interest, emotion or concern about something. This can be hard for the person with MND as well as their family and friends.

About 5–15% of people show more significant changes. When this happens, a doctor may diagnose MND with "Frontotemporal Dementia." This is also called MND/FTD.

Is there a cure for MND?

There is no cure for MND yet but lots of research across the world is searching for one. Research also shows that some treatments can help people living with MND to live better for longer.

Sometimes businesses will advertise on the internet suggesting expensive and unproven treatments for MND. Unproven treatments can be harmful and are likely to have no effect on the progression of MND.

It is best to make choices about treatments with the support of a health care team.

Living better for longer with MND

There is one medicine approved for treatment of MND in Australia: riluzole (Rilutek™ or APORiluzole). Riluzole can prolong survival and slow progression of MND. People who start riluzole soon after diagnosis show the greatest benefits. Not everyone will be prescribed riluzole. A neurologist advises on whether riluzole can be taken.

There are other important treatments. Research finds that multidisciplinary care, good nutrition and using a small machine to help with breathing called non-invasive ventilation (NIV) all play an important part in people living better for longer.

Some people experience changes to their speech. This can make taking part in important health care discussions hard. Early conversations about symptom management can support fast action to make changes and to plan ahead. Learning about palliative care can help, too.

What is multidisciplinary care?

Multidisciplinary care is when a range of health and community care professionals work together to care for a person.

A multidisciplinary care team may have doctors, nurses, and local palliative and community care workers. The team also includes allied health professionals like dietitians, occupational therapists, physiotherapists and speech pathologists.

In many areas of Australia, the MND Advisor and/or Care Coordinators from the MND Association work as part of the team.

A respiratory (breathing) specialist doctor and other professionals become involved as needed.

How can MND Associations help?

Staff at MND Associations play a key role in helping people living with MND. They provide MND specific information, education and support. Associations also help with access to aids, equipment and referral to other services when needed.

Who can I talk to about MND and learn more?

Get in touch with the MND Association in your State or Territory by calling the **MND Info Line 1800 777 175** (9am to 4:30pm Monday to Friday). Or visit www.mndconnect.org.au MND Connect provides a wide range of information and resources. You can also learn about:

- Government support available
- the NDIS, and
- My Aged Care.

Who is MND Australia?

MND Australia is the national peak body supporting people impacted by Motor Neurone Disease. We fund research to find treatments and ultimately a cure.

Getting involved

There are many ways to get involved. Volunteer or participate in fundraising efforts to support the work of MND Associations and the global effort for a world without MND.

- Join in a walk, run, swim or ride for the cause
- Join in events for MND Week and MND Global Day each year
- Get involved with MND clinical trials (check with your neurologist for eligibility).



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