
Motor neurone disease (MND)

Summary

- Motor neurone disease (MND) is still incurable, but not untreatable – many symptoms can be managed.
 - People with MND live better and longer under the care of a multidisciplinary team.
 - The senses of eyesight, hearing, taste, smell and touch are not affected.
 - The Motor Neurone Disease Association of Victoria can provide advice about a range of services and entitlements including NDIS and aged care
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Motor neurone disease (MND) is also called amyotrophic lateral sclerosis (ALS) and Lou Gehrig's disease. It is a rapidly progressing, neurological disease.

MND often begins with weakness of the muscles in the hands, feet or voice, although it can start in different areas of the body and progress in different patterns and at different rates. People with MND become increasingly disabled. Life expectancy after diagnosis is one to five years, with 10 per cent of people with MND living 10 years or more.

The needs of people with MND are complex and vary from person to person.

Symptoms of motor neurone disease (MND)

The physical effects of motor neurone disease can include:

- muscle aches, cramps, twitching
- clumsiness, stumbling
- weakness or changes in hands, arms, legs and voice
- slurred speech, swallowing or chewing difficulty
- fatigue
- muscle wasting, weight loss
- emotional lability – for example, where a slight upset can cause an exaggerated response, such as crying or laughing
- cognitive change (changes in thought processes)
- respiratory changes.

It was thought that MND only affected the nerve cells controlling the muscles that enable people to move, speak, breathe and swallow. However, it is now known that up to 50 per cent of people with MND can experience changes in cognition, language, behaviour and personality. Most people experience relatively mild changes.

Causes of MND

The causes of MND are unknown, but worldwide research includes studies on:

- exposure to viruses
- exposure to certain toxins and chemicals
- genetic factors
- inflammation and damage to neurons caused by an immune system response
- nerve growth factors
- growth, repair and ageing of motor neurons.

Familial (hereditary) MND accounts for about five to 10 percent of cases. Several gene mutations have been

identified since 1993, and current research aims to identify further genes linked to MND. The majority of cases, 90 to 95 per cent, are sporadic.

Effects of MND

People who have MND may:

- develop generalised paralysis (paralysis of both sides of the body)
- lose speech and have difficulty swallowing
- become breathless and experience sleep disturbance
- experience mild cognitive and behavioural change
- become increasingly dependent on others for all aspects of day-to-day activity.

Impact of MND on carers

As MND progresses, the person's physical condition will change rapidly, and require increasing assistance from a carer. Over time, both the carer and the person living with MND will need increasing levels of support, both physically and emotionally.

Carers can seek support through:

- **Carers Victoria** (Tel. **1800 242 636**) or through the **carer association in their state or territory**
- **MND Victoria**.

Treatment for MND

MND is still incurable, but it is not untreatable, as many symptoms can be managed. The drug riluzole – available on the Pharmaceutical Benefits Scheme – has been demonstrated in clinical trials to prolong survival by several months and may help people to remain in the milder phase of the disease for longer.

Research has shown that people live better and longer under the care of a multidisciplinary team. Interventions such as assistance with nutritional intake and breathing improve quality of life.

Costly and unproven therapies are sometimes recommended by well-meaning people. Seek professional advice before trying unproven therapies.

Coping with the effects of MND

MND Victoria can help people to cope with the physical and emotional effects of the diagnosis by providing:

- information about MND and support services via telephone, email, in person, printed and via the MND Victoria website
- **MND Advisor** service
- home visits, and assessment of the needs of people living with MND
- help to connect to services that people need, such as speech pathology, occupational therapy, physiotherapy, attendant care and nursing
- equipment loan service or referral to other agencies for equipment
- volunteer programs.

Where to get help

- Your **GP (doctor)**
- Specialist neurologist
- **Motor Neurone Disease Association of Victoria** Tel. **(03) 9830 2122** or **1800 806 632**
- **Department of Health and Human Services, Disability** Tel. **1800 783 783** or TTY 13 36 77 and ask for 1300 650 172
- Disability, Sickness and Carers line, Centrelink Tel. **13 27 17**
- **NDIS**

- **My Aged Care**

This page has been produced in consultation with and approved by:

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