

## Motor neurone disease explained

Motor neurone disease (MND) often begins with weakness of the muscles in the hands or feet. It eventually leads to generalised paralysis. People with motor neurone disease need help with daily activities and have a life expectancy of one to five years after their diagnosis.

### A variety of physical effects

The physical effects of motor neurone disease can include:

- Muscle weakness or wasting – often first noticed in the hands or feet
- Difficulty swallowing or slurred speech
- Muscle twitching
- Cramps
- Emotional lability
- Fatigue
- Weight loss.

### Causes of MND

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

- Viruses, toxins, genetic factors and immune factors
- Nerve growth factors and chemicals that control nerve cells and allow them to communicate with each other
- Growth, repair and ageing of motor neurones.

Familial (hereditary) MND accounts for about five to ten per cent of cases. Several gene mutations have been identified since 1993, and current research aims to identify further genes linked to MND.

### Effects of motor neurone disease

People who have MND will have:

- A potential to develop generalised paralysis
- Loss of speech and difficulty swallowing
- A dependence on others for all aspects of day-to-day activity
- An average life expectancy of one to five years after diagnosis.

### Needs arising from motor neurone disease

As MND progresses, there will be:

- Rapidly changing physical ability of the person with MND and increasing assistance required of the carer
- Increasing levels of support required for the carer and the person living with MND
- Emotional demands of caring and being cared for.

### There is no cure yet for MND

The drug Rilutek (riluzole) has been demonstrated in clinical trials to show a modest extension of life expectancy, and works best in conjunction with support from a multidisciplinary team of health professionals. Rilutek is available on the Pharmaceutical Benefits Scheme.

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

## **Coping with the physical and emotional effects**

The Motor Neurone Disease Association can help people to cope with the physical and emotional effects of the diagnosis by providing:

- Information about MND and support services via telephone, in person, printed material, the Internet, DVD's and group meetings – this includes information about experiences that other people have found helpful
- Home visits and assessment of the needs of people living with MND
- Help to connect to services that people need, such as attendant care, nursing, speech pathology, occupational therapy and physiotherapy
- Equipment loan service or referral to other agencies for equipment
- Trained volunteers who provide 'a listening ear' via the telephone and offer companionship by visiting people.

## **Where to get help**

- Your local doctor
- A specialist neurologist
- Motor Neurone Disease Association Tel. (03) 9830 2122 or 1800 806 632
- A physiotherapist, occupational therapist, speech pathologist or other health professional at your local hospital or community health centre
- The Community Services Department of your local council
- Department of Human Services, Disability Services Tel. 1800 783 783 or TTY 1800 008 149.
- Centrelink Tel. 132 717 (Disability, Sickness and Carers)

## **Things to remember**

- There is no evidence to suggest that motor neurone disease is contagious.
- In most cases, the person with MND can make their own decisions.
- In the majority of cases, the intellect and memory are not affected, nor are the senses of eyesight, hearing, taste, smell and touch.
- The Motor Neurone Disease Association can provide advice about pensions and other benefits.

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

Motor Neurone Disease Association of Victoria

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