

What you should know

- There is no cure for motor neurone disease (MND) yet, but research shows there are things you can do to live better, more independently and for longer with MND.
- MND is a life-limiting illness that can affect how you walk, talk, eat, drink, swallow and breathe. Progression is usually different for each individual. You may not get all of the symptoms and there is no set order in which they happen.
- How you manage early symptoms of MND may affect the management of symptoms developed later in the progression of the disease.
- Early discussion about symptom management will help you to plan ahead.

About the *Living Better for Longer* evidence-based fact sheets

The MND Australia 'Living Better for Longer' fact sheet series describe support and treatments that research has shown to help people live better for longer with motor neurone disease. This overview fact sheet (EB1) is the first in this evidence-based series. Others in the series are listed below.

▶ **Multidisciplinary care (EB2) and the Multidisciplinary care team (EB3)**

The health professionals you consult can give you better care and advice when they are knowledgeable about motor neurone disease and have a coordinated, multidisciplinary team approach to your care. Read fact sheets EB2 and EB3 to find out about what makes up multidisciplinary care, who is in a multidisciplinary care team and where to find them.

▶ **Riluzole (EB4)**

Riluzole (Rilutek™) is a medication that does not cure motor neurone disease but, for people with the most common forms of motor neurone disease, it probably prolongs median survival by two to three months (median is the mid-point – half those taking riluzole have survival prolonged by more than two to three months). People who start taking riluzole early in their disease progression are more likely to remain in the milder stages of the disease for longer than those not taking riluzole. Read fact sheet EB4 for information about riluzole.

▶ **Breathing and motor neurone disease: an introduction (EB5)**

Motor neurone disease causes the muscles you have control over to weaken. This includes the muscles involved in breathing – the respiratory muscles. Read fact sheet EB5 for information about how respiratory muscles work and why it is a good idea to have a 'baseline measurement' of your breathing function soon after diagnosis with motor neurone disease.

▶ **Breathing and motor neurone disease: what you can do (EB6)**

Positioning, adjusting room airflow, staying away from coughs and colds and conserving energy are just some of the simple techniques you can use to manage mild respiratory symptoms. Read fact sheet EB6 to learn about these and other strategies that may help you feel more comfortable.

▶ **Breathing and motor neurone disease: medications and non-invasive ventilation (EB7)**

Increasingly, many people with motor neurone disease use non-invasive ventilation (NIV) to get more air into their lungs. Read fact sheet EB7 to find out about NIV and who to see for medications that may help you feel more comfortable if you are experiencing breathlessness.

Some people are not offered a key point of contact when they are diagnosed with motor neurone disease and are left to find their own way around a rather complex health and community care system. If this is the case for you, talk to your general practitioner, neurologist or MND Association. They should be able to guide you and ensure you can access the services and information you need.

► **Considering gastrostomy - PEG and RIG (EB8)**

Motor neurone disease may cause the muscles involved in chewing and swallowing (the bulbar muscles) to weaken. A gastrostomy is a medical procedure during which a fixed tube is placed into the stomach through the abdominal wall. This tube can be used for liquid feeds, fluids and medications. Other symptoms of motor neurone disease, such as significant respiratory muscle weaknesses, can affect your recovery from this procedure. To find out more about gastrostomy, read fact sheet EB8.

About MND Australia, State MND Associations and Alternative Treatments

MND Australia is the national voice representing all Australians who share the vision of a world without MND. We improve the lives of people living with MND by:

- influencing policy
- providing current and accurate information
- raising awareness
- funding the best research with the greatest chance of stopping MND, and
- providing care and support through the state MND Associations.

The six state MND Associations, representing all states and territories, are members of MND Australia and the MND Association of New Zealand is an associate member. MND Australia is an active member of The International Alliance of ALS/MND Associations, which represents ALS/MND Associations around the world.

Why research into effective treatments matters

Research is the only way that we can change the future of MND.

Every dollar we receive for research is directed to the research arm of MND Australia, the MND Research Institute of Australia (MNDRIA), and invested in research with the greatest chance of leading to the development of effective treatments and improving the lives of people with MND.

We believe that it is only a matter of time and hard work before we unravel MND's mystery. A cure is out there and researchers in Australia and around the world are working hard to find it.

How to sort fact from fiction

MND Associations are often contacted by people living with MND and their families about treatments being offered both here and overseas that claim to treat or cure MND. Often, these treatments are promoted on websites that feature in internet search results when people are searching for information about MND. It can be difficult to sort fact from fiction and to distinguish good quality health information from paid advertising.

The facts sheets in this series focus on effective treatments currently available for MND, that enable a person with MND to live better, more independently and for longer.

To learn more, including information about research trials and what helps with treatment:

- contact the [MND Association in your state or territory](#), or
- read about [clinical trials testing new treatments and interventions](#).

Living Better for Longer: MND Australia evidence-based fact sheets

► **MND evidence-based support and treatments - an overview (EB1)**

Multidisciplinary care (EB2)

Multidisciplinary care team (EB3)

Riluzole (EB4)

Breathing and motor neurone disease: an introduction (EB5)

Breathing and motor neurone disease: what you can do (EB6)

Breathing and motor neurone disease: medications and non-invasive ventilation (EB7)

Considering gastrostomy - PEG and RIG (EB8)

To find out about motor neurone disease and other fact sheets in this series contact the MND Association in your state or territory ph. 1800 777 175 or visit www.mndaustralia.org.au