

Motor neurone disease evidence-based interventions: an overview

What you should know

- Although there is no cure for motor neurone disease yet, research has shown there are some things you can do to live better for longer with MND.
- Symptoms of MND vary significantly from person to person.
- How you manage your earlier MND symptoms may affect how symptoms you later develop can be managed.
- 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 explores interventions 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 these fact sheets to find out about multidisciplinary care and the multidisciplinary care team.

▶ **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 this fact sheet 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 this fact sheet 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 this fact sheet 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 this fact sheet to find out about NIV and to also find out who to see for medications that may help you feel more comfortable if you are experiencing breathlessness.

▶ **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 permanent tube is placed into the stomach through the abdominal wall. This tube can be used for liquid feed and fluids. Other symptoms of motor neurone disease, such as significant respiratory muscle weaknesses, can affect your recovery from the procedure. To find out about gastrostomy, read this fact sheet.

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.

About MND Australia

MND Australia is the national peak body for MND in Australia. The MND Australia network comprises six state Associations, representing all states and territories and the MND Research Institute of Australia (MNDRIA). Internationally, motor neurone disease is also known as amyotrophic lateral sclerosis (ALS). MND Australia is an active member of the International Alliance of ALS/MND Associations.

International Alliance of ALS/MND Associations

Statement on Alternative Treatments (short version)

For the purposes of this document, the term 'Alternative' used here refers to treatments or interventions that are not part of mainstream (conventional or Western) medicine and generally have not been scientifically documented and/or may not be recognised as being safe and effective for ALS/MND.

The International Alliance of ALS/MND Associations:

- recognises the interest that people affected by ALS/MND can have in seeking alternative forms of treatments
- supports the individual's right to choose what treatment they wish to undertake but would strongly encourage anyone considering any treatment to fully discuss the issues around such treatment with their doctor, health care professional and family before making a final decision
- believe that treatments for, and research into, ALS/MND should be legal, have a sound scientific rationale and have the potential to bring us closer to the cause, treatment or cure for the condition
- only recommends treatments that have been proven through thorough scientific testing and clinical trials to be safe and effective
- recommends all providers of non-proven and/or alternative treatments for those affected by ALS/MND to conduct scientific research and submit papers to the appropriately recognised journals so that peer review can be undertaken and the information can be shared amongst the whole ALS/MND community.

Guidance Principles

When looking at alternative treatments, the International Alliance would recommend that you give careful consideration to the following questions to help you think through the issues and to make an informed decision:

What claims are being made for the treatment?

Often there will be claims of stopping the progression of the disease or of a reversal or improvement in symptoms. Check who is making these claims and what evidence there is to back them up. If the claims are genuine then they will have been published in recognised scientific journals and there will be published results of clinical trials.

How are people finding out about the treatment?

Any genuinely safe and effective treatment will be promoted and recommended by your doctor and the ALS/MND Associations.

Who is offering the treatment?

Is the treatment being offered by an appropriately recognised institution? Is it being offered by a number of different institutions or just one? If it's just one then why are others not following and doing the same? Do you have to travel to another country to receive the treatment and if so why is it not available in your own country?

What are the risks involved?

Is it clearly stated what risks are involved in undergoing the treatment? Are there any side effects and how long may they last? Has the treatment been proved to be safe and effective and if so how was this done? Don't forget that there can be financial risks associated with treatment particularly if it is expensive and involves overseas travel.

What follow-up monitoring is carried out after the treatment?

Follow-up monitoring is extremely important not just for you but for all those with ALS/MND. For you it is important to know that you will be monitored so that any adverse effects can be picked up as soon as they occur. For all those with ALS/MND they need to know if the treatment is successful and that they can rely on the claims being made.

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

► **MND evidence-based interventions - 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.mndaust.asn.au