

Breathing and motor neurone disease: what you can do

What you should know

- Motor neurone disease causes the muscles you have control over to weaken. This can include the muscles involved in breathing – the respiratory muscles.
- Getting advice about respiratory management soon after your diagnosis with motor neurone disease can help you live better for longer.
- Positioning, adjusting air flow in the room, staying away from coughs and colds and saving your energy are just some of the simple techniques you can use to manage mild respiratory symptoms.
- Let your doctor or clinic know if you think your respiratory muscles are weakening.

What you can do

Seek assessment and advice about respiratory management soon after your diagnosis with MND, even if you have not noticed any changes in your breathing (Andersen et al 2007). This will give you more time to get information, have discussions and decide which strategies are right for you.

If your respiratory muscles are affected, some of the strategies below may be suggested.

Positioning your body

The way you position your body while sitting or lying down can assist your breathing. Electric recliner chairs and adjustable wheelchairs enable you to easily experiment with a number of different positions.

Some people find it more comfortable to sit in a slightly reclined, or not so upright, position. Others prefer a fully upright position. When in bed, you may find maximum comfort in a semi-reclined position. You can use regular pillows, boomerang pillows, foam wedges and bed adaptations, such as an electric bed with head-raiser, to support your upper body and head. Your physiotherapist or occupational therapist can advise you about positioning and where to get equipment.

Adjusting room airflow and temperature

Having an open window in the room and using a fan to circulate air can also assist your breathing. You may find it helpful to use a humidifier to increase the moisture in the room air. Room temperatures that are too hot or too cold can also make you feel uncomfortable.

Staying away from coughs and colds

Avoid people with coughs and colds. Have an influenza vaccine before winter to reduce the risk of getting the flu. Your doctor or respiratory physician may also recommend that you have a pneumonia vaccine.

Having a well-balanced diet

If you are undernourished your muscles, including your respiratory muscles, will be weaker. You are also more likely to get coughs and colds. Maintain a healthy diet with the right mix of proteins, carbohydrates and other nutrients.

A well-balanced diet, including enough fluids, will also help you avoid getting constipated. You will need to use more effort to empty your bowel if you are constipated. Also, because your diaphragm is involved in helping you to push down to empty your bowels, respiratory muscle weakness can affect how efficient you are at emptying your bowels.

Your dietitian, community nurse or general practitioner can advise you about specific dietary issues and constipation.

Breathing exercises

Breathing exercises may slow the progression of respiratory muscle weakness. They also cause your lungs to expand more fully and this reduces pooled air in the lungs. One simple exercise is to take five to ten deep breaths, with short rests in between, several times a day. Your physiotherapist, palliative care team, specialist respiratory nurse and respiratory physician can advise you about the right breathing exercises for you.

Saving your energy for what you really want to do

Fatigue can be a major problem for people with MND. Unfortunately there is no advantage in 'pushing yourself'. Rather, the key is to try and save your energy for what you really want to do.

- Learn to respect your body's limitations and pace yourself.
- Find short-cuts for things you have to do.
- Use gadgets and labour-saving devices.
- Use equipment which helps save your energy. For example, you can take a wheelchair, that you may not need to use all the time, when you are going out.

Health professionals, such as respiratory nurses, physiotherapists, occupational therapists and rehabilitation specialist staff can teach you how to save your energy. They can also give you advice about equipment and labour-saving devices.

Relaxation techniques

Anxiety or worry about breathlessness can affect your breathing efficiency. Controlled breathing and other techniques can help you to relax and make breathing easier. Your physiotherapist, palliative care team, specialist respiratory nurse and respiratory physician can advise you about the right techniques for you.

Eating foods of the right consistency

A weak cough can make it more difficult for you to clear thin liquids or thick and chunky foods that may accidentally enter your airways when you are eating and drinking. Your speech pathologist and dietitian can provide you with advice and recipes for foods and drinks, including advice about thickening agents. Your physiotherapist can show you and your carer how to use an 'assisted cough' to clear your airways.

Managing saliva

When your cough is weak you may be more likely to get chest infections or have difficulty in getting rid of excess saliva. Your doctor or healthcare team may suggest:

- assisted cough technique - to clear secretions when your cough is weak
- room humidifier
- medication to reduce the production of saliva
- nebuliser
- home suction device
- mechanical insufflation-exsufflation - using a positive expiratory pressure (PEP) valve device that forces you to cough.

Your speech pathologist, physiotherapist or doctor can provide you with advice and more information about saliva management.

Other strategies

Other strategies for managing breathing with motor neurone disease include using medications or supplementing breathing with non-invasive ventilation (see below, Living Better for Longer fact sheets).

More information

For more information about respiratory management contact your general practitioner, neurologist, respiratory physician, palliative care team, MND clinic or service or your MND Association.

References

Andersen et al, 2007, 'Good practice in the management of amyotrophic lateral sclerosis: clinical guidelines: an evidence-based review with good practice points. EALSC Working Group.', *Amyotroph Lateral Scler* 8(4).

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