

## Breathing and motor neurone disease: what you can do

### What you should know

- Motor neurone disease (MND) causes the muscles you have control over to weaken. The affected muscles include those involved in breathing – the respiratory muscles.
- Problems with the respiratory muscles can occur at any stage of disease progression, and lead to symptoms such as fatigue, difficulty sleeping and shortness of breath.<sup>1, 2</sup>
- Positioning, adjusting air flow in the room, physiotherapy, breathing exercises, assisted coughing techniques, staying away from people with colds, influenza or respiratory tract infections and saving your energy are just some of the simple techniques you can use to manage mild respiratory symptoms.
- Getting advice about respiratory management soon after your diagnosis with MND can help you live better for longer. Let your doctor or clinic know if you think your respiratory muscles are weakening.

### What you can do

Seek regular assessment and advice about respiratory management soon after your diagnosis with MND, even if you have not noticed any changes in your breathing.<sup>1</sup> You will have more time to obtain information, discuss your options and decide which strategies are right for you. The strategies below can help with respiratory muscle problems.

#### Positioning your body

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

Some people are more comfortable when sitting 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. Regular pillows, boomerang pillows, foam wedges and bed adaptations, such as an electric bed with head-raiser, can 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.<sup>3</sup> A humidifier may also help 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 a pneumonia vaccine.

#### Having a well-balanced diet

If you are undernourished your muscles, including your respiratory muscles, will be weaker. You're 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, with enough fluids, will also help you avoid getting constipated. More effort is required to empty your bowel with constipation. Also, because your diaphragm helps you to push down to empty your bowels, respiratory muscle weakness can affect how well you empty your bowels. Eating smaller amounts, more often, may help. 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.<sup>4</sup> The exercises help lungs to expand more fully, reducing pooled air in the lungs. One simple exercise is to take five to ten deep breaths, with short rests in between each breath, several times a day. Speak with your physiotherapist, palliative care team, specialist respiratory nurse and respiratory physician 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'. Instead, 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 technology and labour-saving devices.
- Use equipment which helps save your energy. For example, take a wheelchair when you go out, even though you may not use it all the time

Respiratory nurses, physiotherapists, occupational therapists, rehabilitation specialist staff and other health professionals can teach you how to save your energy, and share advice on equipment and labour-saving devices.

## Relaxation techniques

Anxiety or worry about breathlessness can affect how well you breathe. Controlled breathing and other techniques can help you to relax and make breathing easier. A calm, confident approach by your carer is also helpful. 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 during 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 and cough effectiveness

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
- head and neck support
- oral hygiene (e.g. mouth swabbing, low foaming toothpaste)
- room humidifier
- breath stacking
- medications to reduce the production of saliva
- nebuliser
- home suction device
- mechanical cough assist device

A speech pathologist, physiotherapist or doctor can provide you with advice and more information about saliva management and techniques to improve cough effectiveness.<sup>2</sup>

## Other strategies

Other strategies for managing breathing with motor neurone disease include medically supervised use of medications such as opioids or benzodiazepines<sup>1</sup>, 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

1. Berlowitz et al. 2016, 'Identifying who will benefit from non-invasive ventilation in amyotrophic lateral sclerosis/motor neurone disease in a clinical cohort', *J Neurol Neurosurg Psychiatry*, 87(3), 280-86. 2. National Institute for Health and Care Excellence (NICE) 2016, 'Motor neurone disease: assessment and management', retrieved from <https://www.nice.org.uk/guidance/NG42/chapter/Recommendations#managing-symptoms> 3. Swan et al. 2019, 'Airflow relieves chronic breathlessness in people with advanced disease: An exploratory systematic review and meta-analyses', *Palliative Medicine*, 33(6), 618-633. 4. Cheah et al. 2009, 'INSPIRATIONAL - INSPIRATORY muscle training in amyotrophic lateral sclerosis', *Amyotrophic Lateral Sclerosis*, 10(5-6), 384-392.

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

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Multidisciplinary care (EB2)  
Multidisciplinary care team (EB3)  
Riluzole (EB4)  
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Considering gastrostomy - PEG and RIG (EB8)

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