Motor Neurone Disease NZ

Breathing with MND

Information sheet for people living with MND and their whānau

Motor neurone disease (MND) causes the muscles you have control over to weaken, including the muscles we use to breathe.

As a result, breathing becomes shallower so that:

- less air is drawn into the lungs, so less oxygen is absorbed into the blood
- less carbon dioxide is breathed out.

Getting advice about breathing management can help you live better for longer. A baseline assessment of your breathing by a respiratory specialist soon after diagnosis provides details about your 'usual breathing' and can be helpful for future treatment. An early assessment also gives you more time to get information, have discussions and decide which strategies are right for you.

Breathing muscle weakness usually develops gradually but, in some cases, can occur suddenly.

Breathing muscle weakness can sometimes be the first sign of MND.

It is important to let your doctor or Motor Neurone Disease NZ Support Advisor know if you are noticing changes in your breathing.

Changes that may result from respiratory muscle weakness include:

- disturbed nighttime sleep or loss of sleep
- vivid dreams
- daytime sleepiness
- morning headaches
- increased fatigue
- decreased appetite
- impaired concentration or confusion
- irritability and anxiety

- quiet voice and fewer words per breath
- shallow, faster breathing
- reduced movement of the rib cage or abdominal muscles
- excessive use of the muscles in the upper chest and neck
- breathlessness (dyspnoea) even when resting
- breathlessness when lying flat (orthopnoea)
- weakened cough and sneeze.

Non-invasive ventilation

Many people with motor neurone disease choose to use non-invasive breathing support, known as NIV. This support provides relief from symptoms such as fatigue, breathlessness and disturbed sleep.

NIV involves wearing a mask connected to a small pump that creates just the right pressure to keep your airways open so that the air in the room can easily move in and out of your lungs when you breathe.

NIV is not oxygen therapy.

The pressure can be adjusted on these machines to provide increased breathing support if needed.

The NIV machine is usually used at night but as the breathing muscles weaken you may use it at times during the day as well.

While NIV is suitable for many people with MND, it is not suitable for everyone. This will not be known until you have had a breathing assessment.

Over time, as MND progresses, NIV will be less effective in reducing the symptoms associated with breathing difficulties.

What can you do?

Some simple tips that can help to ease difficulties with breathing:

- **Save your energy** for what you really want to do.
- **Pace yourself**, taking breaks when you need to. Do not plan to do too much at any one time or on any day.
- **Use labour-saving devices to save energy**. There are many gadgets available that can make tasks easier. Your occupational therapist (OT) will be able to give advice and perhaps help you source some of these devices.

- **Positioning**: sitting up may be better than lying down. You could raise your head and chest with extra pillows or sit and possibly even sleep in an adjustable recliner chair. Some people find it easier to breathe if they are in a slightly raised position, others prefer to be completely upright. Your OT and physiotherapist (physio) will be able to give advice on positioning.
- **Adjust the air flow**: position yourself near an open window or have a gentle fan directed towards your face. A humidifier may be helpful to increase the moisture in the room air.
- **Breathing exercises** may help to slow the progression of muscle weakness. and help your lungs to expand more fully. Your physio, palliative care team or respiratory specialists can advise about the correct breathing exercises for you.
- **Relaxation techniques:** anxiety about breathing will hamper your breathing ability even further. Your physio, palliative care team or respiratory specialists will be able to advise you about relaxation techniques and controlled breathing. It is important for whānau/family to understand that a calm and reassuring environment will lessen panic that may arise due to breathlessness and 'air hunger' episodes.
- **Avoid being with other people who have coughs or colds.** Your doctor may advise you to have a flu vaccine.
- **Secretions:** problems with excess saliva or thick sticky mucus will hamper your breathing further. Your speech and language therapist (SLT), physio and OT will be able to advise you on techniques for managing secretions, such as positioning, exercises and cough. In some cases, a suction machine or a cough assist machine can be helpful, but these are not available in all regions.
- **There are medications** that can help with managing the symptoms of breathlessness. Talk to you doctor or palliative care team about this.

Motor Neurone Disease New Zealand is a charitable trust dedicated to making time count for people affected by MND by offering personal support; advocacy; education; and supporting research. Find out more at www.mnd.org.nz or call 0800 444474.

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