Motor neurone disease (MND) - help with daily activities

Summary

- As MND progresses, you may find that you have difficulty with everyday items in your home.
- The right aids and equipment can you retain some independence and quality of life in your own home when living with MND.
- There are professionals who can help you identify the appropriate resources, aids, equipment and support.

Motor neurone disease (MND) affects the muscles that enable us to move, speak, breathe and swallow. Problems associated with the weakening of these muscles include difficulty moving about, breathlessness, fatigue, difficulty with speaking and swallowing, sleeping problems (insomnia), stiffness, swelling and cold limbs. Techniques and aids can help to ease these problems.

Moving about with MND

People with MND have a tendency to fall and may need help moving about. It’s important to take care when lifting someone with MND, as it can cause discomfort to the person lifting and the person being lifted.

If you are caring for someone with MND, talk to an occupational therapist, physiotherapist or district nurse about lifting techniques and aids.

Tiredness and MND

Fatigue is common with MND. Factors that may lead to fatigue include immobility, overexertion, sleep disruption, pain, weakened breathing, stress, anxiety, smoking, alcohol and some medications.

Symptoms of fatigue include slower speech and movement, shortness of breath and lack of interest in daily planning.

Conserving energy can improve quality of life. It may help to:

- Plan activities in advance.
- Respect your body’s limitations and pace yourself.
- Find short cuts where possible, and sit rather than stand.
- Use gadgets and labour-saving devices to make tasks easier. Make your environment easy to move around in.
- Take regular breaks and stop an activity if it causes breathlessness.
- Establish a regular sleeping pattern.

Insomnia and MND

Insomnia (sleeplessness) can be caused by discomfort, muscle pain and stiffness, shortness of breath or a dry mouth, or any combination of these and other things. To encourage sleep:

- Go to bed at the same time each night.
- Make sure your bedroom is quiet, cool, dark and comfortable.
- Avoid heavy meals and caffeinated drinks.
- Change position in bed often.
- Use satin or silk sheets to make it easier to move.
- Use pillows to spread body pressure or to raise your head and chest for improved breathing and swallowing.

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• Try equipment such as an electric bed that can be adjusted to different positions.
• Talk to your doctor about medications that may help.
• Talk to your physiotherapist about exercise or massage that may promote relaxation.

**Breathlessness and MND**

Breathlessness is a common problem for people with MND. Ways to avoid or reduce it include:

- sitting up straight with the back and head supported to relieve pressure on the lungs and to alleviate saliva or mucus problems
- checking room airflow (fan, open window) and temperature
- avoiding contact with people with colds or flu – ask your doctor about influenza (flu) vaccination
- fatigue management
- breathing exercises
- speaking to professionals such as speech pathologists and physiotherapists about techniques to reduce breathlessness.

**Coldness and MND**

People with MND are prone to coldness. To keep warm:

- wear warm clothing, preferably woollen
- use sheepskin slippers, seat pads, rugs and leg warmers
- try gentle massage and changing position to help circulation and stimulate warmth.

**Swelling and MND**

Your feet and legs can swell due to a build-up of fluid. It may help to:

- Talk to your doctor about the possible causes and treatments.
- Keep your legs elevated with cushion support.
- Use massage and gentle exercise to help disperse the fluid.
- Ask your doctor about elastic stockings and crepe bandages.

**Pain, stiffness and cramp with MND**

People with MND may suffer some pain from stiff joints, muscle tension and cramp. To help alleviate the pain:

- Support your arms by using slings or specially adapted clothing when walking.
- When seated, use cushions, armchairs or tables for support.
- Alleviate cramp by gently massaging the affected part and keeping it warm until the pain subsides.
- Talk to a physiotherapist about how physiotherapy and careful positioning can help.
- Talk to your doctor about whether muscle-relaxing drugs may help to relieve your pain – they can be helpful, but they can also have side effects such as drowsiness and weakness.
- Use regular turning and re-positioning to prevent sore areas of skin from developing, especially where bones are close to the surface.

**Neck weakness from MND**

Weak neck muscles can cause the head to drop. You can:

- Use a reclining chair, headrest, collar or chin support.
- Use a velcro or elasticised band placed around your forehead and attached to the back of the headrest of your chair.
- Speak to your occupational therapist for advice.

**Arm function and MND**

There are many aids and devices that can help you continue to do tasks independently. These include:
- specially designed cutlery with large handles and straps
- plates with deep rims or a guard
- cups with two handles and flexi-straws
- lightweight utensils and bowls.

Speak to your occupational therapist for advice.

**Where to get help**

- **Your GP (doctor)**
- **MND Victoria** Tel. 1800 806 632 or (03) 9830 2122
- Specialists such as neurologists, speech therapists, occupational therapists, physiotherapists, dietitians and psychologists

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This page has been produced in consultation with and approved by:

Motor Neurone Disease Association of Victoria

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