

Motor neurone disease - help with daily activities

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 alleviate these problems.

Moving about

People with MND have a tendency to fall and may need help moving about. It's important to take care when lifting someone suffering from MND, as it can cause discomfort to the person lifting and the person being lifted. Talk to an occupational therapist, physiotherapist or district nurse about lifting techniques and aids.

Tiredness

Fatigue is common with MND. Factors that may aggravate fatigue include immobility, overexertion, sleep disruption, pain, weakened breathing, stress, anxiety, smoking, alcohol and some medications. Symptoms 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.
- Take regular breaks and stop an activity if it causes breathlessness.
- Establish a regular sleeping pattern.
- Use mechanical aids to make tasks easier.

Insomnia

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:

- 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 the head and chest for improved breathing and swallowing.
- 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

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

- Sit up straight with the back and head supported to relieve pressure on the lungs and to alleviate saliva or mucus problems.
- Avoid contact with people with colds or flu and ask your doctor about influenza (flu) vaccination.
- Speak to professionals such as speech pathologists and physiotherapists about techniques to reduce breathlessness.

Coldness

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

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 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

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

- Support your arms – when walking, use slings; when sitting, use cushions, armchairs or tables for support.
- Physiotherapy and relaxing medications may help. So can massage and gentle exercise.

Neck weakness

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

- Use reclining chairs, headrests, collar or chin supports.
- Speak to your occupational therapist for advice.

Arm function

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.

Where to get help

- Your doctor
- Your local community health centre
- Motor Neurone Disease Association of Victoria Tel. 1800 806 632
- Specialists such as neurologists, speech therapists, occupational therapists, physiotherapists, dietitians and psychologists
- Home care nurses
- Social workers.

Things to remember

- As MND progresses, the person will need assistance with daily tasks.

- The right aids and equipment can help people with MND retain some independence and quality of life.
- There are professionals who can help identify the appropriate resources, aids, equipment and support.

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

Motor Neurone Disease Association of Victoria

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