

Motor neurone disease - personal care

People with motor neurone disease (MND) gradually lose the use of their muscles and often need assistance with personal care. They may also need support to cope with the emotional impact of a progressive and disabling illness. Access to appropriate aids and equipment, as well as providing emotional and psychological support, can help maximise the quality of life of people with MND.

Emotional aspects of MND

Anxiety and depression are understandable emotions for people coping with MND. It may be helpful to:

- Share feelings with family or friends, or join a support group to meet other people coping with the same problems.
- Discuss your feelings with your doctor.
- Try to stay calm and concentrate on breathing to get through anxious periods.
- Set up a system so that you know you can contact someone to help you quickly if you need it.
- There are times when a slight upset can cause an exaggerated response, such as crying or laughing. This is called emotional lability. Don't worry about this – try to treat it in a matter of fact way.

Sex

While MND does not directly affect a person's ability to enjoy a normal sex life, the effects of the disease – such as fatigue, muscle wasting and dependence on others – can impact on sex. It may be helpful to discuss your concerns with a counsellor.

Using the toilet

Problems using the toilet and bathroom can be stressful for both the person with MND and their carer. Independence, privacy and safety are very important. Aids to assist in using the toilet range from simple paper dispensers, grab rails and raised toilet seats to bidets, commodes and toilets with foot-operated spray washers and warm air dryers.

Bathing

Warm baths and showers can have a soothing effect on muscles. However, they can also be difficult to get in and out of. Simple aids, such as grab rails, a bath board or seat, non-slip mats, lever taps, long-handled sponges and soap-on-a-rope, can all help people bathe themselves safely and in private. When bathing becomes too difficult, mechanical devices such as hoists and seats may help.

Skin care is important, so always make sure that the skin is properly dried after bathing, particularly in the folds of the underarm, breast and groin areas. It may help to:

- Make the bathroom warm
- Dress in a towelling robe after bathing
- Use a wall-mounted electric drier to dry the body.

Hair care

Washing hair may be easier to do with the person sitting or standing over a tray and with another person to help. Whichever method is preferred, it is best to use a baby shampoo that doesn't sting the eyes.

Ear care

Ears should be washed every day with warm water, and rinsed and dried well. Don't clean the inner ear – ask your nurse or doctor what to do if a wax problem develops.

Eye care

Some people with MND find that, as their muscles weaken, they blink less often and so their eyes become dry and sore. Eyes can be cleaned using a wad of cotton wool soaked in clean warm water. If your eyes are sore, ask your doctor about eye drops.

Mouth and tooth care

Teeth should be brushed carefully after meals. Make sure that excess moisture doesn't collect in the mouth, as this can cause problems swallowing. It may be helpful to use an electric toothbrush.

Swabbing the mouth with a cotton wool bud soaked in bicarbonate of soda and water (half a teaspoon to a glass of water) will help keep the mouth clean. Wiping the mouth with lemon and glycerine swabs, or plain water icy poles are refreshing. An artificial saliva spray can help relieve a persistently dry mouth. Ask your doctor to advise you on the appropriate mouth care options for you.

Nail care

Nails should be kept short to avoid scratching. Cut toenails straight across and fingernails rounded. Consult a podiatrist if problems develop. Nail care aids include nailbrushes and files fixed to basins, walls or tables, and easy-grip scissors and clippers.

Shaving

Electric shavers are easier to use than razors. Try different methods to find out which is most comfortable.

Dressing

Take your time. Begin dressing on the weakest side and undressing on the strongest side. Clothing can be adapted to make dressing easier and there are some aids, such as Velcro, or hooks for doing up buttons.

Where to get help

- Your doctor
- Your local community health centre (see the Local Services Directory)
- Motor Neurone Disease Association of Victoria Tel. (03) 9830 2122 or 1800 806 632
- Specialists such as neurologists, speech therapists, occupational therapists, physiotherapists and psychologists (your doctor can refer you)
- Home care nurses (contact your local council)
- Social workers (contact your local council).

Things to remember

- As MND progresses, the person will need assistance with personal care.
- The right aids and equipment can help people with MND retain some independence and quality of life.
- Psychological support is also important.
- 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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