Motor neurone disease (MND) - personal care

Summary

- As motor neurone disease (MND) progresses, you will need help with personal care.
- The right aids and equipment can help you retain some independence and improve your quality of life with MND.
- Psychological support is also important if you have MND.
- There are professionals who can help identify the appropriate resources, aids, equipment and support for people with MND.

People living with motor neurone disease (MND) gradually lose the use of their voluntary 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 your feelings with family or friends – talking through fears and worries can be very worthwhile.
- Communicate with other people coping with similar issues. Discuss your feelings with your doctor or other health professionals.
- 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 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 and MND

Issues of intimacy and sexuality are about more than intercourse. They concern the need to communicate and receive love and physical closeness. 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.

MND and 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 help 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.

Talk to an occupational therapist for more information about how you can adapt your home facilities to suit you.

Bathing and MND

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 you bathe yourself 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 your skin is properly dried after bathing, particularly in the folds.

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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 your body.

Hair care for a person with MND

If someone is washing your hair for you, it may be easier to do if you are sitting or standing over a tray, bucket or sink. Whichever method you prefer, it is best to use a baby shampoo that doesn’t sting the eyes.

Ear care for a person with MND

Wash your ears daily with a face washer and warm water and dry thoroughly. Don’t clean inside the ear canal – ask your nurse or doctor what to do if a wax problem develops.

Eye care for a person with MND

Some people with MND find that, as their muscles weaken, they blink less often and so their eyes become dry and sore. Clean your eyes with 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 for a person with MND

Brush your teeth carefully after meals to prevent damage to gums. Make sure that excess moisture doesn’t collect in your mouth, as this can cause problems swallowing. Low foaming toothpastes may be helpful, as may an electric toothbrush.

Swabbing your mouth with non-alcohol based solutions of bicarbonate of soda (half a teaspoon to a glass of water), can be an alternative to brushing teeth.

An artificial saliva spray can help relieve a persistently dry mouth. Ask your doctor or speech pathologist to advise you on the appropriate mouth-care options for you.

Nail care for a person with MND

Keep nails 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 and MND

Electric shavers are easier to use than traditional razors for people with limited movement. They also enable new techniques, for example, holding the razor still and moving your face over it. You could also try putting a larger handle on the razor.

Getting dressed and MND

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.

The Motor Neurone Disease Association (UK) has more information about getting dressed and feeling comfortable in your clothes as MND progresses.

Where to get help

- Your GP (doctor)
- Local community health centre
- MND Victoria Tel. (03) 9830 2122 or 1800 806 632
- Specialists such as neurologists, speech pathologist, occupational therapists, physiotherapists and psychologists (your doctor can refer you)
- Home care nurses (contact your local council)
- Social workers (contact your local council)