



Although there are no known medications that will cure MND, there are medical treatments, therapies, and assistive devices which help people maintain active and independent lives for as long as possible. These disease management and adaptive strategies promote the well-being of both you and your family. Communicate openly with your carers, therapists, and doctors about your symptoms and challenges so that you can work together to find solutions that work best for you in a timely manner. Some of the problems associated with MND and the strategies for managing them are discussed in more detail in other factsheets.

When you decide you are ready to learn more about these topics or you are experiencing problems in these areas, the information will be available for you.

Common Symptoms that Affect Daily Living

Eating

Continue to feed yourself as long as possible. However, if you feel too weak to manage a meal by yourself, or have trouble using cutlery, ask for help from your carer. For instance, your carer could help a lot just by cutting your food for you. An occupational therapist can also help by showing you how to adapt your eating and drinking utensils so they are easier to grip, or adjust the height of your eating surface so you have less distance between the plate and your mouth. When swallowing difficulties arise, or jaw muscles involved in chewing are

weakened or stiff, your dietician will be able to help you with how to eat, what to eat, and how to modify food textures to make eating easier and safer. If difficulty with eating is accompanied by weight loss, you should talk to your doctor about the possibility of tube feeding.

Constipation

Constipation may occur as a result of inactivity or lack of adequate fibre or water in the diet. If you are experiencing constipation, ask a dietician about ways to add more fibre to your diet. If adding fibre to your diet doesn't solve the problem, see a doctor about an appropriate medication.

You should be aware that weakened tummy muscles can mean that some people with MND are unable to “push” when they go to the toilet, so may have problems in going. If this happens you should mention it to your GP or MND Care Team Specialist.

Fatigue

Some MND patients have extreme tiredness (fatigue) which occurs as a result of weakening muscles, and declining breathing function. One of the first ways you can combat fatigue (tiredness) is to conserve your energy for really important tasks or activities that you really enjoy. An occupational therapist can plan a daily routine with you that will help you to adapt to life with MND. Some tasks can be done in different ways that will save your energy. There are a large number of aids that can help you to do the things you might now find difficult. It

MND Scotland is the working name of the Scottish Motor Neurone Disease Association, the only charity funding research and providing care and information for those affected by MND in Scotland.

Factsheet 33 Managing MND

is essential that you consult your MND Care Team Specialist before buying any aids as many of these can be loaned or provided for free.

If you tend to wake up in the morning feeling very fatigued and light headed, or are suffering from headaches on waking and excessive drowsiness during the day, discuss these symptoms with your doctor promptly as you may not be breathing well enough in the night.

Getting to Sleep and Positional Problems

Some people with MND have difficulty moving and get very uncomfortable lying in the same position for several hours. There are special beds which help an immobile person sleep.

A satin or silk bottom sheet and nightwear helps turning. Getting to sleep can also be problematic for some people. Talk to your doctor about relaxation exercises or medication you could use to try to get to sleep.

Use of Alcohol and Medication

If you are taking any medications, be very careful about drinking alcohol. The combination of alcohol and many medications can cause serious problems.

Excessive Emotional Outbursts

Uncontrollable emotions such as excessive laughing or crying may be experienced by some people with MND. This is called emotional lability and can be particularly frustrating because the outburst is often caused by something very trivial and may be misunderstood by other people. This symptom usually catches people by surprise when it first happens; however, over time, many learn how to modify these emotional outbreaks and how to avoid some of the situations in which they occur. If this is happening to you, talk to your doctor about

medications that may help control this problem.

Cognitive and Behavioural Changes

Until fairly recently, it was assumed that MND did not affect thinking. However, researchers have found that changes in the way one thinks, perceives, and processes information (cognition), and behaves can occur in some patients with MND and sometimes early in the disease before an MND diagnosis has been made. This is not to say these changes will occur in all persons with MND and the exact nature of the changes can vary from person to person. You and your family can better identify any such changes and discuss effective management strategies with your MND care team member.

If you know about them proper management may lessen the impact of cognitive and behavioural changes on daily living and coping with MND. The following may indicate changes in thinking:

- Reduced reasoning, insight, and problem-solving ability
- Reduced word recognition and word choice.

Some of the following symptoms of personality and behavioural changes may be experienced:

- Apathy
- Loss of inhibition
- Restlessness or overactivity
- Social inappropriateness
- Mood swings
- Compulsive rituals such as repeatedly dressing, using the bathroom, eating, hoarding, etc.

For more information about cognitive,

personality, or behavioural changes in MND, consult with an MND Care Team Specialist.

Mobility

Experience over many years has shown that it is to the advantage of someone with MND to stay as mobile and supple as possible. Despite attempts to this effect mobility can be affected by some of the following topics.

Joint and Muscle Pain

People with MND who lose significant muscle function in areas that involve joints may end up not using those joints to their full capacity. Lack of use can cause stiffness and joint pain. Range-of-motion exercises are designed to prevent these joint problems. Careful attention to your exercise regime, whether active (doing it yourself) or passive (with assistance), will eliminate much potential joint pain. However, there are still a number of common pains that can develop. If your arms are weak and you allow them to hang unsupported from the shoulder, there is a tendency for the shoulder joint to become painful. It is helpful to support weak arms whenever possible on pillows, armrests or on a table. A shoulder sling may also give the arm some support and decrease strain on the shoulder joint while you are walking. Hip pain can result from prolonged sitting in a sagging seat or chair. Speak to an Occupational Therapist or Physiotherapist for advice on how best to deal with this.

Leg and Foot Swelling

If your lower limb mobility is reduced, you may experience mild leg and foot swelling, which is best reduced by moving the toes and ankle, if possible, and by elevating the leg and/or using an elastic stocking. Talk to your GP or MND Care Team Specialist about how best to

address this problem.

Muscle Cramping

Cramps are not uncommon in people with MND. They can be alleviated to some extent by keeping the affected muscle warm and by stretching and massaging. Severe or frequent cramps should be discussed with your doctor. There are a number of medications available to reduce cramping.

Changes to Posture

If the muscles that maintain your upward posture weaken, you may have discomfort in your lower back, neck and shoulder blade region. Special cushions, chair backs, lower back and neck supports are available to help you to maintain correct sitting posture. Your occupational therapist can assist you in choosing the right support.

Difficulty Walking

Weakening of leg and ankle muscles along with unexpected fatigue, can cause tripping and falling to become problems. If these problems occur you should contact your Physiotherapist or OT who might recommend using splint devices that provide added support to weakened muscles, or a stick, walker or stroller as soon as you experience unexpected falls. Some people are self-conscious about having to use walking aids, or see it as an announcement that their condition is worsening. These are completely normal reactions. However, you must also think about preventing injuries that will inhibit your independence further, or cause serious harm to you such as a head injury.

Difficulty Gripping and Holding

Some people with MND lose strength in the hand and wrist muscles, losing the ability to manage small hand movements such as holding a pen to write, or cutlery to eat, turning a key to start a car, or

turning a handle to open a door. There are a variety of products designed to assist you with weakened grip strength. For example, some tubular foam around the handles of cutlery can “thicken” them up to make them graspable in a hand that can no longer close fully. See factsheet 5A Assistive Equipment for further suggestions.

Speaking and Swallowing

For those who do lose their ability to speak, there is now a wide range of communication aids available from low-cost low-tech to very high cost high-tech. Suggested strategies vary from using signalling systems and “Magic Slates” to eye-gaze controlled computers. See factsheet 30, “Communication Strategies” for further information.

Swallowing difficulties can arise from several different causes. Weakened jaw muscles can cause problems when food is not properly chewed and too lumpy to be swallowed easily. Loss of reflexes can cause food to stick in the throat while “on the way down” and can also prevent the muscular flap, called the epiglottis, from covering the wind-pipe during swallowing, so allowing food or liquid to enter causing choking.

Although it can be very distressing, choking is common in people with MND and is a manageable symptom of swallowing difficulties. If choking becomes a problem it should be mentioned to your health care team as there are things you can do regarding how you eat and what you eat that can lower the risk of getting food stuck in your throat.

Difficulties with swallowing are discussed in factsheet 34 “Adapting to Swallowing Problems.”

Build-up of Saliva and Drooling

People with Bulbar MND often develop an excessive drooling problem as they have difficulty swallowing the normal production of saliva. Sometimes an increase in the actual production of saliva may occur as a side-effect of tube feeding diets. Your doctor can offer various medications to limit saliva production to reduce this problem. More specific advice is also given in the parts of this manual dealing with the following topics, Adapting to Swallowing Problems and Maintaining Good Nutrition, Maintaining Oral Health and Adapting to Changes in Speech and Maintaining Communication.

Excessive Saliva and Mucus

Should muscles involved in breathing (diaphragm) and coughing (abdominal and intercostal muscles) weaken, it can become difficult to cough up mucus. If you are having this problem, see your doctor or MND Care Team Specialist as soon as possible. There are several “assisted coughing” techniques for freeing mucus from the throat and lungs that can be taught.

A small suction unit can help remove saliva from the mouth and prevent it from flowing back into the lungs.

Coughing

People with MND may develop weak coughs due to breathing muscle weakness which makes it difficult to effectively clear airways that may be blocked. Talk to your doctor or physiotherapist about techniques to produce an effective cough. See Factsheet 35 “Breathing Matters”.

Sexual Concerns

Sexuality and intimacy are basic aspects of human life. Sexual desires and abilities may not be affected by the

Factsheet 33 Managing MND

disease process, except for the physical limitations imposed by physical discomfort, muscle weakness, fatigue or low energy levels, or medication side-effects. A person with MND may worry about not being able to please a healthy partner. For men, anxiety may cause erectile dysfunction. Other factors that may contribute to unsatisfactory sexual relations are:

- Adjustment to assistive devices or support systems
- Dealing with everyday survival
- Negative self-image
- Reduced independence with self-grooming
- Reduced communication ability
- Limited mobility
- Changes in physical appearance
- Altered role
- Emotional state
- Functional level

You and your partner may want counselling with an empathetic professional to openly deal with mutual concerns and expectations. If you are both willing, you could explore different sexual techniques, role flexibility, and alternative methods of sexual expression. The following suggestions may prove helpful in dealing with sexual concerns:

- Using techniques, assistive devices, and positioning to

accommodate increasing muscle weakness and other symptoms of MND

- Identifying techniques and assistive devices that enable you to maintain good grooming and personal cleanliness
- Maintaining communication (the open expression of affection and need is important.)
- Respecting the boundaries of the other partner
- Altering the living environment to provide adequate privacy and reduce embarrassment
- Scheduling of "adult time" if there are young children in the family
- Wearing street clothes rather than night attire whenever possible during the day to emphasise normality and reduce playing the sick role
- Re-focusing interests and energies into other areas

Partners should realise that touching is as important as sexual performance in reducing tension and maintaining emotional intimacy. Preservation of personal integrity should be an overriding concern. If you have any questions or concerns, speak with your doctor and request a referral to a sexual health clinician in your area.

Further Information:

Factsheet 5A	Assistive Equipment
Factsheet 6	Feeding Tubes
Factsheet 27	Coping with MND
Factsheet 34	Adapting to Swallowing Problems
Factsheet 35	Breathing Matters
Factsheet 36	Oral Health