



Motor neurone disease: Information for dental teams

Motor neurone disease (MND) is a fatal, rapidly progressing disease that results in degeneration of the motor neurones, or nerves, in the brain and spinal cord.¹ Over time, this leads to weakness and wasting of muscles causing increasing loss of mobility in the limbs, and difficulties with speech, swallowing and breathing.¹

MND kills a third of people within a year and more than half within two years of diagnosis.² Up to half of all people with MND experience changes in thinking and behaviour, with a proportion experiencing frontotemporal dementia.¹

Although MND does not directly affect oral health, the progressive nature of the disease can make mouth care challenging. Knowledge and understanding of MND, its potential symptoms and other aspects of the condition are essential when planning for someone's dental care and any adjustments required³ and can also help to reassure the person when attending dental appointments.⁴

This information sheet is for the dental team, including dentists, hygienists, therapists, clinical dental technicians and nurses. It gives an overview of potential issues people with MND face with oral health and access to dental services, and suggestions to help support people with the condition.

Information for people affected by MND

Information sheet 11B - *Mouth care*

Includes practical suggestions for people with MND and carers to continue effective oral care at home.

Information for professionals

We have a wide range of publications on MND for health and social care professionals, including detailed information on the symptoms mentioned in this information sheet.

Publications can be downloaded from www.mndassociation.org/publications or contact our MND Connect helpline to order hard copies. The team can also help with any queries you may have about supporting someone with MND. Call 0808 802 6262 or email mndconnect@mndassociation.org

MND and oral health

Although MND does not directly affect the teeth and gums, the progressive physical disabilities can lead to poor oral health and a higher rate of extraction.⁵ This is largely due to impaired mobility compromising access to dental services, which in turn affects the ability to receive preventive care, advice and treatment. People with MND therefore have a higher need for emergency care, usually due to acute pain.

Management of oral health is an essential component of maintaining general health and comfort and has a bearing on quality of life.⁶

Providing preventive care at an early stage of the disease to minimise the risk of gum disease and tooth decay may help the person with MND to⁶:

- communicate and eat orally for as long as possible
- remain free of pain and discomfort from the mouth
- maintain social contact
- maintain dignity and self-esteem
- reduce the risk of aspiration pneumonia.⁷

Medical care for people with MND should be coordinated, involving a specialist MND multidisciplinary team.¹ This should ideally include a dental professional to establish an oral health care plan. Liaising with the person with MND, their family, carers and health and social care team will help achieve the appropriate preventive care and treatment plan for a person’s needs. It can also help to ensure care can be carried out effectively, both in the surgery and at home.^{8,9,10}

Treatment modifications and considerations

In the early stages of MND, preventative oral care, advice and treatment can be provided at a general dental practice. As the disease progresses, referral to local community dental services or special care dental services may become necessary. Local NHS clinical commissioning groups or GPs should be able to signpost to the nearest service.

Although guidelines on dental management of people with MND are limited, the tables below outline the possible modifications and adjustments to consider when treating a person with MND.

Muscle weakness and reduced mobility

MND involves weakness and wasting of muscles. Loss of upper limb motor function will make brushing the teeth and other mouth care activities challenging. Someone with MND may be reliant on a family or professional carer for personal care, relying on their knowledge and skill in maintaining oral hygiene.⁵

Fatigue is prevalent in MND and can have a huge impact on quality of life. There is no effective drug treatment for fatigue, so management is focused on energy conservation.¹² As MND progresses and muscles weaken, getting around becomes more difficult. Some people with MND will use walking aids and most will eventually need to use a wheelchair.¹¹

Issue	Modifications/consideration
Access to the surgery	<ul style="list-style-type: none"> • offer flexible appointments to ensure appropriate support is available from family or professional carers to accompany the person with MND • scheduling appointment for a ground floor treatment room supporting wheelchair access • compile and share information about local transport systems that are accessible to people with mobility problems⁵ • ensure the surgery building is accessible and allow sufficient space to manoeuvre large powered wheelchairs • ideally, the surgery should be arranged so the wheelchair can be brought alongside the dental chair for transfer - this arrangement will also allow treatment to take place in the person’s wheelchair, using an appropriate headrest if needed • offer a domiciliary dental service⁹ - refer them to the specialist community or domiciliary dental team if needed.

Issue	Modifications/consideration
Access to the dental chair	<ul style="list-style-type: none"> • do not lie a person with MND flat¹³ • allow enough time to get the person in the preferred position. <p>For people who still have some independent movement:</p> <ul style="list-style-type: none"> • use assistive equipment such as a turntable or transfer/banana board • use a break-leg design dental chair • adjust the height of the dental chair to the wheelchair to help the patient transfer. <p>For people who cannot move independently:</p> <ul style="list-style-type: none"> • use a hoist to transfer the person from wheelchair to dental chair • position the wheelchair on a portable or fixed wheelchair recliner • use a tilt-in-space mechanism on their powered wheelchair and a specialist head rest.
Fatigue	<ul style="list-style-type: none"> • ask whether the person prefers more frequent, shorter appointments, or longer appointments to avoid repeated travel • allow time for frequent breaks during appointments • use a bite block to keep the mouth open.
Difficulty managing mouth care at home	<ul style="list-style-type: none"> • highlight importance of daily oral hygiene to the person with MND and their carers • offer training and advice to the person providing oral care • share information sheet 11B - <i>Mouth care</i> which includes practical suggestions for people with MND and carers to continue effective oral care. See page 1 for order information.

Bulbar weakness

Bulbar weakness, affecting the muscles of the tongue, jaw and throat, is common in MND. This can lead to dysphagia, oromotor dysfunction, pooling of saliva and aspiration.^{3,4}

Oral health has been shown to be poorer in those with dysphagia.¹⁴ People may avoid oral hygiene for fear of aspirating toothpaste or mouthwash, which can lead to perioral infections.⁴

A weak, inefficient swallow due to bulbar weakness can lead to:

- saliva pooling in the mouth and drooling
- stagnant food debris remaining in the oral cavity, contributing to periodontal disease.

Although MND does not affect the amount of saliva produced, excess saliva is a commonly reported symptom of MND. In most cases, saliva problems are the result of increasing weakness of muscles in the mouth, tongue and throat. This can make it difficult to manage saliva, both in the mouth and during swallowing.

Some people with MND will experience xerostomia (dry mouth) caused by mouth breathing, dehydration or medications.

Issue	Modifications/consideration
Limited mouth opening	<ul style="list-style-type: none"> • use of a mouth prop or bite block. Alternatively, a toothbrush handle between the teeth on the opposite side can help prevent closure when the muscles become tired • fitting of prosthetic mouth opener • a finger guard can protect fingers from being inadvertently bitten.
Brisk gag reflex	<ul style="list-style-type: none"> • minimise contact with soft palate and the back end of the hard palate • gentle introduction of dental instruments into the mouth.
Tongue or cheek biting	<ul style="list-style-type: none"> • provision of a soft mouth guard • use a mouth prop or bite block to keep the mouth open – this may also be useful for mouth care at home • silicone positioners and prostheses have been used in some cases^{15,16} • the above suggestions can also be helpful if the person experiences excessive yawning.
Dysphagia	<ul style="list-style-type: none"> • reassure the person with MND, as they may feel anxious about drooling or choking • upright or semi-reclined position • high speed oral suction available at all times • keep treatments simple and use minimal amount of instrumentation • avoid anaesthesia, such as inferior nerve blocks. Consider using intrapapillary injections if local anaesthesia is needed. Use of single tooth anaesthesia as an option as this technique only affects the tooth being treated • liaise with the person's dietitian about nutrition, as high calorie diets are often recommended to people with MND.
Excessive saliva	<ul style="list-style-type: none"> • ensure oral suction is available at all times • keep the person in an upright or semi-reclined treatment position.
Dry Mouth	<ul style="list-style-type: none"> • consider artificial saliva sprays or gels and prescription only higher fluoride toothpaste • ensure instruments are moistened before placing in the mouth • ensure oral suction is available if the person is not able to spit.
Tube feeding	<ul style="list-style-type: none"> • highlight that mouth care is very important, possibly even more so if the person is not eating and drinking by mouth.¹⁷ Feeding tubes will also need to be cleaned regularly, as directed by the person's MND care team.

Respiratory problems

Most people with MND are affected by respiratory problems during the course of the disease, caused by weakness of the diaphragm and accessory muscles used for breathing. This may lead to symptoms including breathlessness, poor sleep or daytime fatigue.¹ Bulbar muscle weakness contributes to respiratory complications, with weak cough and increased risk of aspiration.¹⁸

Some people with respiratory impairment will use assisted ventilation: most often, this will be non-invasive ventilation (NIV), either using a mask or nasal cushion, or alternatively invasive ventilation via tracheostomy.¹⁸ Assisted ventilation may affect oral hygiene and be a barrier to effective mouth care.

Issue	Modifications/consideration
Respiratory problems	<ul style="list-style-type: none"> • an upright or semi-reclined position, with the head turned slightly to one side, may help prevent feelings of breathlessness • avoid general anaesthetic, sedation or oxygen • upright or semi reclined treatment position • refer to specialist services, if appropriate.
Aspiration	<ul style="list-style-type: none"> • an upright or semi-reclined position during treatment may help to prevent aspiration of saliva or dental debris • oral suction should be used at all times during dental treatment.
Oxygen	<ul style="list-style-type: none"> • oxygen therapy should not be routinely used with people with MND.¹⁹ Supplementary oxygen therapy can have a serious detrimental effect on people with neuromuscular weakness and must only ever be used with great caution • supplemental oxygen should only be used under the guidance of a specialist neurologist, respiratory or palliative care consultant, with careful arterial blood gas monitoring.
Use of sedatives	<ul style="list-style-type: none"> • note that people with MND retain sensation, including perception of pain²⁰ • Any sedation of a person with MND must take place in an appropriate setting under the guidance of an anaesthetist and with respiratory support. Consultation with the person's neurologist and a consultant anaesthetist may help decide the most appropriate course of action.⁷

Cognitive change and dementia

Up to half of all people with MND experience some degree of cognitive or behavioural change. A small proportion will be diagnosed with frontotemporal dementia. These changes may manifest as problems responding to new situations, making plans and decisions, and using language.²¹

Oral health can be compromised by the severity of cognitive, social and behavioural impairment.⁶ These changes may affect the ability to:

- comply with dental care
- follow instructions
- carry out oral hygiene tasks
- request care or treatment
- make informed decisions
- give valid consent for treatment.

Behaviour changes may result from hidden problems with oral health as the person may be unable to express difficulties they are having. Pain may be expressed through aggression, restlessness, problems sleeping and refusal to eat.

Issue	Modifications/consideration
Cognitive change	<ul style="list-style-type: none"> liaise with family and carers to establish how the person's cognition is affected and plan appropriate treatment.
Consent	<ul style="list-style-type: none"> gain consent before examination or treatment, either from the person with MND or a person legally assigned to give consent bear in mind that a written signature is not required as long as the verbal consent is witnessed appropriately and properly documented liaise with MND specialist team for advice and support.

Speech and communication difficulties

Bulbar weakness and reduced breath support for speech can lead to communication difficulties for many people with MND. Some people will use strategies and devices to help them communicate, known as alternative and augmentative communication (AAC).¹ This could be as simple as a pen and paper or may include high-tech computerised systems.

Issue	Modifications/consideration
Communication difficulties	<ul style="list-style-type: none"> find out how the person prefers to communicate, and any equipment they like to use be patient, as communication can take time avoid interrupting or finishing the person's sentences unless they ask you to find out whether the person uses a simple code for yes and no - this may be a movement of any part of the body that can be carried out reliably, such as eye blinking try to ask closed questions that require a yes/no or single word answer ensure the person with MND is the focus of the communication - face them and avoid any distractions check back that the person has understood and check on what you think has been said admit when you do not understand, rather than pretending you do try not to alter the rate or sound of your speech unless the person with MND has asked you to allow the person to correspond with the dental surgery by letter, email or text. They may prefer to send any questions or concerns in advance, so they can be addressed during the appointment.

References

- 1 National Institute for Health and Care Excellence (NICE). *Motor neurone disease: assessment and management*. Clinical guideline NG42. February 2016.
- 2 SEALS Registry (for background information see Abhinav K et al. *Amyotrophic lateral sclerosis in South-East England: a population-based study. The South-East England register for amyotrophic lateral sclerosis (SEALS Registry)*. *Neuroepidemiology*. 2007; 29:44-8).
- 3 Parsons KM and Schneider AJ. *Clinical Considerations for Treating the Dental Patient with ALS*. RDH 2014.
- 4 Asher RS and Alfred T. *Dental management of long-term amyotrophic lateral sclerosis: case report*. *Special Care Dentistry*. 1993; 13(6):241-4.

- 5 British Society for Disability and Oral Health. *Guidelines for Oral Health Care for People with a Physical Disability*. 2000.
- 6 Fiske J et al. *Guidelines for the development of local standards of oral health care for people with dementia*. *Gerodontology* 2006; 23 (Suppl 1): 5-32.
- 7 Koichiro UEDA. *Preventing Aspiration Pneumonia by Oral Health Care*. 2011; *Japan Medical Association Journal* 54(1): 39–43.
- 8 Steifel D. *Dental Care Considerations for Disabled Adults*. *Special Care Dentistry*. 2002; 22(3):265-395.
- 9 Dougall A and Fiske J. *Access to special care dentistry, part 1*. *British Dental Journal*. 2008; 204:605–616.
- 10 Tay CM, Howe J and Borromeo GI. *Oral health and dental treatment needs of people with motor neurone disease*. *Australian Dental Journal*. 2014; 59(3):309-13.
- 11 Trail M et al. *Wheelchair use by patients with amyotrophic lateral sclerosis: a survey of user characteristics and selection preferences*. *Archives of Physical Medicine and Rehabilitation*. 2001; 82(1):98-102.
- 12 Abraham A and Drory VE. *Fatigue in motor neuron diseases*. *Neuromuscular Disorders*. 2012; 22:S198-S202.
- 13 Austin S et al. *Dental treatment for a patient with motor neurone disease completed under total intravenous anaesthesia: a case report*. *Journal of Disability and Oral Health*. 2011; 12(3):124-127.
- 14 Ortega O et al. *Oral health in older patients with oropharyngeal dysphagia*. *Age and Ageing*. 2014; 43(1):132-7.
- 15 Rover BC and Morgano SM. *Prevention of self-inflicted trauma: dental intervention to prevent chronic lip chewing by a patient with a diagnosis of progressive bulbar palsy*. *Special Care Dentistry*. 1988 Jan-Feb;8(1):37-9.
- 16 Yavnai N and Aizenbud D. *Orthodontic silicone positioner for the treatment of oral symptoms in Amyotrophic Lateral Sclerosis (ALS) patients*. *Refuat Hapeh Vehashinayim*. (1993). 2013; 30(3):22-9, 61.
- 17 Takeshita, Toru et al. *Enteral Tube Feeding Alters the Oral Indigenous Microbiota in Elderly Adults*. *Applied and Environmental Microbiology* 77.19 (2011)
- 18 Raiq MK et al. *Respiratory management of motor neurone disease: a review of current practice and new developments*. *Practical Neurology*. 2012;12(3):166-76.
- 19 Bott J et al. *Guidelines for the physiotherapy management of the adult, medical, spontaneously breathing patient*. *Thorax*. 2009; 64(Suppl)ii1-i51.
- 20 Brettschneider J, Kurent J and Ludolph A. *Drug therapy for pain in amyotrophic lateral sclerosis or motor neuron disease*. *Cochrane Database of Systematic Reviews*. 2013 Jun 5; 6.
- 21 Goldstein LH and Abrahams S. *Changes in cognition and behaviour in amyotrophic lateral sclerosis: nature of impairment and implications for assessment*. *Lancet Neurology*. 2013; 12(4):368-80.

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How we can support you and your team

MND Connect

Our helpline offers help, information and support, and signposting to people living with MND, carers, family and health and social care professionals.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

Information resources

We produce high quality information resources for people living with MND, carers, family members and health and social care professionals.

www.mndassociation.org/publications

MND Association website

We have a wide range of information to support health and social care professionals working with people affected by MND.

www.mndassociation.org/professionals

Education

Our education programme is designed to improve standards of care and quality of life for people living with and affected by MND. Opportunities include online modules and face-to-face training.

www.mndassociation.org/education

Support grants and equipment loan

Where statutory provision is not available, we may be able to offer a support grant or loan equipment.

www.mndassociation.org/getting-support

Research into MND

We fund and promote research that leads to new understanding and treatment and brings us closer to a cure.

www.mndassociation.org/research

MND register

The MND Register of England, Wales and Northern Ireland aims to collect information about every person living with MND to help plan the care and discover more about the cause of the disease.

www.mndregister.ac.uk

Regional staff

We have a network of regional staff with specialist knowledge of MND. They work closely with local statutory services and community care providers. Contact MND Connect for further information.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

MND care centres and networks

We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist multidisciplinary care for people with MND.

www.mndassociation.org/care-centres

Branches and groups

We have volunteer-led branches and groups nationwide providing local support and practical help to people with MND and their carers.

www.mndassociation.org/branchesandgroups

Association visitors (AVs)

AVs are trained volunteers who provide one-to-one local support to people affected by MND. They can support people affected by MND in person, by telephone or by email or through support groups.

www.mndassociation.org/associationvisitors

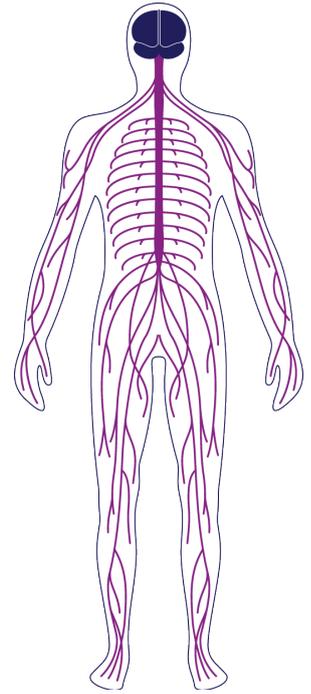
We value your feedback

Your feedback helps improve our information for the benefit of people living with MND and those who care for them. Visit www.smartsurvey.co.uk/s/mndprofessionals or email your comments to infofeedback@mndassociation.org

If you would like to help us by reviewing future versions of our information resources, please email us at infofeedback@mndassociation.org

About MND

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work. MND does not usually affect sight, hearing or sensation.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- It affects people from all communities.
- Some people may experience changes in thinking and behaviour, with some experiencing a rare form of dementia.
- MND kills a third of people within a year and more than half within two years of diagnosis.
- A person's lifetime risk of developing MND is up to 1 in 300.
- Six people per day are diagnosed with MND in the UK.
- MND kills six people per day in the UK.
- It has no cure.



Would you like to find out more?

Contact our helpline if you have any questions about MND or want more information about anything in this publication.

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www.mndassociation.org/professionals