MND Association | For professionals

P12

Motor Neurone Disease: information for dental teams

Motor neurone disease (MND) results from the progressive loss of motor neurones in the brain and spinal cord. These are the nerve cells that control movement. It leads to muscle weakness and can cause difficulties with movement, breathing, swallowing and speaking.[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. Understanding the potential issues that someone with MND may face with oral health and access to dental services is essential for planning and adjusting dental care.[3] It also helps 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 covers:

1. **MND and oral health**
2. **Treatment modifications and considerations**

Information to share with people with or affected by MND:

Booklet — Personal care for people with MND or Kennedy's disease, and their carers

Information for professionals:

Information sheet P3 — Managing saliva problems in MND
Information sheet P6 — Evaluation and management of respiratory symptoms in MND
Information sheet P8 — Dysphagia in MND
Information sheet P9 — Oral suction
Booklet — Cognitive change, frontotemporal dementia and MND
Booklet — Caring for a person with MND: a guide for care workers

See page 12 to order publications.

1. MND and oral health

MND affects the teeth and gums indirectly by affecting the person's ability to maintain dental hygiene due to the progressive disabilities. These can lead to poor oral health and gum disease, with decay resulting in a higher rate of tooth extraction.[5] This is compounded by the impaired mobility resulting in compromised access to dental services. People with MND may therefore have a higher need for emergency care, usually due to acute pain.

Management of oral health has been shown to influence general health, and it's essential to maintain general health and comfort both generally and orally. Poor oral health can adversely affect a person and has a bearing on quality of life.[6] Preventive care to minimise the risk of oral health problems, such as gum disease and tooth decay, may help the person with MND to:[6]

- communicate and express themselves more easily
- eat orally for as long as possible
- remain free of pain and discomfort from the mouth
- maintain social contact, dignity, confidence and self-esteem
- reduce the risk of aspiration pneumonia.[7]

Medical care for people with MND should be co-ordinated, involving a specialist MND multidisciplinary team.[1] This should ideally include a dental professional to establish an oral health care plan. If this is not possible, liaise with the person's MND nurse who can support you to develop a suitable treatment 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 ensure care can be carried out quickly and effectively, both in the surgery and at home.[8,9,10]

2. 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 Integrated Care Boards (ICBs) in England, Health Boards in Wales, Local Commissioning Group (LCGs) in Northern Ireland, or the person's doctor should be able to signpost to the nearest service.

Guidelines on dental management of people with MND are limited. In this section, we have included an overview of how MND symptoms may affect oral health management. For each symptom, there is also a table outlining possible modifications and adjustments that should be considered 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/considerations
Access to the surgery	— Offer flexible appointments to ensure appropriate support is available from family or professional carers to accompany the person with MND. — Schedule treatments in a ground floor room supporting wheelchair access, or ensure there's a lift to other floors. — Compile and share information about local transport systems that are accessible to people with mobility problems.[5] — 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 service – refer the person to the specialist community or domiciliary dental team if needed.[9]

Issue	Modifications/considerations
Access to the dental chair	— Do not lie a person with MND flat.[13] — Allow enough time to get the person in the preferred position. **For people who still have some independent movement:** — 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. **For people who cannot move independently:** — Use a hoist to transfer the person from the wheelchair to the 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	— 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	— Highlight the importance of daily oral hygiene to the person with MND and their carers. — Offer training and advice to the person providing oral care, including on the use of aids such as water flossers (for example, Waterpik). Ensure the person is able to effectively close their airway to prevent accidental inhalation of fluids before using/recommending water flossers. Care should be taken to avoid aspiration by tilting the person's head forward and spraying away from the throat, or using an aspirator. The flosser can be used in short bursts, allowing the mouth to drain in-between. — Share our booklet for people with MND and carers on personal care which includes practical suggestions to continue effective oral care. See page 12 to 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 peri-oral 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/considerations
Limited mouth opening	— Use 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. — Fit a prosthetic mouth opener. — Use a finger guard to protect fingers from being inadvertently bitten.
Brisk gag reflex	— Minimise contact with soft palate and the back of the hard palate. — Be gentle when introducing dental instruments into the mouth.
Tongue or cheek biting	— Provide a custom-made 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. — Consider using silicone positioners and prostheses. [15,16] Note that the above suggestions can also be helpful if the person experiences excessive yawning.

Issue	Modifications/considerations
Dysphagia	— Reassure the person with MND, as they may feel anxious about drooling or choking. — Keep the person in an upright or semi-reclined position. — Ensure high speed oral suction is available at all times. — Keep treatments simple and use minimal amount of instrumentation. — Avoid regional anaesthesia, such as inferior nerve blocks. Consider using buccal infiltration, intrapapillary injections or an intraligamentary injection if local anaesthesia is needed. Use of single tooth anaesthesia is ideal, as this technique only affects the tooth being treated and no regional numbness occurs. — Liaise with the person's dietitian about nutrition, as high calorie diets are often recommended to people with MND and some supplements contain high levels of sugar.
Excessive saliva	— Ensure oral suction is available at all times. — Keep the person in an upright or semi-reclined treatment position.
Dry mouth	— 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	— 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/considerations
Respiratory problems	— Placing the person in an upright or semi-reclined position during treatments, with the head turned slightly to one side, may help prevent feelings of breathlessness. — Avoid general anaesthetic, sedation or oxygen. — Refer to specialist services, if appropriate.
Aspiration	— Placing the person in an upright or semi-reclined position during treatment may help prevent aspiration of saliva or dental debris. — Oral suction should be used at all times during treatment.
Oxygen	— 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	— Note that people with MND retain sensation, including perception of pain.[20] — Sedation of a person with MND must take place in a hospital 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 and carry out oral hygiene tasks
- request care or treatment
- make informed decisions
- give valid consent for treatment.

Behavioural 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/considerations
Cognitive change	— Liaise with family and carers to establish how the person's cognition is affected and plan appropriate treatment. — Ensure that family and carers are clear about the steps they may need to take to support oral health.
Consent	— 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 documented. — Liaise with MND specialist team for advice and support. — Consider a best interest meeting to agree a plan if the person cannot consent and there is no legally assigned person.

Emotional lability

Some people with MND experience emotional lability (also known as pseudobulbar affect), which can result in uncontrollable laughter or crying. There might be inappropriate responses at embarrassing times, for example laughing when upset or in pain. It is important to be mindful of this, and to double check the person is happy for you to continue with the examination or treatment if they laugh or cry unexpectedly.

It is important to reassure the person and their family this is a factor of MND, as some people find it easier to manage the impact when they understand the cause. The person's MND care team may be able to provide medication and strategies to help with this symptom.

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.

Tips for supporting people with MND with speech difficulties:

- Find out how the person prefers to communicate, and any equipment they 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, 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 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 questions or concerns in advance, so they can be addressed during the appointment.

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How we can support you and your team

Our MND Connect helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. They can also provide further information about our services mentioned below.
Email: **mndconnect@mndassociation.org**
Tel: **0808 8026262**

MND Association website

Our website offers supporting information on MND, our work, services, and how to get involved.
mndassociation.org/professionals

Stay updated on events, publications and opportunities for professionals.
mndassociation.org/educationupdate
X: **mndeducation**
Bluesky: **mndeducation.bsky.social**

Information resources

We produce high quality information for people with MND, carers, families and professionals, available in multiple formats and languages.
mndassociation.org/pro-info-finder
mndassociation.org/careinfofinder

Education

Our education programme aims to improve standards of care and quality of life. Opportunities include webinars and face to face equipment training.
mndassociation.org/education

MND Professionals' Community of Practice

A peer led group supporting cross disciplinary learning in MND care. Membership can contribute to CPD and offers access to networking and learning events.
mndassociation.org/cop

Local support

We offer online and local peer support, plus trained volunteers who provide practical help by phone, email or visits.
mndassociation.org/local-support

We fund and develop specialist care centres and networks across England, Wales and Northern Ireland, offering multidisciplinary care.
mndassociation.org/care-centres

Financial support

We offer a range of grants to support people living with MND, their families and unpaid carers. These are not in place of any statutory funding that should be available.
mndassociation.org/getting-support

MND register

The Register aims to collect information about everyone with MND in England, Wales and Northern Ireland to support care planning and research.
mndregister.ac.uk

Research into MND

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND. We also produce information sheets on MND research for people with or affected by MND.
mndassociation.org/research

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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 **smartsurvey.co.uk/s/mndprofessionals** or email your comments to education@mndassociation.org.

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

How to order our publications

Our publications are free for anyone with or affected by MND or Kennedy's disease, including professionals. Health and social care professionals can also order items on behalf of someone with or affected by MND or Kennedy's disease.

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**Every day we support people affected by Motor Neurone Disease.
Because with MND, every day matters.**