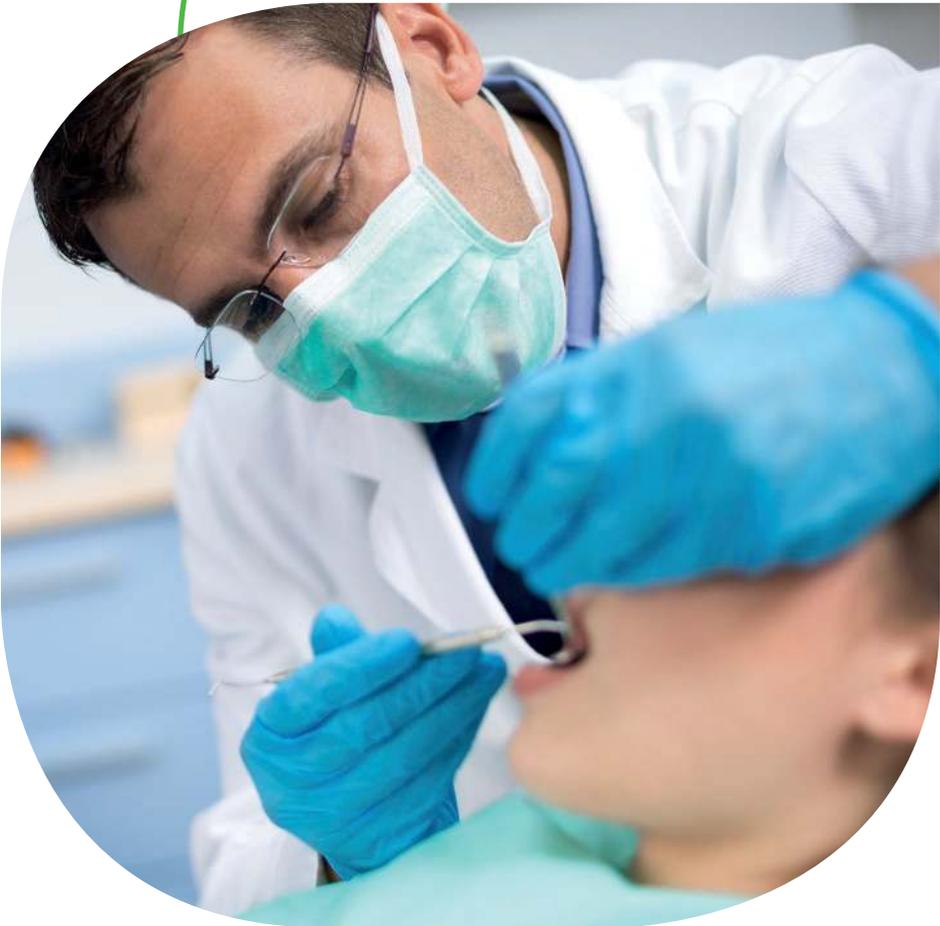


Motor neurone disease for dental professionals



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. This booklet is for dental professionals, 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.

Knowledge and understanding of MND, its potential symptoms and other aspects of the condition can help plan for someone's dental care and any adjustments required³, and can also help to reassure the person when attending dental appointments.⁴

Would you like to find out more?

You can contact our helpline MND Connect if you have any questions about MND or want more information about anything in this booklet.

Ordering other publications

The MND Association produce a wide range of publications for people with MND, their family and carers, and health and social care professionals. Visit www.mndassociation.org/publications or call our MND Connect helpline.

mndconnect
0808 802 6262
mndconnect@mndassociation.org

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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.⁵

MND symptoms can also affect oral health in specific ways.^{3,4,6}

Weakness of the arms and hands:

Can make it more difficult to carry out mouth care tasks, for example use of toothbrushes and handling of oral hygiene products, such as mouthwash.

Limited mobility:

Can be a barrier to accessing dental care and treatment. These patients may be unable to travel and many buildings are not easily accessible. Unless there is specialist provision, patients may not be able to transfer onto a dental chair.

Difficulty tolerating dental treatment due to discomfort and the time taken for restorative procedures is one of the main reasons for treatment often taking the form of tooth extractions.

Weakness in the tongue, mouth and throat:

Known as bulbar weakness, this can lead to dysphagia, problems with mouth opening, aspiration and communication³.

Saliva problems:

May include sialorrhoea due to dysphagia, thickened mucus, or dry mouth (xerostomia) resulting from mouth breathing or medication.³

Hyperactive gag reflex:

Due to nerve degeneration, which can make dental treatment difficult.

Diet and nutrition:

High calorie supplements recommended for weight maintenance may increase risk of tooth decay due to high sucrose content.⁸

Respiratory muscle weakness

Can lead to breathlessness (especially when lying flat) and contribute to weak cough with an increased risk of aspiration.⁹

Cognitive and behavioural problems:

May lead to lack of understanding of the importance of dental care. The compromised oral health can cause pain or discomfort, which may affect the person's behaviour.⁸

Fatigue:

Compromises attendance to appointments, self-care and prolonged mouth opening.^{10,11}

MND can affect a person's ability to perform oral care at home, and may compromise the delivery of dental care in professional settings if appropriate adjustments are not made.

People with MND need a personalised approach to dental and oral health care as the symptoms progress differently for each person and can change quickly.

The importance of good oral health in MND

Management of oral health is an essential component of maintaining general health and comfort, and has a bearing on quality of life.⁸

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 to⁸:

- 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.²⁵

Multidisciplinary team care

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 and treatment plan for a person's needs. It can also help to ensure care can be carried out both in the surgery and at home.^{6,10,11}

A specialist should be available to answer any queries about MND or the provision of specific care or treatment relevant to individual patients.¹ Ask the person with MND for details of the professional who coordinates their care.

Information to share

Living with MND - Our main guide about managing daily life with MND

Caring and MND - Support for you - Our main guide for family and unpaid carers

Information sheet *11B - Mouth care*

See page 2 for order details.

Summary of treatment modifications

General dental practitioners and dental therapists are able to provide preventive oral care and advice, including treatment in the early stages of MND.

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 table below outlines the possible modifications and adjustments needed to provide these patients with dental care.^{3,4,11}

Issue or symptom	Management
Muscle weakness/spasticity	<ul style="list-style-type: none">• adaptations and equipment for oral care at home (see page 28)• bite blocks to hold the mouth open• adapting surgery access• domiciliary visits or referral to specialist services (see page 12)• involve carers or careworkers in oral health education and preventive care
Problems with mouth opening	<ul style="list-style-type: none">• use of a mouth prop or bite block• fitting of prosthetic mouth opener
Problems with self-biting the tongue or cheeks	<ul style="list-style-type: none">• provision of a soft mouth guard

Issue or symptom	Management
Dysphagia	<ul style="list-style-type: none"> • avoid anaesthesia, such as inferior nerve blocks. Consider using intrapapillary injections if local anaesthesia is needed • upright or semi-reclined position • high speed oral suction available at all times • liaison with dietitian about nutrition
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
Dysarthria	<ul style="list-style-type: none"> • consider communication needs
Excessive saliva	<ul style="list-style-type: none"> • oral suction available at all times • upright or semi-reclined treatment position • toothbrush attachment for oral suction machine can help if the person is unable to spit
Respiratory problems	<ul style="list-style-type: none"> • avoid general anaesthetic, sedation or oxygen • upright or semireclined treatment position • referral to specialist services (see page 21)

Issue or symptom	Management
Cognitive change and dementia	<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 • liaise with MND specialist team for advice and support
Fatigue	<ul style="list-style-type: none"> • more frequent, shorter appointments, or longer appointments to avoid repeated travel – ask the person which they prefer • frequent breaks during appointments • a bite block to keep the mouth open
Advanced disease	<ul style="list-style-type: none"> • family carer or professional careworker to learn home oral care • domiciliary visits
Advance decisions	<ul style="list-style-type: none"> • People with MND may have recorded preferences for end of life care, which could include a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order or other advance decisions. Be aware of any advance decisions and action you would need to take in case of cardiac or respiratory arrest. <p>See also our booklet - <i>A professional's guide to end of life care in MND</i>. See page 2 for order information.</p>

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.⁵

The use of electric toothbrushes for cleaning and water jets may be of benefit to help optimise oral health.

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

- Involve caregivers in tooth brushing and cleaning.
- Highlight to carers the importance of daily oral hygiene regimes and cleaning to ensure continuity of oral care.¹¹
- Offer training and guidance to the person providing oral care.

See *Strategies for mouth care at home* on page 28.

Access

Access to the surgery

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.¹²

The ability to get to the dental surgery for appointments can depend on whether:

- they are able to get out of the house
- they are still able to drive or can be driven, and whether or not they can access an appropriate vehicle
- someone is available to accompany them, if required

- appointments are appropriately timed to consider travel needs
- the surgery premises are accessible to them and whatever walking aid or wheelchair they use – powered wheelchairs can be bulky.⁵

You can help overcome barriers to dental care by:

- offering flexible appointments to ensure appropriate support is available from family or professional carers to accompany the person with MND
- scheduling the appointment for a ground floor treatment room
- supporting wheelchair access
- offering a domiciliary dental service.¹⁰

Domiciliary care

If a person with MND is not able to access the dental surgery, domiciliary visits may be preferred.

A wide range of procedures can be carried out away from the dental surgery due to advances in portable equipment.¹⁰

Transportation

Guidelines outlined by the British Society for Disability and Oral Health recommend dental care providers minimise barriers to attendance by considering transport problems before arranging appointments.

They advise compiling information about local transport systems that are accessible to people with mobility problems.⁵

Referral to specialist services

If it is not possible for the person with MND to access a service, refer them to the specialist community or domiciliary dental team.

A community or hospital dental service may be best placed to offer specialised dental care if a person has respiratory problems.

Access to the dental chair¹⁰

If a person with MND uses a wheelchair, the following information may help to achieve correct positioning for dental examination.

Surgery environment:

- consider the space needed 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.

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 wheel chair to help the patient transfer.

For people who cannot move independently:

- 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 a powered wheelchair.

Time:

- time should be allowed to get the person in the preferred position for treatment.
- dental care for these patients should not be rushed.

Body positioning:

- modifications to positioning may limit treatment choices¹⁰ and length of appointments.



Do not lie a person with MND flat.

People with MND-related breathing problems may feel breathless and be at increased risk of aspiration when lying flat.⁷

An upright or semi-reclined position, with the head turned slightly to one side, may help prevent feelings of breathlessness. This position may also help to prevent aspiration of saliva or dental debris if the person is unable to cough or clear their throat due to weakened respiratory muscles.

Oral suction should be available at all times during examination and treatment.

If a person with MND has a powered wheelchair, it may have a tilt-in-space mechanism. If the person remains in their wheelchair during examination or treatment, it may be beneficial to use this mechanism.

Correct positioning is important when the person is on the examination chair, and also when they are transferring to and from the chair.

Dental surgery staff should receive training in moving and handling to help with safe transfers from a wheelchair to the dental chair, including safe use of assistive equipment such as a transfer or banana board, turntable or hoist.⁵

Information for you

Information sheet *P2 - Wheelchairs for people with MND*

Information to share

Information sheet *11C - Equipment and wheelchairs*

See page 2 for order details.

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}

Mouth opening

People with weak bulbar muscles or fatigue may not be able to move or hold their mouth in the required position for examination or treatment.

Use a mouth prop or bite block to keep the mouth open. Alternatively, a toothbrush handle between the teeth on the opposite side can help prevent closure when the muscles become tired. A finger guard can protect fingers from being inadvertently bitten.

Self-biting

Some people with bulbar muscle weakness are prone to accidental self-biting. Silicone positioners and prostheses have been used in some cases.^{17,24}

Use a mouth prop or bite block to keep the mouth open. This solution may be useful in the surgery, but also for mouth care at home.

Dysphagia

Oral health has been shown to be poorer in those with dysphagia.¹³ 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
- food debris remaining in the oral cavity, resulting in periodontal disease

- coughing and choking on food and liquids, including toothpaste, mouth wash and saliva
- inability to protect the airway, with increased risk of aspiration.^{3,13}

Information for you

Information sheet *P8 - Dysphagia in MND*

Information to share

Information sheet *7A - Swallowing difficulties*

Information sheet *11B - Mouth care*

See page 2 for order details.

Gag reflex

Impaired swallowing may be accompanied by problems with the gag reflex. The gag reflex may be brisk, and in some cases overactive due to muscle spasticity and nerve degeneration.⁷ People who are aware of their swallowing problem may become very sensitive to objects in their mouth.¹⁵ This can affect oral healthcare to an extent that treatment planning is compromised.¹⁰

Every attempt should be made to prevent activating the gag reflex. There is risk of aspiration on vomiting.

Aspiration

When a person has swallowing problems, aspiration is a real risk. Respiratory muscle weakness can result in reduced strength of cough, making it more difficult for a person to expel an obstruction, leading to feelings of choking.⁹ It is important to bear in mind that respiratory failure, usually with associated chest infection, is the usual cause of death in MND.⁹

Effective oral care will reduce respiratory infections resulting from inhalation of secondary colonising pathogens that grow when early dental plaque is not routinely removed.¹⁴ Long term poor oral hygiene increases the risk of aspiration pneumonia.

An upright or semi-reclined position during treatment may help to prevent aspiration of saliva or dental debris. Oral suction should be available at all times during dental treatment.

Communication

Bulbar weakness and reduced breath support for speech can lead to communication difficulties for people with MND. Some people will use strategies and devices to help them communicate, known as alternative and augmentative communication (AAC).¹

- Find out how the person prefers to communicate, and any equipment they like to use.
- Be patient, as communication can take time for people with MND. Avoid interrupting or finishing the person's sentences, unless they want 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 a 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.
- If a person with MND has problems with speech and uses a communication aid, they may find it useful to correspond with the dental surgery by email or text. They may prefer to email any questions or concerns in advance, so they can be addressed during the appointment.

Information to share

Information sheet *7C - Speech and communication support*

See page 2 for order details.

Saliva problems

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.

Reduced salivary flow can lead to rapid deterioration of oral health. Saliva provides protection in the mouth to prevent tooth decay and self-cleansing as it has a buffering capacity. In those with reduced salivary flow it is important to discuss the use of additional preventive measures such as daily fluoride mouth rinses, use of high fluoride toothpastes (prescription only) and more regular visits to the dentist.

The quality of saliva may vary from being thin and watery to thick and stringy. This will also be important in understanding how this could affect the mouth.

Patients with dysphagia may drool with saliva pooling at the corner of the mouth leading to infections (angular cheilitis). Drooling may also be related to poor lip seal or poor posture caused by lip and neck muscle weakness.

The NICE Guideline on MND recommends that oral health should be monitored when someone has problems with saliva.¹

Treatments are available to manage problems with saliva and dry mouth.¹⁶ Medication should be monitored to ensure it doesn't cause further problems and impact on oral health. Medication to reduce thin, runny saliva may lead to dry mouth, difficulty eating and the potential for cavities.^{8,11}

Some people may use a suction machine for clearance of saliva from the mouth. A toothbrush attachment is available to fit on suction machines. Oral suction should be available at all times during dental treatment.

The MND specialist team can advise on medicine management.

Dry mouth

Some people with MND will experience xerostomia (dry mouth) caused by mouth breathing, dehydration or some medications.⁶

Oral hygiene is especially important in these cases, as lack of saliva increases risk of caries, periodontal disease and other oral lesions.⁶ Artificial saliva sprays or gels and prescription only higher fluoride toothpaste may be used.

The person's healthcare team should also consider:

- checking and changing medication dosages, if needed
- ways to increase fluid intake, either orally or via feeding tube
- use of a room humidifier.

Halitosis

People with MND may be more vulnerable to halitosis because of problems maintaining oral hygiene or mouth breathing.¹¹ This symptom may affect quality of life. Management will be similar to those without MND, emphasising good hygiene practices.¹¹

High calorie diets

As MND leads to muscle wasting and dysphagia, food intake may be affected³. Many people with the condition are advised to consume a high calorie diet to maintain weight. This may include nutritional supplements containing sucrose.⁸ Liaise with the dietitian regarding nutritional advice and effects on intraoral tissue health.

Tube feeding

Some people with MND will receive most or all of their hydration and nutrition via a feeding tube. Although they may not realise it, oral hygiene may be even more important if a person is not receiving food or drink by mouth.¹⁸ A reduction in oral food and fluid intake can lead to dysfunction in the salivary glands through disuse.¹⁹ The consequence may be dry mouth – see page 20.

Information to share

Information sheet *7B - Tube feeding*

See page 2 for order details.

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.⁹

People with MND who have respiratory problems may feel breathless on lying flat, so appropriate positioning is critical.⁹

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.⁹

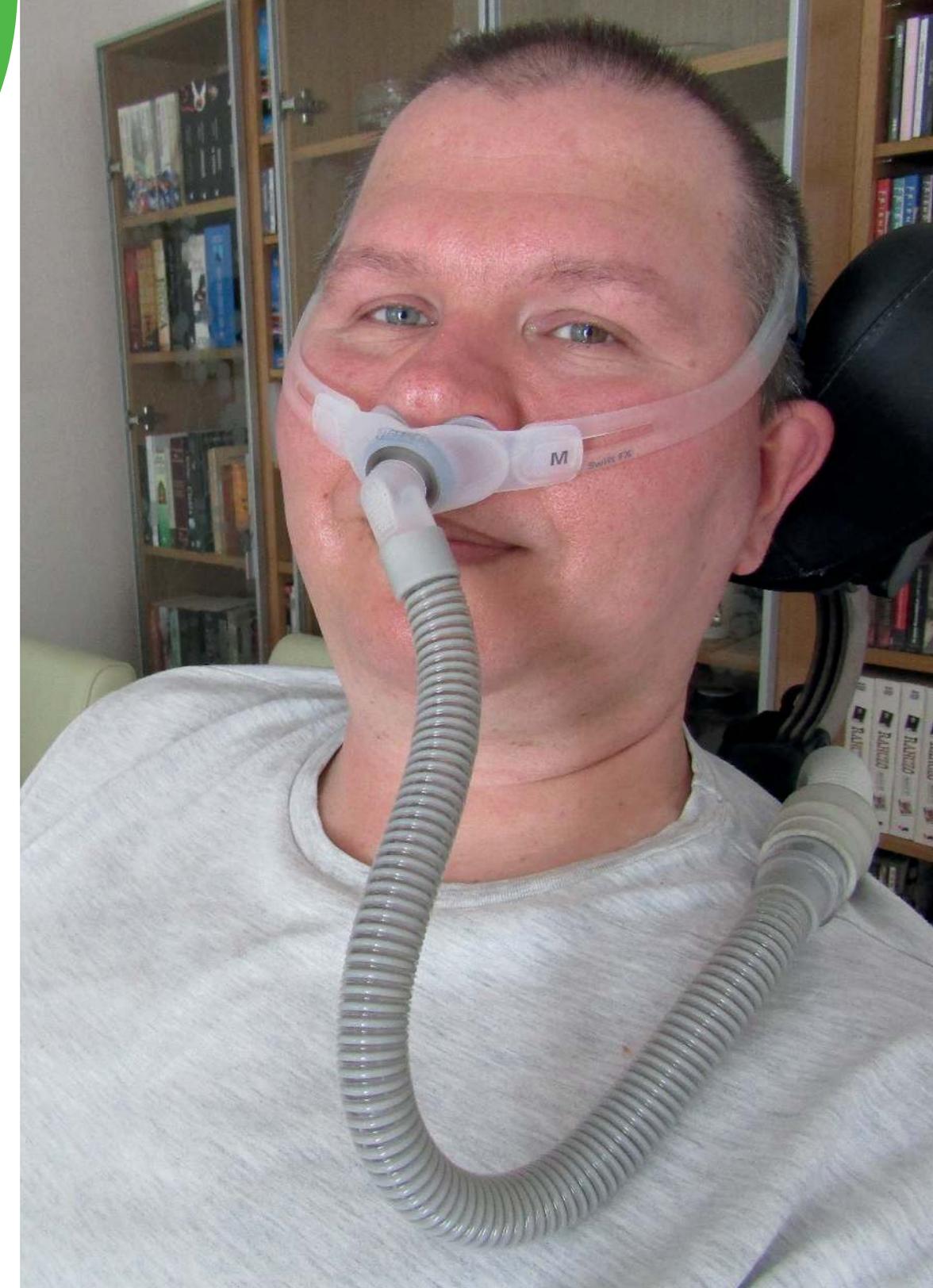
Both NIV and tracheostomy may affect oral hygiene and be a barrier to effective mouth care.

Oxygen

Oxygen therapy should not be routinely used with people with MND.²¹

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

Dental professionals should note that people with MND retain sensation, including perception of pain.²⁰

Primary care dentists should avoid use of general anaesthesia and sedatives including muscle relaxants for people with MND. They may exacerbate muscle weakness and precipitate respiratory depression.⁷

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 to decide the most appropriate course of action.⁷

Information for you

Information sheet *P6 - Evaluation and management of respiratory symptoms in MND*

Information to share

Information sheet *8A – Support for breathing problems*

Information sheet *8B – Ventilation for MND*

Information sheet *8D – Troubleshooting for non-invasive ventilation (NIV)*

Information sheet *8E – Air travel and ventilation for MND*

See page 2 for order details.

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.²²

Oral health can be compromised by the severity of cognitive, social and behavioural impairment.⁸ 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.

A person may be unable to express any difficulties they are having. Pain may be expressed through aggression, restlessness, problems sleeping and refusal to eat.

Behaviour changes may result from hidden problems with oral health.

Every effort should be made to gain consent from the person with MND before any treatment is carried out.

In some cases, someone else may be legally assigned to give consent using a Lasting Power of Attorney (England and Wales only).

Emotional lability

Some people with MND experience emotional lability, where they cry or laugh uncontrollably at inappropriate times. This is not necessarily a sign of cognitive change and can affect people who have no cognitive impairment.¹

Be aware that emotional lability is a potential motor symptom of MND and that emotions may be heightened or inappropriate. For example, a person with emotional lability may laugh when in pain, or cry for no obvious reason, giving the impression they are distressed.

Information for you

Cognitive change, frontotemporal dementia and MND

Information to share

Information sheet *9A – Will the way I think be affected?*

Information sheet *9B – How do I support someone if the way they think is affected?*

Information sheet *9C – Managing emotions*

See page 2 for order details.

Fatigue

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.²³ Fatigue may make it more difficult for the person to keep their mouth open for safe access to dental care. Getting to the dental surgery may also be affected by, or contribute to, fatigue.³

Consider the impact of travel, appointment timing and fatigue when booking in a person with MND, as this may deter a person from attending.¹¹

A bite block may help to support mouth opening. Alternatively, a toothbrush handle between the teeth on the opposite side can help prevent closure when the muscles become tired.

Shorter appointments may be necessary. However, time may be needed to:

- ensure the person is in an appropriate position for treatment
- communicate with a person with MND
- allow for breaks if a long period of treatment is needed.

If there is difficulty in getting to the dental surgery, a person may prefer a longer appointment rather than several shorter appointments.⁶

Information to share

Information sheet *11D - Managing fatigue*

See page 2 for order details.



Strategies for mouth care at home

Strategies and equipment may help a person maintain their own oral hygiene for as long as they can functionally do so. Carers and careworkers may seek advice from dental professionals, and may wish to attend dental appointments to learn techniques for mouth care at home.³

Strategies to share:

If the person cannot tolerate a toothbrush in their mouth:

Some people may be reluctant to brush their teeth due to brisk gag reflex or concerns about choking.¹⁵

Encourage better positioning, with an upright seated position, the chin level or downward, and the head turned slightly to one side.

Try a softer toothbrush, introducing it into the mouth gently, with slower movements.

For limited arm strength or movement, suggest:

- propping elbows on to the arms of a chair or wheelchair, placing the toothbrush on to the teeth and moving the head from side to side
- a lightweight cordless electric toothbrush
- long handled toothbrushes
- three sided toothbrushes that brush all sides of the tooth at once.

For problems gripping the toothbrush, try:

- large toothbrush handles
- a polystyrene foam ball pushed on to the handle of a toothbrush to make it easier to grip.

For swallowing difficulties, suggest:

- non-foaming, dissolving, 'no rinse' toothpaste for those concerned about choking on standard toothpaste or mouthwash
- a toothpaste that doesn't contain sodium laurel sulphate
- preventive treatment with fluoride gels (using cotton swabs) or mouthwash rinses.⁴

Other advice on swallowing problems can be accessed via a speech and language therapist.

If a person with MND uses a feeding tube:

- advise that oral hygiene is still necessary even if food or drink is not taken by mouth.

If a person with MND uses a suction machine:

- this can be used to remove excess saliva and toothpaste during brushing
- a specialist toothbrush accessory can be attached to the machine.

If a person with MND has problems opening their mouth:

- pressing gently on the chin below the bottom lip may help the mouth to open more easily
- a bite block or mouth rest may be used to keep the mouth open for brushing. Alternatively, a toothbrush handle between the teeth on the opposite side can help prevent closure when the muscles become tired
- finger protectors may be used by carers assisting with oral hygiene.

How the MND Association can support you

We support health and social care professionals to provide the best possible care for people living with MND, their carers and families. We do this in a number of ways:

MND Association website

Access information for care workers on our website at **www.mndassociation.org/careworkers**

MND Connect

Accredited by the Helplines Standard, MND Connect offers information and support, and signposting to other services and agencies.

Main contact number: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Information resources

We produce high quality information resources for professionals who work with people with MND. We also have a wide range of resources for people living with and affected by MND. You can order copies from MND Connect, or downloads of most of our publications are available from our website at **www.mndassociation.org/publications**

Education and training

Training in specific areas of care for people with MND may be provided by relevant members of the specialist MND team. Regional staff from the MND Association can also offer awareness training about MND and the Association's services, as well as more detailed study days. Visit **www.mndassociation.org/education**

MND Association membership

Join us now and help fight MND. Membership costs £12 for individuals. It is free for people with MND and for carers, spouses or partners of people living with MND. Call **01604 611855** or email **membership@mndassociation.org**

MND support grants and equipment loan

Where statutory funding or provision has been explored but is not available, we may be able to provide a support grant or equipment loan. Referrals for this support need to be made by a relevant health or social care professional. For enquiries, call the MND Connect or visit www.mndassociation.org/getting-support

Wheelchair service

If you are seeking information on wheelchairs, or if there are delays in assessment or provision of an appropriate wheelchair for someone with MND, our wheelchair service may be able to help, through training, joint assessments, advice or support. Call MND Connect on **0808 802 6262** or email wheelchairqueries@mndassociation.org

Research into MND

We fund and promote research that leads to new understanding and treatment and brings us closer to a cure. Contact the Research Development team on **01604 611880** or research@mndassociation.org Visit www.mndassociation.org/research for more information.

Local support

Regional care development advisers

Our network of regional care development advisers (RCDAs) have specialist knowledge of the care and management of MND. They work closely with local services and care providers to ensure effective support for people affected by MND, provide education for health and social care professionals in MND, and are champions at influencing care services.

MND care centres and networks

We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist clinical expertise from diagnosis onwards.

Branches and groups

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

Association visitors (AVs)

Association visitors are volunteers with experience of MND who provide one-to-one local support to people affected by MND.

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Feedback form

Please send us your feedback on *Motor neurone disease: a guide for dental professionals*

Thank you for taking the time to provide your feedback on one of our information resources.

This questionnaire can be accessed online if preferred, using the following link: www.surveymonkey.com/r/MND4Dentists

What is your profession or specialism?

Did you find this resource useful?

Yes Somewhat Not really No

Please explain your answer

Will this information resource help you to provide people affected by MND with any of the following? (tick all that apply)

- an increased understanding of their symptoms
- an increased understanding of their condition
- more independence
- an increased ability to raise awareness of their needs
- more confidence
- improved quality of life
- a greater ability to maintain dignity

Continued overleaf

Feedback form continued

Were there any particular topics that were useful to you?

Was there any information that you didn't find useful or relevant?

Are there any other MND-related topics you would like more information about?

Would you be happy to help us improve our information by becoming an expert reviewer?

Yes (please include your email address below) No

Do you have any experiences of working with people with MND you could share as an anonymous quote or case study for future resources?

Yes (please include your email address below) No

Please return your completed form to:

Education and information team

MND Association

PO Box 246

Northampton NN1 2PR

Name:

Email:

Acknowledgements

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**Dr Andrew Bottomley, BDS Ncle., MClinDent,
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About us

The MND Association was founded in 1979 by a group of volunteers with experience of living with or caring for someone with MND. Since then, we have grown significantly, with an ever-increasing community of volunteers, supporters and staff, all sharing the same goal – to support people with MND and everyone who cares for them, both now and in the future.

We are the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.

Our mission

We improve care and support for people with MND, their families and carers.

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND.

We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

MND Association

PO Box 246, Northampton NN1 2PR

Tel: 01604 250505

Email: enquiries@mndassociation.org

www.mndassociation.org



@mndeducation



/mndassociation



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 the senses such as sight, sound and feeling.
- 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 a proportion 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.

mndconnect
0808 802 6262

mndconnect@mndassociation.org