mnda
motor neurone disease association

For health and social care professionals

Managing saliva problems in motor neurone disease

Motor neurone disease (MND) is a progressive and terminal disease that attacks the motor neurones, or motor nerves, in the brain and spinal cord.[1] Many people with MND experience problems with saliva control and dysphagia (swallowing problems).[2] These can make eating and drinking difficult, and cause anxiety for people with MND who have concerns about choking on saliva, food or liquids.[3]

Everyone with MND has a different experience of the disease, with different dominant symptoms and no standard rate of progression.[4] Each person should have an individual assessment for treatment, and regular review.

Someone with MND may experience difficulties with thin, runny saliva that drools out of the mouth, thick tenacious saliva or phlegm. Thick saliva and phlegm can be particularly difficult to clear if the person has a weakened cough.[2] Some people may experience all of these difficulties at different times.

This information sheet is for health and social care professionals working with people with MND and provides suggestions, medication options and practical tips for saliva management.

Information for people affected by MND

Information sheet 7A – *Swallowing difficulties*
Information sheet 7B – *Tube feeding*
Information sheet 11B – *Mouth care*

Information for professionals

P6 – *Evaluation and management of respiratory symptoms in MND*
P9 – *Oral suction*

Download at **www.mndassociation.org/publications** or contact MND Connect. Call 0808 802 6262 or email **mndconnect@mndassociation.org**

Problems with saliva

Thin, watery saliva

People with MND may find they experience pooling of large amounts of thin watery saliva, which can cause drooling. Although a normal amount of saliva is produced by those with MND, around two to three pints every day, excessive saliva (sialorrhoea) is a commonly reported symptom.[2]

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.[2] Drooling is worse if the person has a poor lip seal or swallowing difficulties (dysphagia).

Thick, tenacious saliva, mucus and phlegm

People with MND may experience thickened mucus in the mouth and throat, which is difficult to swallow. Additionally, phlegm in the airways may be difficult to cough up due to weakened respiratory muscles and an ineffective cough.[3]

Thick mucus can build up in the mouth and at the back of the throat due to:

- dehydration
- mouth breathing or open mouth posture, which can lead to evaporation of saliva
- non-invasive ventilation (NIV) drying out their airways.

This may produce stringy mucus and cause airways to become partially blocked.[2] This can be very distressing for the person with MND and those who care for them.

Managing saliva problems

If a person with MND has problems with saliva, the volume and viscosity of the saliva should be assessed, along with the person's respiratory function, swallowing, diet, posture and oral care.[5]

Saliva problems can be difficult to control. All management options should be explored, as it is often a case of trial and error to find the right solution.

A tool can be used to assess the scale and impact of saliva problems. Research has highlighted the clinical saliva score for MND (CSS-MND) to be an easy-to-use tool to assess and reflect the impact of saliva problems.[6] Visit **http://bit.ly/CSS-MND** for further information and to access the tool.

Professionals who can help

The consultant or MND specialist practitioner will usually manage saliva problems with solutions which may include:

- self-help techniques
- prescription medication
- organising equipment/treatment.

This may vary where the specialist centre is not within easy reach. A speech and language therapist or physiotherapist may be able to provide suggestions or strategies to help with saliva control.

A speech and language therapist can:

- help to identify any problems that may be present, including poor lip seal and/or weakness in oral and facial muscles or the tongue
- advise on different swallowing techniques that may make swallowing easier.

A physiotherapist can advise on:

- cough management techniques, which may help to clear thick, tenacious saliva (see page 6).

An occupational therapist can advise on:

- postural problems and ways to alter the person's position. In some cases, improving posture may help to control the flow of saliva. Neck weakness and a drooping posture can cause the head to tilt forward, and saliva may flow through the lips before it can be swallowed
- head supports or neck collars to improve the posture of the person with MND. In some cases, the person may only be able to wear the collar for short periods due to discomfort. In this case, a reclining armchair or wheelchair can support the head and maintain an upright posture. An assessment by an occupational therapist can provide access to equipment to support posture and positioning.

Medication

Medication options are outlined on pages 4-5. Before medication is prescribed, the problem should be properly assessed. Medication that can 'dry up' or reduce watery saliva may lead to thick, tenacious saliva or worsen the situation if saliva is already thick. If mucoid secretions are the problem, medication to thin these might be considered.[2]

Key actions

Medication should always be prescribed by a doctor or a professional trained as a prescriber. Other medicines, including those available without a prescription, should never be taken without consulting a doctor, as there may be contraindications.

Some people with MND will have an enteral feeding tube. Medication can sometimes be given through the tube, but before putting any medication through, check with a pharmacist that it won't harden or clog the tube, or affect how well the drug works.

Treating thin, watery saliva

Strategies and equipment that may help

- Advice should be given on swallowing, diet, posture, positioning and oral care.[5]
- Portable oral suction units are helpful if saliva builds up in the mouth (see page 6).[5]
- Protect surrounding skin with a barrier cream to prevent soreness.
- Clothing may be adapted to include a discreet waterproof insert to protect clothes and prevent skin irritation.
- Encourage a well-supported head position. A slightly reclined chair, and a collar or chin support may be used. A physiotherapist, occupational therapist or orthotist should be able to suggest a suitable option.
- At night, the person should lie on their side, supported by pillows, so saliva doesn't collect in their throat. This may not be an option if the person has postural or respiratory needs.

Medication for thin, watery saliva

A prescribing professional may consider the following drugs, recommended in the NICE Guideline on MND.

- Consider a trial of antimuscarinic medicine as the first-line treatment for sialorrhoea.[5]
- Consider glycopyrrolate as the first-line treatment for sialorrhoea in people with MND who have cognitive impairment, because it has fewer central nervous system side effects.[5]

NB: antimuscarinics can cause confusion in older people, urine retention and other side effects that should be monitored.

For drug dosages please refer to the British National Formulary (BNF).

Antimuscarinics	Preparation
Glycopyrronium bromide (Glycopyrrolate)	Oral tablet. A suspension is available, which can be given orally or via a feeding tube. A parenteral form can be given under the skin (subcutaneously) as an injection when needed or as a continuous infusion using a syringe pump.
Hyoscine butylbromide (Buscopan)	Tablets can be taken orally or crushed[13] and given via a feeding tube, with care. They can also be crushed and dissolved in water. A parenteral form can be given under the skin (subcutaneously) as an injection when needed or as a continuous infusion using a syringe pump. It can also be given orally or via feeding tube, depending on the dose.
Hyoscine hydrobromide	A skin patch is available that is applied behind the ear and changed every 72 hours. Tablets can also be taken orally or crushed and given via a feeding tube. A parenteral form can be given under the skin (subcutaneously) as an injection when needed or as a continuous infusion using a syringe pump.
Atropine	Although unlicensed for this symptom, eye drops can be given under the tongue (sublingually). Benefits only last a few hours, so it may be more suitable for specific, timed events such as appointments. To avoid overdose, these should not be dropped directly into the mouth from the original container. The dose should be given using a disposable dropper, or may be dropped on to a spoon first.
Tricyclic antidepressants Amitriptyline/Imipramine	Low dose given at night. Available as a suspension to be given orally or via a feeding tube. Usually given at night as it can cause sedation in some people.

Potential next steps

Botulinum toxin A (Botox)

If first-line treatment for sialorrhoea is not effective, not tolerated or is contraindicated, consider referral to a specialist service for botulinum toxin A.[5] Studies have shown that injecting this nerve toxin into the salivary glands may decrease saliva production for weeks or months[2] by interrupting the messages from the nerves that tell the glands to secrete.

Effects from a single dose can last up to three months. Be aware that treatment with botulinum toxin A may have the side effect of increasing dysphagia, so some suggest only resorting to these injections if the person already has enteral feeding in situ. Botulinum toxin A should only be administered by specialist practitioners.[5]

Radiotherapy

Another possible treatment for excessive, watery saliva is single-dose radiotherapy, where x-rays are used to destroy part of the salivary glands. The effect is permanent, but may be partial depending on the amount of x-rays used. The effect of radiotherapy is seen gradually over several weeks after treatment.

The radiotherapist may treat one side only first.

Treating thick saliva, mucus and phlegm

Strategies and equipment that may help[8]

- Review of all current medicines, especially any treatments for sialorrhoea.[5]
- Advice should be given on swallowing, diet, posture, positioning, suctioning and hydration.[5]
- Improvement of oral hygiene. A district nurse may be able to help with this. The teeth, tongue and gum margins should be cleaned regularly and especially before or after oral medication is given.
- Rehydration. Increase the intake of fluid, for example with jelly, frozen mousses or ice lollies, if safe to swallow. Seek advice from the speech and language therapist. Cold temperatures may stimulate the swallow.
- Avoidance of mouth breathing, if possible. This may not be an option for people with bulbar symptoms.
- Drinking pineapple or papaya juice before/with a meal. These juices contain proteolytic enzymes, bromelain (pineapple – most concentrated in the core) and papain (papaya), which help break down protein in mucus. The juices can also be applied gently on a sponge as part of a mouth care regimen. Bromelain and papain enzymes are also available as tablets.[14]
- Reducing intake of dairy products may be helpful. Check with the dietitian, as some people with limited diets due to dysphagia may rely on dairy products to maintain their weight.
- Sucking on sugarless lozenges can stimulate saliva flow and reduce the viscosity of saliva, providing it is safe to do this and will not cause the person with MND to choke. Avoid lozenges containing menthol as these can have a drying effect.
- Inhaling water vapour or humidification can decrease the viscosity of mucus and help to loosen secretions.[5]

Medication for thick, tenacious mucus or saliva

A prescribing professional may consider the following drugs. For drug dosages please refer to the British National Formulary (BNF).

Medication	Preparation
Mucolytics[9] Carbocisteine	Available as capsules or liquid. The liquid form can be administered by feeding tube.
Saline[10]	Given using a nebuliser, this can help to loosen chest secretions.[15]
Beta blockers Propranolol/metoprolol	This is given in tablet form. There is limited evidence that this type of medication can reduce secretions. The person with MND should be monitored for hypotension[16] (low blood pressure) and bradycardia (slow heart beat).

Removing secretions

People with MND may be unable to clear secretions from the mouth and throat because they have an ineffective cough. This can lead to respiratory infections.

The following techniques, which need to be taught by a specialist respiratory physiotherapist, may help to remove phlegm or mucus from the throat or respiratory tract.

The NICE Guideline on MND recommends:

- unassisted breath stacking and/or manual assisted cough as first-line treatment. Breath stacking involves adding additional air to that already in the lungs to add force to a cough[5]
- assisted breath stacking (eg using a lung volume recruitment bag with a one-way valve) for those with bulbar dysfunction or whose cough is ineffective with unassisted breath stacking[5]
- if available, use of a mechanical insufflation:exsufflation machine (MI:E, sometimes known by the brand name CoughAssist), if assisted breath stacking is not effective and/or during a respiratory tract infection. This machine clears secretions by gradually applying a positive pressure to the airway, then quickly shifting to negative pressure. This rapid change in pressure simulates a natural cough.[5]

The provision or loan of MI:E machines varies from region to region and sometimes servicing and maintenance can be problematic. If a person is likely to benefit from an MI:E machine, professionals are urged to make a case and push for provision as soon as possible.

If you experience difficulties, contact MND Connect. Email **mndconnect@mndassociation.org** or call 0808 802 6262.

Suction units

A suction unit can help to remove saliva, mucus or food particles in the mouth.[2] Suction units should be available via the person's GP or district nurse. In some areas, suction units are only available through the local MND care centre. If statutory provision has been explored and is not available, it may be possible to loan a suction unit from the MND Association.

Ask the GP or district nurse to contact our Support Services team, or speak to your local MND care centre. If a suction unit is borrowed from the MND Association, the local health authority or health and social care trust will need to make a small contribution to the cost of the unit. Contact our MND Connect helpline for further details. Email **mndconnect@mndassociation.org** or call 0808 802 6262.

Instructions on how to use a suction unit will be provided by a nurse, respiratory physiotherapist or the specialist team.

It is important that the person with MND and their carers are appropriately trained to use the unit, and do not use it to suction deeper than the mouth cavity.

Information for professionals

Information sheet P9 – *Oral suction*

Download at **www.mndassociation.org/publications** or contact MND Connect. Call 0808 802 6262 or email **mndconnect@mndassociation.org**

Dry mouth

Some people will experience a dry mouth, which may be caused by the medication they are taking, thrush, a coated tongue, insufficient fluids or breathing through the mouth.[11]

Treatments and strategies for dry mouth

Dosage of medication should be checked by a prescribing professional and changed if needed.[12]

Preparations such as artificial saliva sprays or gels, for example Aquoral, Biotene Oralbalance, Orthana or Xerotin, can help to relieve a dry mouth.[12] They also help to reduce odour-causing bacteria. These treatments are given using a swab around the mouth before meals or at bedtime. Clean the mouth before gels are given. Some of these items are available without a prescription. These products may contain sorbitol and overuse can have a laxative effect.

Oral hygiene should also be checked.[12] A district nurse may be able to help with this. Teeth, tongue and gum margins should be cleaned regularly, especially before oral medication is given.

The amount of fluid taken in by the person should be increased, whether orally or through a feeding tube.[12] A dietitian, nurse or doctor can advise on ways to increase fluid intake.

Some people with MND and professionals report that olive, grapeseed or groundnut oil (where appropriate) or ghee can be used as a lubricant when swabbed around the mouth, or swilled in a way similar to mouthwash known as oil pulling.

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Further Reading

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Acknowledgements

Thank you to the following people for their valuable contributions to this information sheet:

Dr Emma Husbands, Consultant in Palliative Medicine, Gloucestershire Hospitals NHS Foundation Trust

Nina Squires, Speech and language therapist, Northamptonshire Healthcare NHS Foundation Trust

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

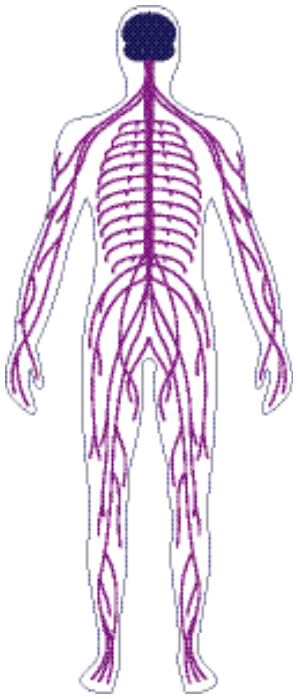
We value your feedback

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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Last revised 04/20
Next review 04/23
Version 1