

P3

Managing saliva problems in motor neurone disease

Information for health and social care professionals

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.

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

Information you can share

We have two relevant information sheets for people affected by MND, both endorsed by the British Dietetic Association:

Information sheet 7A – *Swallowing difficulties*

Information sheet 7B – *Tube feeding*

Information for you

We have a wide range of relevant information to support health and social care professionals manage the symptoms of MND, including:

P6 – *Evaluation and management of respiratory symptoms in MND*

P9 – *Oral suction*

You can download most of our publications from our website at

www.mndassociation.org/publications or see page 9 for details of how to order copies.

Problems with saliva

The salivary glands produce two different types of secretions: thin, watery saliva and thick mucus. In addition, the membranes of the respiratory passages secrete a thick mucus known as phlegm.

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 difficult to clear² particularly if the person has a weakened cough. Some people may experience all of these difficulties at different times.

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 dysphagia (swallowing difficulties).

Thick, tenacious saliva, mucus and phlegm

People with MND may experience thickened mucus in the mouth and throat, which is difficult to swallow, or phlegm in the airways, which is 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 problems with saliva

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, although the research has highlighted some areas for the improvement of this tool.⁶

Professionals who can help

The consultant or MND specialist practitioner will usually manage saliva problems with:

- 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. All of these can contribute to problems with saliva management
- 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 5).

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, which may 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 and 6. Before medication is prescribed by an appropriate professional, the problem should be properly assessed. This is because 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. For drug dosages please refer to the British National Formulary (BNF).

- 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.

Antimuscarinics	Preparation
Glycopyrronium bromide (Glycopyrrolate)	<p>Oral tablet.</p> <p>A suspension is available, which can be given orally or via a feeding tube.</p> <p>A parenteral form can be given under the skin (subcutaneously) as an injection when needed or as a continuous infusion using a syringe pump.</p>
Hyoscine butylbromide (Buscopan)	<p>Tablets can be taken orally or crushed¹³ and given via a feeding tube, with care. They can also be crushed and dissolved in water.</p> <p>A parenteral form can be given under the skin (subcutaneously) as an injection when needed or as a continuous infusion using a syringe pump.</p> <p>It can also be given orally or via feeding tube, depending on the dose.</p>
Hyoscine hydrobromide	<p>A skin patch is available that is applied behind the ear and changed every 72 hours. The new patch should be applied behind the other ear, or on another site such as an arm, to reduce any skin irritation.</p> <p>Tablets can also be taken orally or crushed and given via a feeding tube.</p> <p>A parenteral form can be given under the skin (subcutaneously) as an injection when needed or as a continuous infusion using a syringe pump.</p>
Atropine	<p>Although unlicensed for this symptom, eye drops can be given under the tongue (sublingually).</p> <p>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.</p>
Tricyclic antidepressants Amitriptyline/Imipramine	<p>Low dose given at night. Available as a suspension to be given orally or via a feeding tube.</p> <p>Usually given at night as it can cause sedation in some people.</p>

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 months² 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, tenacious saliva, mucus and phlegm

Strategies and equipment that may help⁸

- 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 liquids are hard to swallow. 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) 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 tablets¹⁴.
- Some people may find it helps to reduce their intake of dairy products.
- 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.
- 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 ¹⁵ secretions.
Beta blockers Propranolol/metoprolol	This is given in tablet form. There is limited evidence that this type of medication can thin 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 (see page 10 for other actions a physiotherapist may help with), 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 cough⁵
- 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 stacking⁵
- 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. The local MND Association Regional Care Development Adviser (see page 10) may be able to help you with this process.

Suction unit

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. See page 9 for more information.

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 you

We have an information sheet with more detailed information:
Information sheet P9 - *Oral suction*

See page 9 for details of how to order resources.

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.

Although there is a lack of supporting evidence, some people with MND and professionals have found that olive, grapeseed or groundnut oil (where appropriate) or ghee can be used as a lubricant when swabbed around the mouth.

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Further Reading

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How the MND Association can support you and your team

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 Connect

Our helpline offers help, information and support, and signposting to other services and agencies. The service is for people living with MND, carers, family members, health and social care professionals and Association staff and volunteers who directly support people with MND.

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Please contact MND Connect if you have any questions about the information in this publication.

Information resources

We produce high quality information resources for health and social care professionals who work with people with MND. We also have a wide range of resources for people living with and affected by MND. Downloads of all our information sheets and most of our publications are available from our website at **www.mndassociation.org/publications**. You can also order our publications directly from the MND Connect team.

MND Association website

Access information for health and social care professionals on our website at **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, such as conferences and masterclasses. Find out more at **www.mndassociation.org/education**

MND support grants and equipment loan

Where statutory funding or provision has been explored and is not available, we may be able to provide a support grant or equipment loan. Our support grant service consists of providing care and quality of life grants for people with MND. This service is supported by MND Association branch and group funds, and by the Association's central fund.

Our equipment loan service is focused on three core types of equipment to help people with day-to-day tasks and communication:

- riser-recliner chairs
- specialist communication aids
- portable suction units.

For suction units, a small charge is made to statutory services for carriage, maintenance and cleaning.

Referrals for support grants or equipment loan need to be made by a relevant health or social care professional. For enquiries about MND support grants or equipment loan, call the MND Support Services team on **01604 611802**, email **support.services@mndassociation.org** 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. For our wheelchair service, call MND Connect on **0808 802 6262** or email **wheelchairs@mndassociation.org**

Communication aids service

This service helps people with MND and health and social care professionals with queries about communication aids. The service provides limited financial support for communication aids or some items on loan, if unavailable or delayed through health and social care services. Our aim is to improve provision and information on a local and national level, through collaboration with professionals. Call **01604 611767** or email **communicationaids@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**. Alternatively, visit **www.mndassociation.org/research** for more information. For the latest research news, visit our research blog at **www.mndresearch.wordpress.com**

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**

Local support

Regional care development advisers

We have a network of regional care development advisers (RCDAs) covering England, Wales and Northern Ireland. RCDAs have specialist knowledge of the care and management of MND.

They work closely with local statutory services and community care providers to ensure effective support for people affected by MND. RCDAs provide education for health and social care professionals in MND, and are champions at influencing care services in their areas.

MND care centres and networks

Care centres and networks are teams of professionals who are specialists in MND. 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 provide one-to-one local support to people affected by MND. Managed by regional care development advisers, they are volunteers with experience of MND who can visit people affected by MND within their homes or contact them by telephone, email or through local support groups. They can also provide a link with health and social care professionals.

Please send us your feedback on
Managing saliva problems in motor neurone disease

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/s/professionalinformation

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)

- | | |
|---|--|
| <input type="checkbox"/> an increased understanding of their symptoms | <input type="checkbox"/> more confidence |
| <input type="checkbox"/> an increased understanding of their condition | <input type="checkbox"/> improved quality of life |
| <input type="checkbox"/> more independence | <input type="checkbox"/> a greater ability to maintain dignity |
| <input type="checkbox"/> an increased ability to raise awareness of their needs | |

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 that you'd like more information about?

Do you have any other feedback about this resource or our other information for professionals?

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:

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MND Association

PO Box 246, Northampton NN1 2PR
Tel: 01604 250505
Email: enquiries@mndassociation.org
www.mndassociation.org



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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.

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