An Expert Core Resource

Saliva management pathway for motor neurone disease

Saliva problems are a common and often distressing symptom for people living with motor neurone disease (MND). Difficulties may include excessive thin, watery saliva (sialorrhoea), thick tenacious saliva or a mixture of both. The person living with MND may also experience a dry mouth at the same time. These issues can significantly impact quality of life, contributing to discomfort, anxiety, and an increased risk of choking.

This pathway has been created by the Expert Core of the MND Professionals' Community of Practice. It is designed as a practical tool to support health and social care professionals in assessing, and managing saliva problems effectively. While the evidence base for saliva management in MND is still emerging, this pathway brings together current best practice, clinical experience, and expert guidance to help alleviate this challenging symptom and improve the comfort and wellbeing of people living with MND.

Where a person with MND is experiencing both thin, watery saliva and thick, tenacious saliva, it is recommended that the thick saliva is addressed first.

Medications listed have a space where local recommended dosages can be recorded. However, as every person with MND experiences the disease differently, it is essential that saliva management is tailored to the individual and reviewed regularly.

- **Successful secretion management requires the clinician to complete a full multifactorial assessment to be able to select the right treatment solution. See the appendix for examples of assessment tools.**
- **Always get specific details from the person with MND on location of secretions, pattern of when secretions are problematic, viscosity, site of origin, the person's distress level and co-morbidities.**
- **Anticholinergic medications are contraindicated in older adults due to the potential of confusion. Consider using an anticholinergic load scale calculator to calculate the anticholinergic burden for your patient.**

Information for people affected by MND

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

Information for professionals

P3 – *Managing saliva problems in MND*
P9 – *Oral suction*

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

Saliva management pathway for thick or tenacious saliva

Assessment

See appendix for assessment tools.

Consider SLT referral if dysphagia signs present eg coughing/choking/ recurrent chest infections.

1st line non-pharmacological

- **Consider non-pharmacological interventions where appropriate.**
- Ensure upright posture with trunk/head support (eg neck collar). Refer to occupational therapy if required.
- Assess for reversable causes (reflux, oral inflammation or chest infection).
- Review anticholinergic medications and stop if able.
- Ensure adequate hydration.
- Consult with dietitian regarding reducing or avoiding dairy products.
- Avoid caffeinated drinks and alcohol.
- Seek guidance from dietitian if taking oral nutritional support products
- Trial steam inhalation/humidification/nebulisers.
- Advise regular breathing exercises including unaided breath stacking, active cycles of breathing techniques.
- Cough augmentation to support airway clearance, reviewed regularly by the local specialist respiratory or assisted ventilation team.
- Papase (papaya enzyme) as a tablet or wiped around mouth.
- Fresh pineapple/dark grape/papaya juice to thin saliva.
- Consider suction for thick secretions.

1st line pharmacological

- Carbocisteine - tablet or oral liquid.
- Acetylcysteine - effervescent tablet.

2nd line pharmacological

- Saline or hypertonic saline nebuliser.

Local dosage information

This box can be typed in

For dosages, please refer to the Electronic Medicines Compendium, British National Formulary (BNF) or the Palliative Care Formulary (PCF).

Saliva management pathway for thin saliva or sialorrhoea

Assessment

See appendix for example assessment tools.

If a person with MND experiences both thin, watery saliva and thick, tenacious saliva, the thick saliva should be addressed first.

Consider SLT referral if dysphagia signs present eg coughing/choking/wet voice/recurrent chest infections.

1st line non-pharmacological

- **Consider non-pharmacological interventions where appropriate.**
- Ensure upright posture with trunk/head support (eg neck collar). Refer to occupational therapy if required.
- Try ginger or sage tea, or dark grape juice (may reduce effect of anticholinergics).
- Consider oral suction unit for drooling.
- Use low foaming toothpaste free of sodium lauryl sulphate and/or a suction toothbrush for oral care.
- Encourage regular swallowing. Prompt apps are available on Apple/Android.

If central nervous system side effects **may be harmful** (eg cognitive impairment, elderly).

1st line pharmacological

Less central nervous system effects

- Glycopyrronium bromide (solution or tablets)
- Atropine 1% drops, used sublingually - drop onto a spoon first to avoid accidental overdose.

If central nervous system side effects **are unlikely to be harmful**.

1st line pharmacological

Possible central nervous system effects

- Amitriptyline (tablets)
- Hyoscine **hydrobromide** (tablets or patch)
- Hyoscine **butylbromide** (tablets)

2nd line: Botulinum neurotoxin Type A

- Option for chronic sialorrhoea in neurological patients or if multiple treatments failed.
- May not be available in all areas.

3rd line

If all steps and combinations are unsuccessful, consider further MDT discussion with specialist services, eg the MND Care Centre, ENT or radiotherapy.

Local dosage information

This box can be typed in

For dosages, please refer to the Electronic Medicines Compendium, British National Formulary (BNF) or the Palliative Care Formulary (PCF).

Saliva management pathway for dry mouth

Assessment

Review interventions that can cause dry mouth including NIV, medications etc. Liaise with the prescriber about possible alternatives or dose adjustments if appropriate.

Consider SLT referral if dysphagia signs present eg coughing/choking/recurrent chest infections.

Suggestions for managing dry mouth

- Encourage good oral hygiene, for example:
    - twice-daily brushing with fluoride toothpaste, and a soft-bristled brush to prevent gum irritation
    - low-foaming toothpaste free from sodium lauryl sulphate and alcohol-free mouthwashes
    - flossing or using interdental brushes if dexterity allows
    - tongue cleaning with a scraper or toothbrush to reduce bacteria and improve oral freshness
    - an electric or suction toothbrush if motor function is limited
    - carers to support good oral hygiene if the person is unable to do so themselves.
- Ensure the person is well hydrated. Encourage frequent sips of water or use of ice chips (check swallow safety).
- Swill the mouth throughout the day. Oils such as ghee, butter, olive oil, coconut oil can be used to moisturise the mouth, either swabbed around the mouth or swilled (known as oil pulling).
- Limit caffeine and alcohol intake.
- Use sugar-free gum/lozenges if chewing/swallowing is safe.
- Advise regular lip balm application to prevent drying/cracking.
- Recommend artificial saliva substitutes (sprays, gels, lozenges).
- Educate about mouth breathing. Explain how habitual mouth breathing contributes to oral dryness.
- Suggest humidifier use, especially overnight.

Appendix - examples of assessment tools

The saliva assessment tools listed below are presented in alphabetical order and are intended as a starting point for further exploration. Each tool offers a different approach to assessing saliva-related symptoms, and their inclusion here aims to support informed decision-making in clinical practice.

For accurate use and interpretation, please refer to the original research publications associated with each tool to gain a comprehensive understanding of their application and limitations.

If you are using a digital version of this document, the links are clickable.

A. Clinical Saliva Scale for MND (CSS-MND)

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. Scoring is based on a questionnaire completed by the person with MND or their carer.

McGeachan AJ, et al. Developing an outcome measure for excessive saliva management in MND and an evaluation of saliva burden in Sheffield. Amyotroph Lateral Scler Frontotemporal Degener, 2015;16:108–13.

B. Drooling severity and frequency score (DSFS)

Score	Severity	Score	Frequency
1	Dry (Never drools)	1	No drooling
2	Mild drooling, only lips wet	2	occasionally drools
3	Moderate drooling; drool reaches the lips and the chin	3	Frequently drools
4	Severe drooling; drool drips off chin and onto clothing		
5	Profuse drooling; drooling off the body and onto objects		

Find the tool in the 'Supporting information' menu.

Evatt ML, et al. Dysautonomia rating scales in Parkinson's disease: sialorrhea, dysphagia, and constipation--critique and recommendations by movement disorders task force on rating scales for Parkinson's disease. Mov Disord. 2009 Apr 15;24(5):635-46.

C. Oral Secretion Score

This tool was developed to measure oral secretions in correlation with the ability to swallow saliva and clear the upper airway in people with MND.

Cazzolli PA, Brooks BR, Nakayama Y, Lewarski JS, McKim DA, Holt SL, Chatburn RL. The oral secretion scale and prognostic factors for survival in subjects with amyotrophic lateral sclerosis. Respiratory Care. 2020 Aug;65(8):1063-76.

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This information sheet has been endorsed by the MND Professionals' Community of Practice.

How we can support you and your team

MND Connect

Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals.

Email: mndconnect@mndassociation.org
Phone: 0808 802 6262

MND Association website

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

www.mndassociation.org/professionals

Stay updated on information for professionals:

www.mndassociation.org/educationupdate

X: **mndeducation**

Bluesky: **mndeducation.bsky.social**

Information resources

We produce high quality information for people with MND, carers, family members and health and social care professionals. Our information can be available in various formats and languages.

www.mndassociation.org/pro-info-finder

www.mndassociation.org/careinfofinder

Education

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

www.mndassociation.org/education

Research into MND

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

www.mndassociation.org/research

MND Professionals' Community of Practice

A peer led group of health and social care professionals supporting cross disciplinary learning and the development of good care for people with MND. Join for unique networking and learning events. Being an active member could count towards your professional CPD requirements.

www.mndassociation.org/cop

Financial support

Where statutory provision is not available, we may be able to offer financial support.

www.mndassociation.org/getting-support

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

Local support

We run online and local peer support groups and have trained volunteers and volunteer-led groups offering practical help and support for people with MND, via phone, email or visiting their own home.

www.mndassociation.org/local-support

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

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

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