



11B

Mouth care


Information for people with or affected by motor neurone disease, or Kennedy's disease

Taking care of your mouth and teeth is an important part of everyday living. Everyday routines become more difficult with motor neurone disease (MND) and this task may become challenging. However, you still need to carry out mouth care each day. If you are living with Kennedy's disease, you may have similar symptoms and also find this information useful.

This information sheet explains why oral hygiene is so important and explores how to care for your mouth more easily with MND. Before trying products or methods, ask your dentist or GP to ensure they are suitable for your needs.

The content includes the following sections:

- 1: **Why is oral hygiene important?**
 - 2: **How can I care for my teeth and mouth?**
 - 3: **What can I do about saliva problems or a dry mouth?**
 - 4: **Do I still need to visit my dentist?**
 - 5: **How do I find out more?**
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 This symbol is used to highlight **our other publications**. To find out how to access these, see *Further information* at the end of this sheet.

 This symbol is used to highlight **quotes** from other people with or affected by MND.

1: Why is mouth care important?

A thin film of bacteria forms in the mouth, called plaque. When combined with sugars and carbohydrates, plaque creates acid which can lead to tooth decay. Dentists encourage us to brush our teeth every day because brushing helps to remove plaque.

As many people with MND are advised to consume a high calorie diet to maintain weight, there is an increased risk of tooth decay from eating sugary foods.

If plaque remains in the mouth for a long time it can harden on the teeth. This creates what is known as scale and may require a dentist or dental hygienist to remove.

If scale is left to build on the teeth it can irritate the gums and lead to gum disease. This can also affect the bone that supports the teeth, causing loosening or loss of teeth. It can also enable bacteria to enter the system, so it is essential that plaque is removed on a regular basis.

2: How can I care for my teeth and mouth?

Brushing your teeth is recommended last thing at night and at least one other time during the day, using a fluoride toothpaste.

Cleaning between the teeth and cleaning the tongue is also recommended. Products to floss teeth or small interdental brushes are available to purchase. You can also buy special tongue cleaners. You can get these items from chemists, supermarkets and dentists.

Check the mouth every day, if possible, for anything unusual:

- mouth pain
- sores
- bleeding gums
- dryness
- ulcers
- red or white patches on the tongue or inside the mouth, these may indicate an infection such as thrush (Candida).

What if I have limited arm strength or movement?

Try using a lightweight cordless electric toothbrush which helps do some of the work.

When brushing, try propping your elbows onto the arms of a chair or wheelchair. Then place the toothbrush onto the teeth and move your head from side to side to clean them.

Try to ensure the bristles of the brush reach where the gum meets the tooth. An extra long handled toothbrush may be helpful if you find it difficult to reach your mouth. Some suppliers provide three-sided toothbrushes which brush all sides of the tooth at once, so fewer movements are needed. See *Useful organisations* in section 5: *How do I find out more?*

What if I have difficulty gripping the toothbrush?

Large toothbrush handles can be purchased from aid and mobility shops or a small polystyrene foam ball can be pushed onto the handle of the toothbrush to make it easier to grip. Ask your dentist or occupational therapist for more information.

What if I have swallowing difficulties?

If swallowing is difficult, you may worry about small amounts of toothpaste or mouthwash 'going down the wrong way'. If these get into your airways (known as 'aspiration'), it may lead to a chest infection. Non-foaming toothpaste may help as it simply dissolves, taking away the bacteria. Ask your GP about this, as it may be available on prescription.

If you purchase a retail product, choose toothpaste that doesn't contain sodium laurel sulphate, as this is the ingredient that creates the foam. It is important that the toothpaste contains fluoride to protect the teeth against dental decay.

If you use a suction machine, this can be used to suck up excess saliva and toothpaste while brushing your teeth. A specialist toothbrush accessory can also be attached. See *Useful organisations* in section 5: *How do I find out more?*

If you gag when placing a toothbrush or mouth cleaning aid into your mouth, try:

- keeping your chin in a level or downward position
- using gentle, slower movements
- introducing toothbrushes and other mouth cleaning items into the mouth more gently.

Keep breathing passages open during oral care by remaining in an upright position, with the head turned slightly to one side.



For more detailed information about swallowing see:
Information sheet 7A – *Swallowing difficulties*

What if I can't tolerate a toothbrush in my mouth?

A soft washcloth or a piece of gauze soaked in dental gel or fluoride mouthwash can be used to gently clean the teeth and remove any bits of food from the teeth. This is best used as a temporary measure, as it is not as effective as brushing. The scrubbing action can cause irritation and damage to the softer parts of the mouth.

A soft baby toothbrush may help, as it is quite small and the soft bristles are less invasive in a sensitive mouth.

What if I find it difficult to open my mouth?

Using a bite block or mouth rest in the other side of the mouth will help keep the mouth open for brushing and mouth care and help to protect the fingers. Finger protectors can also be used to reduce biting accidents. Discuss this with your dentist to find the best solutions for your needs.

Alternatively, try pressing gently on the chin below your bottom lip or ask your carer. This can help the muscles relax, so the mouth can open more easily. If you have a carer, they could try yawning in front of you, as this may also encourage you to open your mouth.

Is oral hygiene important if I use a feeding tube?

Yes. If you use a feeding tube you should care for your mouth and teeth as normal. Bacteria will grow in the mouth whether or not food is being eaten.



For more information on tube feeding, see:
Information sheet 7B – *Tube feeding*

Is oral hygiene important if I wear dentures?

Yes. If you have dentures these should be kept as clean as possible to prevent infections and further tooth loss.

The Oral Health Foundation advise that you brush your dentures gently before soaking them, and then brush them again after soaking. They recommend using a denture cleaning paste and a small to medium toothbrush for brushing.

Using a denture cleaner for soaking will help remove stains. Dentures should be removed at night and soaked in water or cleaned according to your dentist's instructions.

3: What can I do about saliva problems or a dry mouth?

Saliva is constantly made in your mouth to:

- wet food, so that it is easier to swallow
- help you taste food and drink
- begin the process of digestion
- help clean and rinse the inside of your mouth
- help fight off infections in the mouth.

Your saliva also neutralises acid in the mouth to prevent damage to teeth. This usually takes about an hour after eating and drinking. It is best not to brush your teeth until then, as brushing with acid present can damage tooth enamel.

If you want to clean your mouth in the meantime, a fluoride mouthwash may help to refresh the mouth or clear away bits of food. If you find it difficult to rinse and spit using mouthwash, then a drink of water can also help to clear your mouth.

What type of saliva problems can happen with MND?

Around 1 in 4 people with MND find that they have problems with their saliva. If this is the case, you may experience:

- pooling of thin, watery saliva gathering in the mouth (this is not caused by producing more saliva but by not being able to swallow effectively)
- saliva leaking out from the mouth if you are unable to close your lips fully
- discomfort if saliva collects at the back of the throat
- dehydration, if the fluids you lose are not replaced (this can be made worse if you are drinking less due to swallowing difficulties)
- thick, sticky saliva which is difficult to clear from your mouth and throat, which can happen if you are dehydrated (thick saliva may lead to acid forming in the mouth and damaging teeth).

As saliva helps to keep your mouth clean, having a dry mouth can lead to a build up of bacteria which may cause tooth decay and infections.



For more information about saliva problems see:
Information sheet 7A – *Swallowing difficulties*

How do I treat a dry mouth?

Specialist products for dry mouths include gels and toothpastes that support the natural antibacterial defence system in the mouth. These are available from chemists.

The following can help to relieve a dry mouth with MND:

- sipping water, milk or other sugar free non-acidic drinks often
- saliva substitutes are available from most chemists, such as saliva replacement sprays to lubricate the mouth (these should not be over used)
- sucking sugar free ice lollies or ice cubes on sticks
- ripe bananas are a good lubricant and it is thought that pineapple and papaya can help to break down mucus, but be aware of the acid content in these fruits.

How do I treat excessive saliva?

If you are experiencing problems with thin saliva pooling in the mouth, or drooling, this can be treated using a variety of prescription medications. Ask your GP or wider health and social care team what would be suitable. You may have to try different medications to find what suits you best.

Occasionally a suction machine may be offered. If your health and social care team feel a suction machine may be helpful, but are unable to get one for you, they can contact the MND Association Support Services team on 0808 802 6262 or support.services@mndassociation.org

4: Do I still need to visit my dentist?

Regular visits to the dentist are recommended if you are able to travel.

If access to your dental surgery becomes a problem, your dentist should be able to refer you to a community dental service which may be more suited to your needs. These community dentists have hoists available to assist wheelchair users to use the dental chair. They may also have wheelchair recliners so that you can stay in your wheelchair throughout your appointment.

You can also be referred by any health or social care professional.

Community dental services may also be able to arrange for a dentist to visit you. Your own dentist or a member of your health and social care team can make the referral.

You can also call NHS England on 0300 311 2233 and ask for the details of the community dental service in your area.

You will be able to get a check-up and advice at home, but types of treatment may be limited. The visiting dentist may be able to perform some procedures, but surgical treatments, x-rays and other digital imaging may not be possible. Ask your community dental officer to explain which treatments are available at a home visit.

If breathing is an issue, your dentist should automatically refer you to a community dental service or a hospital dental service. They are better equipped to deal with specialised dental care.



"It was only after a visit to an emergency dental hospital that I was referred to the community dentist, as my registration had lapsed with my NHS dentist. I hadn't realised you needed to stay on their books. Now I have a sympathetic dentist and regular check-ups."

5: How do I find out more?

Useful organisations

We do not necessarily endorse the external organisations listed here. These have been provided to help you search for further information if necessary. Details are correct at the time of print, but may change between revisions.

If you need help to find an organisation, contact our MND Connect helpline (see *Further information* at the end of this sheet for details about our helpline and how they can support you).

Approach Medical Ltd

Suppliers of suction toothbrushes and other mouth care packs.

Address: West House, King Cross Road, Halifax, West Yorkshire, HX1 1EB
Telephone: 01484 663 951
Email: info@approachmedical.com
Website: www.approachmedical.com

Dent-o-care

Suppliers of a range of oral hygiene products including three sided toothbrushes, mouth rests and dry mouth care products.

Address: 7 Cygnus Business Centre, Dalmeyer Road, London NW10 2XA
Telephone: 020 8459 7550
Website: www.dentocare.co.uk

Health and Social Care Northern Ireland (NHS Northern Ireland)

Online information on health and social care services in Northern Ireland, including how to find a local dentist.

Email: through the website contact page
Website: <http://online.hscni.net/>

Intersurgical

Suppliers of suction toothbrushes and other mouth care products.

Address: Crane House, Molly Millars Lane, Wokingham, Berkshire, RG41 2RZ

Telephone: 0118 9656 300

Email: info@intersurgical.co.uk

Website: www.intersurgical.co.uk

NHS 111

The NHS telephone service if you need urgent, but not life-threatening medical help or advice. Available 24-hours a day, 365 days a year.

Telephone: 111 (England and some areas of Wales)

NHS Direct Wales

Health advice and information service for Wales.

Telephone: 0845 4647 (or 111 if available in your area)

Website: www.nhsdirect.wales.nhs.uk

NHS UK

The main online reference for the NHS, including information on continuing healthcare.

Website: www.nhs.uk

<https://www.nhs.uk/Service-Search/Dentist/LocationSearch/3>
(to find a local dentist)

Oral Health Foundation

An independent charity providing free and impartial dental advice.

Address: Smile House, 2 East Union Street, Rugby, Warwickshire CV22 6AJ

Telephone: 01788 539 780

Email: mail@dentalhealth.org

Website: www.dentalhealth.org

Plak-Vac

Supplier of Plak-Vac suction toothbrush from the USA.

Address: Trademark Medical LLC, 449 Sovereign Court, St. Louis,
MO 63011, USA

Email: through the website contact page

Website: www.trademarkmedical.com/pro/pro-dental-plakvac.html

References

References used to support this document are available on request from:

Email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park, Northampton NN3 6BJ

Acknowledgements

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Further information

We provide other sheets related to this information:

7A – Swallowing difficulties

7B – Tube feeding

We also produce the following guides:

Living with motor neurone disease – our main guide to MND and how to manage its impact

Caring and MND: support for you – comprehensive information for unpaid and family carers, who are supporting someone living with MND

Eating and drinking with motor neurone disease (MND)

You can download most of our publications from our website at:

www.mndassociation.org/publications or order in print from the MND Connect helpline. The helpline team can also answer questions about this information, and direct you to our services and to other support:

MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park,
Northampton NN3 6BJ

MND Association website and online forum

Website: **www.mndassociation.org**

Online forum: **<https://forum.mndassociation.org/>** or through the website

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with or affected by MND, or Kennedy's disease. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

To feedback on any of our information sheets, access our online form at:

www.surveymonkey.com/s/infosheets_1-25

You can request a paper version of the form or provide direct feedback by email:

infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park, Northampton NN3 6BJ

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