

### Further Reading

Health Education England (2019) Saliva management: reduced saliva control in adults with a neuro-disability. <http://mouthcarematters.hee.nhs.uk/wp-content/uploads/sites/6/2019/09/15-RHN-FS-SM2-Reduced-saliva-control-in-adults-with-a-neuro-disability.pdf>

Alexander J McGeachan, AJ & Mcdermott, CJ (2016) Management of oral secretions in neurological disease: <https://pn.bmj.com/content/17/2/96>

Edited by Donna Banks

Further information about Myotonic Dystrophy can be obtained from:

### Myotonic Dystrophy Support Group

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[www.myotonicdystrophysupportgroup.org](http://www.myotonicdystrophysupportgroup.org)

### Other publications available from the Myotonic Dystrophy Support Group:

- Anaesthesia and Sedation for patients with Myotonic Dystrophy
- Basic Information for Midwives
- Bowel Problems in Myotonic Dystrophy
- Congenital Myotonic Dystrophy
- Excessive Daytime Sleepiness and Myotonic Dystrophy
- Facts for patients, family members and professionals
- Just Diagnosed
- Lungs and Breathing
- Myotonic Dystrophy and the Brain
- Myotonic Dystrophy and the Eye
- Myotonic Dystrophy Support Group
- Myotonic Dystrophy Type 2
- Painkillers and Myotonic Dystrophy – what is safe?
- Relatives Information
- Swallowing Difficulties in Myotonic Dystrophy
- The Heart and Myotonic Dystrophy
- Why do we get new families with Myotonic Dystrophy?

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Strategies for  
Managing Excessive  
Saliva for People  
Living with  
Myotonic Dystrophy  
Type 1

by

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# Myotonic Dystrophy

If you are living with myotonic dystrophy type 1 (DMI), you may experience difficulties with drooling, dribbling or excessive saliva in the mouth or throat. The cause of saliva-related problems can vary from person to person but is usually related to difficulties with:

- closing the mouth
- moving saliva from the mouth into the throat
- swallowing



Accumulation of saliva may also be caused by a difficulty in feeling or noticing it 'build up' in the mouth or throat. This excessive saliva may contribute to any of the following:

- skin around the mouth, chin and neck can become red or sore
- risk of coughing and choking
- increased difficulties with eating and drinking
- risk of chest infections, from saliva not being swallowed and passing into the airway
- mouth odour
- social withdrawal or embarrassment

This leaflet provides some strategies to try and improve your saliva management. You may find some suggestions more helpful than others, depending on the cause of your saliva problem.

## 1) Try to keep your mouth closed

If you can close your mouth but find that it opens

unintentionally when you are concentrating on other tasks (such as reading a book or watching the television), try to switch your focus occasionally to closing your mouth. If you spend time with relatives, close friends, or caregivers, you may want to ask them to help remind you.

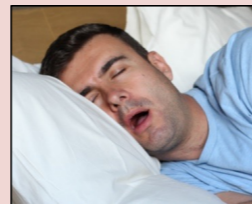


## 2) Remember to swallow

Try to remember to swallow every so often to clear the saliva from your mouth. This is particularly important when your attention is turned to other tasks. As well as enlisting the support of somebody else, you might want to set a reminder on your mobile phone or download a mobile 'app' (such as 'Swallow Prompt: Saliva Control'), which will discreetly beep or vibrate every few minutes to remind you to swallow.

## 3) Keep a good posture

Keeping an upright posture can help to prevent saliva drooling out of the mouth. If you are wheelchair-user, you may want to seek advice on more upright seating support from your occupational therapist or physiotherapist.



If you struggle with saliva management at night, you may find sleeping on your side more comfortable than on your back. This will enable

saliva to collect in your cheek or onto your pillow, rather than run backwards into your throat causing coughing.

## 4) Natural remedies

Several natural remedies are considered helpful for saliva management. Some examples include:

- Drinking dark grape, pineapple or papaya juice can help minimise saliva production.
- Chewing gum or sucking on a sugar-free boiled sweet will help to draw saliva back in your mouth for swallowing.

Please note that these suggestions may not be appropriate for everybody. You should be particularly cautious with these suggestions if you have problems chewing and/or swallowing. Only try things that are suitable and safe for you and, if in any doubt, consult a speech and language therapist.

## 5) Additional suggestions

- You may find it useful to use a waterproof insert discreetly placed between layers of clothes to prevent wetness on the skin. Alternatively, you could try wearing a scarf made of absorbent material.
- At bedtime, placing an absorbent cloth between your pillow and pillowcase can help frequent bedding changes.
- Try to keep tissues or a handkerchief with you

to dab away saliva from around your mouth. Dab, rather than wipe, to avoid irritating your skin. A towelling wrist band might be an easier option, to dab away saliva, if using tissues is difficult.

- Vaseline or lip balm may help if your lips and corners of your mouth are becoming sore.

## Things to avoid:

- Acidic fruits (like oranges) and their juices, or chewy sweets can increase saliva in the mouth.
- If you drink alcohol, be aware that this may stimulate saliva production. You may also wish to consider switching your mouthwash to an alcohol-free version.

## Further help and advice

If none of these strategies are helpful, there are a variety of other treatment options to consider. Some of these options are likely to have side-effects, so you would need to consult with your neurologist and/or speech and language therapist to ensure the treatment is right for you. Examples include:

- Exercises to help optimise (or maintain) movement of the muscles in the mouth and throat
- A suction device
- Prescribed medication
- Botox of the saliva glands.
- In extremely rare cases, surgery or radiotherapy to the saliva glands may be considered.

