

MND Podcast number two:  
Secretion management and dysphagia



My name is Robyn Reid and I am the MND SCW in the Southern Region. This is the second session in a series of talks about the management of MND in Palliative care. This podcast will talk about the management of secretions and dysphagia which is difficulty or discomfort in swallowing.

Dysphagia results in a loss of the ability to seal the lips and chew. When we chew food we form a lump of food with the tongue, which is then moved from the front of the mouth to the back for swallowing. In MND there is a little or no swallow reflex and poor tongue function making eating difficult. The airway may not close while swallowing. There may also be muscle spasm and acid reflux.

The management and treatment of secretions troubles many people with MND. What would happen if you were having difficulty swallowing? This would make eating and drinking hard work and meals would be less enjoyable to say the least. It is difficult to make sure hydration and nutrition are adequate when swallowing is unpleasant and hard to do. We produce one to two litres of saliva a day. We are swallowing continually throughout the day and usually don't think about this process at all.

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The impact of poor swallowing and difficulties with speech on the person with MND is high. A thorough and ongoing assessment of swallowing is important as function may change with disease progression. Mouth care difficulties can mean that the health of the mucosa of the mouth can be hard to maintain. People may have a sensitive gag reflex and so anything placed in the mouth may trigger unpleasant gagging. Gentle mouthwashes and swabbing may be preferable. Low foaming toothpaste may also be of benefit.

Secretions may not be able to be removed easily and this may lead to drooling or pooling of saliva. This means discomfort, embarrassment, and low self-esteem which in turn may lead to social withdrawal, and less participation in activities such as eating with others. It is important to provide protection for the skin if saliva is a problem. Adequate management of secretions is a quality of life issue.

Secretions may be thick or thin depending on the person and the time of day. This means there is no one size fits all approach to treatment. To ensure the best intervention there needs to be a thorough picture of the way secretions are produced throughout a twenty-four hour period. This is done by describing the nature of the secretions, whether they are thick or thin, the colour, the

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time they happen and pattern. How are these changes impacting on the person and how distressing are they?

Due to the difficulties with respiration thick secretions are a problem. Mucus plugs, if very thick, can be dangerous and may need management with medication. Using a nebuliser and increasing hydration can assist to break down thick secretions. Papaya, grape and pineapple juices can assist in thinning down secretions. Physiotherapy input to ensure good posture and head and neck support, are important both for eating and drinking as well as breathing. Training in an assisted cough technique, to strengthen the ability to move secretions out of the chest, can also assist. There is a device called an Assisted cough machine and these seem to be of some value to people with MND.

When a Percutaneous Endoscopic Gastrostomy or Peg tube is inserted into the stomach, there may be increased secretions for a while, so people are encouraged to continue with swallowing. While there are a range of medications available to dry secretions, they work best on a when necessary basis, such as when socialising or going out. Constant use of medication can actually make the secretions worse. The same goes for suction, and it is not a

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recommended treatment as it can cause dependency and make the situation worse, but for some people it may be a comfort. Some things that can assist excessive production of saliva include: Golden rod drops and sodium chloride tablets crushed and sprinkled under the tongue, as well as sage and hibiscus tea. Reducing caffeine intake and reducing acidic and citrus foods may also help. Any intervention should begin with least invasive options and go from there. Botox can be of benefit as can radiotherapy, but the risk is further damage to swallowing capability.

If a person chooses a Peg tube this must be done before poor respiratory function affects the person's ability to cope with an anaesthetic with minimal risk. Radiologically inserted gastrostomy is an alternative to surgery. This discussion needs to take place sooner rather than later and the person can be hard to convince given that at the moment they may not be too impaired.

Although people with dysphagia in MND can continue to enjoy food and fluids orally, it is more difficult for them, so maintaining adequate hydration and nutrition is problematic. A Peg tube if chosen, will significantly assist the carer to hydrate and deliver medication as well as maintain nutrition, so it becomes much easier for the carer. It may also reduce the anxiety associated with meals

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and reduce aspiration of food and fluids. It does help to maintain and stabilise weight and maintain adequate nutrition and hydration.

Food and fluid intake, low mobility and medication may affect regular bowel movements. Although MND does not cause incontinence, issues with mobility, clothing and timely assistance may mean the person does not reach the toilet in time. People may decide to drink less in order not to need assistance as often, so making sure toileting and help are regularly offered is important for the persons dignity, comfort and well-being.

There is also the possibility that aspiration can occur due to coughing fits or impaired swallowing when eating or drinking. For this reason a dietitian will be involved to supervise the diet and intake of the person with MND. They may need to provide assistance with the Peg feeding regime and products, as well as make suggestions about how to thicken foods and present pureed foods to ensure that they are appetising. Input from allied health professionals around the appropriate equipment to assist with meals and posture is necessary. This may include collars for neck support, cutlery and adapted items to assist with independence when eating. When helping someone with MND to eat or drink bear in mind how fatiguing this can be and allow extra time. Reduce the need

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for someone to turn or move their head and ensure their posture is upright and supported to assist swallowing.

Sometimes a video fluoroscopy is performed. Video fluoroscopy examines anatomy and function while swallowing, and is able to determine the cause of difficulties. It detects silent aspiration and educates affected people, carers and others about swallowing. It can reduce fear and distress about food and fluid intake and assist management strategies. It can also establish a baseline of functioning and identify risks.

Choking can occur through aspiration, impaired respiration and muscle spasm. People with MND may fear choking to death so it is important to let them know that the coughing fit will stop. Provide calm reassurance till the choking episode passes.

The enjoyment of food and drink is something that all people participate in and it is often the focus of entertainment, family gatherings and special celebrations. The person with MND may withdraw from participation in social situations and may feel grief at the loss of this activity. They may feel embarrassed or frustrated and no longer find eating and drinking pleasurable. It may in fact be exhausting. Needing to eat pureed food may add to the

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resentment around being dependent on others. They may need assistance with mobility, and the ability to manage and hold equipment, such as cups and cutlery. They may have difficulty communicating their desires for food and fluids, as they must wait until a person is in close by as they cannot shout out. Access to a bell or communication device is critical. Needing to wait for others when they feel hungry or thirsty may mean they don't meet their nutritional needs, with negative outcomes for their health, wellbeing, weight and quality of life.

I look forward to discussing more detail about various aspects of MND management in future sessions which will be available on the SMRPPC website. I would like to take this opportunity to give my thanks to staff at Bethlehem Calvary health care and MND Victoria for the support and training received in my role as MND SCW in the Southern Region. Please feel free to contact me should you wish to have an education session on MND for your agency or to receive a secondary consultation. You can contact me on: 0428264446 or email me at: [Robyn.reid@smrpcc.org.au](mailto:Robyn.reid@smrpcc.org.au)

Thank you.

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