



# P8

## Managing dysphagia in Motor Neurone Disease

**Motor neurone disease (MND) results from the progressive loss of motor neurones in the brain and spinal cord. These are the nerve cells that control movement. It leads to muscle weakness and can cause difficulties with movement, breathing, swallowing and speaking.**

Around 80% of people with MND will experience swallowing problems, known as dysphagia.<sup>1</sup> These issues can make eating and drinking difficult and affect the health and quality of life of people with MND.<sup>1,2</sup>

Dysphagia should be treated early. Support must be tailored to the individual and regularly reviewed to meet their changing needs.

We've created this resource to help professionals provide the best care for people with MND experiencing swallowing issues. It covers:

1. **What is dysphagia?**
2. **Assessing swallowing problems**
3. **Managing swallowing**
4. **Enteral feeding methods**
5. **Other issues related to dysphagia**

# 1. What is dysphagia?

Dysphagia is the medical term for difficulty swallowing. These problems are caused by the weakening of the muscles in the face, mouth, tongue and throat, known as bulbar muscles.<sup>2</sup> About a third of people develop their first MND symptoms in these muscles, and they typically experience dysphagia earlier than people with other forms of MND.<sup>1</sup> Weak bulbar muscles also make speaking difficult.<sup>3</sup>

Swallowing is a complex process involving many muscles and nerves. Depending on whether the food or liquid is in the mouth, throat, or gullet, the swallowing process can be divided into oral (mouth), pharyngeal (throat) or oesophageal stages (gullet).<sup>2</sup> People with MND have the most trouble during the oral and pharyngeal phases when they chew and swallow food or drinks.

Signs of dysphagia <sup>4,5</sup>	
Eating/drinking becoming tiring and taking longer due to weak chewing.	Coughing or choking when eating and/or drinking.
Food or drink leaking out of the mouth due to poor lip or tongue control.	Wet or muffled sounding voice or hoarseness.
Drooling due to reduced/impaired swallowing – this is known as sialorrhoea.	Weight loss – recognisable signs include clothes fitting looser or more visible cheekbones.
Problems co-ordinating breathing and swallowing, especially once the person needs non-invasive ventilation more often.	Changes in eating behaviours, for example avoiding eating or drinking, not enjoying eating or drinking, leaving food or eating slowly.
Difficulty moving the tongue in the mouth or food/liquid backwards to trigger the swallow reflex.	Needing several swallows for each mouthful of food.
	Pain and discomfort when swallowing.

Dysphagia can lead to serious medical complications and increase the risk of death. It can cause unintentional weight loss, malnutrition and dehydration. These impact the overall health of the person with MND, causing, for example, fatigue, reduced strength, bowel problems and fragile skin.<sup>5</sup> People with dysphagia also have trouble swallowing saliva, leading to drooling.<sup>2</sup>

Swallowing effectively is important to protect the airway and lungs. Dysphagia increases the risk of food, drinks and saliva going down the airway. This is known as aspiration and can cause coughing and choking. It can also be silent, without the person realising and causing any coughing or visible signs.<sup>2</sup>

Respiratory issues also make it challenging to protect the airway. For example, a weak cough makes it more difficult to clear the throat and remove the irritant.<sup>6,7</sup> Aspiration increases the risk of chest infections, including pneumonia, which can be fatal.<sup>6,8</sup>

Choking, or sensations of choking, can be very distressing for both the person with MND and those around them, but it is very rarely the cause of death in MND. A small number of people may experience unexpected coughing or choking due to spasms in throat muscles, especially laryngeal muscles (laryngospasm). Medications can help manage these spasms, however people with dysphagia might have trouble swallowing tablets.<sup>9</sup> See pages 17-18 for information on medication and care for laryngospasms.

Swallowing issues can also reduce quality of life, affecting mental wellbeing, independence and participation in social activities. Individuals with MND may stop enjoying meals because they find it uncomfortable, can't eat their favourite meal, or because they eat slowly, so the food becomes cold and unpleasant. They may feel nervous about taking a long time to eat, coughing or drooling in front of others. This might make them miss out on meals with friends and family.<sup>10</sup> Friends and families may also not want to eat in front of the person with dysphagia in case it's upsetting for them.

Overall, dysphagia can change daily life for everyone in the household, disrupting routines and eating habits, which can be hard to adjust to. A person with MND might think they are a burden on carers, who may have to assist them with eating or prepare different meals.<sup>10</sup> Carers may also worry about choking and ensuring the person's safety, or feel frustrated by the inability to stop weight loss.<sup>11</sup>



### **Information to share with people with or affected by MND:**

Information sheet 7A – Swallowing difficulties  
Booklet – Eating and drinking with MND

**See page 22 to order publications.**

## **2. Assessing swallowing problems**

According to NICE guidelines, professionals should assess a person's feeding, drinking, and swallowing abilities at diagnosis and regularly at multidisciplinary team (MDT) visits. Weight, hydration, nutritional intake and oral health should also be monitored.<sup>12</sup> Keep in mind that there are various reasons why a person with MND might lose weight or have trouble eating, including:<sup>6,12</sup>

- swallowing difficulties
- low mood causing loss of appetite and weight loss
- fatigue and limb weakness, making eating and preparing meals tiring and slow
- gastrointestinal problems like nausea or constipation

- poor oral hygiene causing pain or bad taste in the mouth – bacteria in the mouth could also enter the lungs if food or drinks are aspirated, contributing to chest infections. Good oral hygiene helps prevent this risk and improves comfort, however people with MND may need help with it.

Respiratory issues also contribute to making eating and drinking more difficult, so it's important to regularly assess respiratory function, including the efficacy of coughing and throat clearing.<sup>1</sup>

Whoever first notices a problem should immediately refer the person with MND to the right specialists.

Experts at MND care centres or from community teams can advise on dysphagia management and signpost appropriate services. Unregistered professionals must immediately report to their manager any concerns or changes in the person's condition.

Referral to a speech and language therapist (SLT) should be a priority. They can evaluate the ability to eat, drink and swallow and develop an appropriate management plan, which may include:

- Arranging a bedside assessment for dysphagia or, if it's suitable, an instrumental assessment videofluoroscopy and/or fiberoptic endoscopic evaluation of swallowing (FEES).<sup>2,3,12</sup> It is important to assess swallowing periodically, as some people do not report symptoms of dysphagia.<sup>1</sup>
- Looking at factors that contribute to swallowing issues such as positioning, fear of choking, food and drinks consistency.<sup>12</sup>
- Assessing the need for tube feeding options, including gastrostomy.<sup>12</sup> These options should be discussed with the person with MND early on and regularly (see page 11).
- Working with other professionals to manage dysphagia and educate the person with MND, their family, carers and care workers. For instance, teaching feeding techniques and advising on ways to deal with social situations.<sup>12</sup>

Other professionals can also assist with management, including:

- a dietitian to develop a diet that optimises nutritional and fluids intake
- an occupational therapist to recommend strategies and equipment for mobility issues and limb weakness
- a physiotherapist to teach techniques to clear secretions and cough, and recommend head supports and positions to make swallowing easier and safer
- a specialist respiratory team to assess breathing issues contributing to swallowing or eating difficulties
- neurologist and gastroenterology services to evaluate the need for tube feeding
- GPs and pharmacists to prescribe appropriate medications
- dentists and dental hygienists to advise on good oral health, which helps reduce pain, discomfort and the risk of infections.

### 3. Managing dysphagia

Managing dysphagia requires a multidisciplinary approach. Ensuring nutritional and hydration needs are met, maintaining swallowing safety, and managing mealtime challenges are essential aspects of care.

Effective interventions include:<sup>2</sup>

- changing the consistency of food and drinks
- providing nutrition support, for example with high-calorie and protein diets and nutritional supplements<sup>13</sup>
- teaching techniques to swallow safely, co-ordinate breathing, manage secretions and choking
- using aids and equipment to help eat and drink.

As MND progresses, swallowing can become more difficult and/or unsafe, with a higher risk of aspiration. People may need tube feeding to supplement or replace oral intake of food/liquid.<sup>13</sup> However, not everyone will want to choose this option (see page 11).

#### Modifying food and drink consistency

People with dysphagia often find certain food and drink consistencies easier to swallow. For this reason, the SLT might recommend modifying the texture of solid food and the viscosity of drinks, changing meal sizes, or adjusting food presentation and temperature.<sup>4</sup> When suggesting modifications, they should consider:<sup>4</sup>

- the individual's swallowing ability and how changes to diet may affect their quality of life or their carers'
- the risk of aspiration, malnutrition and dehydration
- the capacity of the individual to understand and consent to the care plan
- the input of experts like dietitians and pharmacists to meet nutritional and medication needs
- the individual's habits and whether they want to continue to enjoy certain food/drinks despite the risks (page 16). Supporting these choices can enhance mealtime enjoyment, promote a sense of independence, and empower decision-making, all of which can improve adherence to the treatment plan.<sup>10,11</sup>

**Everyone's ability to swallow is different. The table on the next page only describes general tips. It's always best to seek advice from an SLT, who can recommend which food and drink consistencies are appropriate and which ones to avoid.**

General tips for eating <sup>14</sup>	Food to avoid <sup>15</sup>
Choose softer foods, like blended or puréed items, to make chewing easier.	Food with mixed consistency and liquid with 'bits' such as minestrone soup, cereals in milk or fruits with skins like grapes.
Keep flavours distinct by blending and serving different foods separately, rather than mixed together.	Foods that need a lot of chewing, for example fresh bread or some meats.
Cut food into small pieces or mash it well with a fork so it requires less effort to chew.	Food with stringy fibrous texture, including celery, lettuce, pineapple, onions, melted cheese or some beans.
Add sauce or gravy, as moist food is easier to swallow.	Coarse hard food such as nuts or chewy sweets.
Food with high fluid content, for example soups, casseroles and stewed fruit, can also help prevent dehydration.	Crumbly, dry or crunchy food, for instance toast, biscuits or flaky pastry.
If considered appropriate by the SLT assessment, choose thicker food/ drinks. Consider thickening food with ingredients such as potatoes or cream in stews, casseroles or sauces. Having naturally thicker drinks, for instance milkshakes or smoothies, could also help.	Some vegetable skins which can be difficult to clear in the mouth such as tomato, sweetcorn, black-eyed peas.
	Foods that become sticky in the mouth, for example bread or mashed potatoes.

Consistencies should be described using the terminology set out by the International Dysphagia Diet Standardisation Initiative, or IDDSI, guidelines. This framework defines a continuum of levels (0–7), where drink thickness is measured from levels 0–4, while food texture from levels 3–7.<sup>16</sup>

Visit [iddsi.org](http://iddsi.org) to learn more and see the illustration on the next page.

It's important to document the recommended levels of food and drinks in the individual's care plan and explain them to anyone who prepares food for the person with MND.



© The International Dysphagia Diet Standardisation Initiative 2019

The SLT might suggest adding a thickening powder to drinks, which is available on prescription.<sup>17</sup> For some people, thickened drinks can reduce the risk of aspiration and associated complications and make drinking more comfortable. However, there are potential challenges with this approach, including:<sup>4</sup>

- a higher risk of dehydration and urinary tract infections
- changes in bowel habits
- higher risk of oral and pharyngeal residue
- delayed or reduced absorption of some medications
- an increased chance of respiratory tract infections if thickened fluids are accidentally inhaled
- feeling full too quickly, being unable to finish meals, increased thirst and unpleasant taste and texture. These can contribute to poor treatment adherence, worsen emotional wellbeing and reduce quality of life.

The Royal College of Speech and Language Therapists has developed a position statement and a paper on the use of thickened fluids. They advise that the decision whether to use them should involve a process of informed consent based on a comprehensive assessment that includes the best available evidence of risks and benefits, individual needs and the potential effects on both health and overall quality of life. Health professionals must ensure that the person with MND or their representative understands what thickening fluids as a treatment involves, as well as its potential downsides and advantages.<sup>18</sup> Any decision to trial thickened fluids should always be reviewed.

Visit [rcslt.org/news/our-statement-on-thickened-fluids](https://rcslt.org/news/our-statement-on-thickened-fluids) and [rcslt.org/wp-content/uploads/2024/07/Thickened-fluids-position-paper.pdf](https://rcslt.org/wp-content/uploads/2024/07/Thickened-fluids-position-paper.pdf) for further details.

## Nutritional support

Nutritional support is crucial for those who struggle to eat or drink enough. Modifying food texture and drink thickness can also lower nutritional and fluid intake.<sup>14,19</sup> For example, avoiding risky food such as bread and fibrous fruits and vegetables might result in insufficient fibre intake and cause constipation. Puréed diets can also be less nutrient-dense compared to regular diets.<sup>14</sup>

A dietitian, based on the SLT's advice, can provide a diet plan to enhance energy and nutrients such as proteins and vitamins.<sup>8</sup>

The dietitian can suggest:<sup>11,14</sup>

- high energy food
- ways to add flavour and taste to food
- how to maximise calorie intake and fortify food, for example with butter, yogurt or full cream milk
- supplements available on prescription, which can also be used to fortify food.

Some people with MND might have particular beliefs on healthy eating and might feel hesitant to implement the required changes due to concerns about the impact of calories on their general health.<sup>11</sup> Educating the person with MND and their carers on the importance of maximising energy, calories, and nutrient intake, and how to do so effectively, is essential.

## Teaching swallowing and coughing techniques

It's important to train people with MND and their carers or care workers on techniques to improve swallowing, safety and secretion management.

Recommending ways to maintain the correct posture, as suggested in the table on page 10, can help protect the airway while swallowing and prevent choking.

Saliva can be managed in many ways, including with medication and suction machines. A mechanical insufflation-exsufflation (MI:E) machine, often known as Cough Assist, can effectively enhance cough but may be difficult to use for people with poor bulbar function.<sup>6</sup>

Exercises aimed at strengthening cough or the muscles involved in breathing out can also help. These might include techniques such as assisted breath-stacking using a lung volume recruitment bag, or expiratory muscle strength training (EMST).<sup>6,12,22</sup>

## Eating and drinking aids<sup>10,14,20,21</sup>

Food quality and aesthetics, mealtime environment and feeding assistance all contribute to nutritional intake. These tips can help in preparing and serving food:

- Serving several small meals instead of one large meal can make eating less tiring.
- Be flexible about mealtimes. For example, offer the main meal at lunchtime when energy is higher.
- Take breaks between courses if eating is slow and tiring.
- Make puréed or minced food more appealing: use garnishes and attractive colours, or shape it with moulds to make it look like the original ingredient. Make sure the person can see and smell the food and serve snacks they like. Decorated plates, bowls or cutlery can also improve the visual appeal of meals.
- Keep food warm and reheat if necessary. Using a keep-warm plate may help. Reheat smaller portions of the meal so it does not become soggy.
- A relaxed environment may help the person feel less anxious: allow plenty of time for the meal and let the person concentrate on what they're doing. Wait for them to swallow before asking questions.
- Sipping an iced drink or eating anything cold/frozen before meals and in between mouthfuls can stimulate a stronger swallowing reflex. This may be counterproductive if drinking is difficult.
- Encourage the person with MND to participate in meals with friends and family. They could take a few bites when joining them and finish the rest of their meal when they are alone or more relaxed.
- Encourage good mouth hygiene, even if the person only uses tube feeding. This includes rinsing the mouth and brushing teeth, dentures and tongue using a suction toothbrush and low foam toothpaste. A suction unit can be used to clear away food debris. It's important that the person has regular checks from a dentist, and carers are given instructions on how to help maintain oral health.
- Be mindful that a person's food and meal habits are influenced by their culture and personal views. These should be respected at all times.
- Be aware that a person with cognitive impairments might need extra support as they might have trouble understanding the effects and risks of swallowing difficulties (see page 15).

The equipment listed on the following page can also help with eating and drinking. They can increase independence and make eating and drinking easier and less tiring, improving quality of life.

Potential problem	Strategies to try	Professionals involved
Posture	Sitting upright in a firm, high-backed chair. Sitting straight after eating can also help prevent acid reflux.	Occupational therapist and physiotherapist
	Keeping head erect.	
	Adequate support for arms.	
Weak neck muscles	A collar or chin support may help – although some designs may make swallowing more difficult.	Orthotic services and occupational therapist
Weakened grip and limited wrist movement	Specially designed plates, cups and cutlery.	Occupational therapist
	Attaching cutlery to splints.	
Difficulties in lifting food or drinks to the mouth	An adjustable cantilever table.	Occupational therapist and speech and language therapist
	Specially designed cups.	
	A bed tray (with small legs) on the table.	
	Mobile arm supports.	
	A foot-operated feeding device.	
	Powered feeding devices.	
	Straws with a one-way valve – use with caution. Using a straw often encourages drinking large mouthfuls that arrive further back on the tongue than when drinking from a cup. Aspiration can occur if the person has poor oral control.	



### **Information to share with people with or affected by MND:**

Booklet – Eating and drinking with MND

Booklet – Personal care for people with MND or Kennedy's disease

### **Information for professionals:**

Information sheet P3 – Managing saliva problems in MND

Information sheet P6 – Evaluation and management of respiratory symptoms in MND

Information sheet P9 – Oral suction

Information sheet P12 – MND information for dental teams

Booklet – Occupational therapy for MND

Booklet – Caring for a person with MND: a guide for care workers

Infographic – Dietetics and nutrition

**See page 22 to order publications.**

## **4. Enteral feeding methods**

Tube feeding methods, also known as enteral feeding, can improve survival and help maintain quality of life. For example, they can reduce the anxiety associated with dysphagia and help stabilise weight.<sup>3,6</sup>

NICE guidelines recommend discussing enteral feeding with people with MND at an early stage and regularly as their condition progresses. Professionals should also explain the benefits of placing a feeding tube early and the disadvantages of late intervention (see the next page).<sup>12</sup>

Discussing feeding tubes early will give the patient time to make an informed decision and consider various options before a crisis is reached, such as swallowing becoming too difficult or unsafe.<sup>23</sup>

A feeding tube is often fitted while the person can still eat and drink by mouth. They may continue to eat normally, using the tube to top up their nutrition as needed. As swallowing becomes harder, more of their food and fluids may be given through the tube. The SLT and the dietitian, along with the care team, will help the person decide how to balance oral and tube feeding.

Some people may choose not to have enteral feeding. The MDT must support their decision.



### **Information to share with people with or affected by MND:**

Information sheet 7B – Tube feeding

**See page 22 to order publications.**

## Types of enteral feeding

Enteral feeding involves delivering food, liquids and medication directly to the stomach through a tube. There are different ways to place the tube. A gastrostomy tube is inserted through a small opening in the abdomen. A nasogastric tube, or NGT, is inserted through the nose.<sup>24</sup>

NGT is usually for short-term use, often in hospitals when someone is malnourished or dehydrated or is waiting for a gastrostomy placement. It is also used when gastrostomy is not possible. This method is often considered less comfortable than a gastrostomy tube.<sup>2</sup>

Liquid food can be provided through different methods once the feeding tube is placed:

- Using a syringe.
- Using gravity – where a bag of liquid feed is hung from a stand and allowed to drip through a tube.
- Using a pump – which delivers a set amount of feed into the tube, generally over several hours.

## Gastrostomy placement

Percutaneous endoscopic gastrostomy, or PEG, is the preferred method when someone has good respiratory function. When breathing is significantly compromised, a radiologically inserted gastrostomy (RIG), where the feeding tube is inserted under x-ray guidance, is preferred. Another method is a per-oral image-guided gastrostomy (PIGG), which is a hybrid of PEG and RIG. At present, it is not widely available.

The optimal timing of gastrostomy placement is not entirely clear. NICE recommendations suggest that enteral feeding should be considered for individuals who are malnourished or at risk of malnutrition, have inadequate or unsafe oral intake and have a functional gastrointestinal tract.<sup>5</sup> Studies indicate that the best time for people with MND to get a gastrostomy is when they have lost around 5% of their body weight since symptoms onset.<sup>6</sup>

Earlier placement of a gastrostomy tube is recommended, even if it isn't used immediately. Delaying gastrostomy exposes people to more procedural risks with little nutritional benefit.<sup>6</sup> Possible risks of a late gastrostomy include:<sup>12</sup>

- continued weight loss and dehydration
- respiratory complications
- a higher risk of mortality, failed insertion and procedural complications.

Severe weight loss before having a tube fitted may increase the risks during and after the procedure. Surgery can also become increasingly difficult as respiratory symptoms progress.<sup>25</sup>

Therefore, the conversation about alternative feeding should happen early, before a crisis is reached, and be revisited regularly. It should take into consideration:<sup>12</sup>

- the risk of aspiration and choking
- anxiety when eating
- inadequate food or fluid intake
- the amount of time and effort required to eat, and fatigue from eating
- weight loss and dehydration
- respiratory function.

It should also consider the speed of MND progression and condition overall. If a person is referred for a gastrostomy, it should take place without delay.<sup>12</sup>

## Making the decision

The decision to have a gastrostomy is complex and individual. The pros and cons of this option should be discussed to help the person make an informed choice.

Understanding the factors that influence and/or delay the choice can help professionals in supporting the people in their care. Research has shown that several factors influence decisions about artificial feeding, including:<sup>23</sup>

- positive or negative personal views on gastrostomy – some people may perceive it as “giving up”
- perceived swallowing abilities and nutritional status, which may not match objective measures
- personal beliefs or spirituality
- impact on quality of life, including the impact on their families and carers
- enjoyment associated with oral eating and reluctance to give it up
- struggling with planning for the future and being overwhelmed by information
- perceiving a lack of clear advice.

Any conversations about gastrostomy with the person with MND should cover:

- how alternative feeding can affect quality of life (considering what matters to that person) and any possible side effects, such as discomfort or physical restrictions
- how gastrostomy may be included in an advance decision to refuse treatment (ADRT) – including the possibility of withdrawing from gastrostomy (see page 15)
- current or potential future cognitive problems and how they might impact their ability to decide on a gastrostomy (see page 15). It is essential to assess the capacity of the person to make a decision as per the Mental Capacity Act.<sup>12</sup> Visit [gov.uk/government/collections/mental-capacity-act-making-decisions](https://www.gov.uk/government/collections/mental-capacity-act-making-decisions) to learn more
- the procedure and what managing the feeding tube requires (see below).

While a gastrostomy can enhance quality of life, it can also create challenges for caregivers and individuals with MND.<sup>6</sup> Professionals should assess whether the person is likely to cope with the intervention. To ensure the person makes an informed decision, professionals should consider the following:<sup>5,12,23</sup>

- SLTs, gastroenterologists, dietitians, nurses, respiratory physiologists, and rehabilitation specialists should participate in the decision-making process and provide information on both the procedure and follow-up care.
- Professionals should share information upfront about tube management, transitioning from oral feeding, and what practical support might be necessary. If care support is required, arrangements need to be made at an early stage. Enteral feeding might not be an option if support is not available to manage the tube. Some people report that seeing PEG equipment demonstrated helped them to better understand the procedure and make a decision.
- It is important to recognise that undergoing the procedure after a certain point in the disease progression may be too late.
- These discussions can be emotionally challenging, especially soon after diagnosis, so they should be handled sensitively. Clinicians may find them distressing too. Psychological support services may be helpful. It also helps to have built a good relationship with the person in your care and their family before having these conversations.
- Not everyone with MND will choose this type of intervention and their decision should be respected. It is important to review the decision regularly in case the person changes their mind as the disease progresses.



### **Information to share with people with or affected by MND:**

'Gastrostomy tube: is it for me?' is a web-based patient decision aid for people with MND. [gastrostomychoice.co.uk](http://gastrostomychoice.co.uk)

'MyTube' is an online resource containing short videos and information about tube feeding for people with MND. [mytube.mymnd.org.uk/](http://mytube.mymnd.org.uk/)

## **Maintenance and potential problems**

People with MND and their carers need adequate information and training on how to manage the tube, including any required equipment, how often the feed should be administered, and how to set or use pumps. Having an instruction manual or PEG pathway is recommended.<sup>5</sup>

Potential complications include infections, bleeding, leaks, tube blockage or displacement. It's essential to keep the placement site very clean and only use appropriate liquid food and medication. The tube should be cleaned and flushed daily, even if it has not been used.<sup>21,24,26</sup> This also helps prevent possible blockages caused by residues of food, drinks or medications.

Carers and care workers must be properly trained to do this. Professionals should provide the necessary training and contacts in case of medical complications. The contacts should include professionals who understand the needs and problems of people on home enteral feeding.<sup>5</sup>

Using the tube may cause changes in bowel habits.<sup>24</sup> A dietitian or MND specialist should be consulted about these issues.

## **Refusing or withdrawing a feeding tube<sup>21</sup>**

A person with MND can make an advance decision to refuse treatment (ADRT) to decline certain treatments, including life-saving ones. This could include instructions about initiating or withdrawing artificial nutrition and hydration. Those with a gastrostomy can choose to stop using it whenever they wish. This option should be part of the discussion when deciding on the intervention.

If someone decides not to have a gastrostomy, or to stop using it, they may require other treatments to manage hunger and thirst. Typically, these desires decrease as the disease progresses, but medication may minimise discomfort. Consult the specialist palliative care team to help manage discomfort or pain.

## **5. Other issues related to dysphagia**

### **Cognitive change**

About half of all people with MND experience some degree of cognitive and/or behavioural change.<sup>27</sup> This rises to 80% in the final stages of the disease.<sup>28</sup> Some develop frontotemporal dementia, or FTD, which involves severe cognitive changes.<sup>27</sup>

If someone experiences these changes, they might struggle to understand the need for certain interventions or to make a decision about care. People may also have trouble following or tolerating certain treatments.

It's important to talk about future care plans before the person can no longer communicate or before their thinking and behaviour change significantly. This should include their preferences about feeding options and the possibility of making an ADRT.

If the person lacks the capacity to make an informed decision and has not documented their wishes in an advance care plan, consult their family and the specialist palliative care team in your area. A best interests meeting may be needed to determine whether any procedure is right for that person.<sup>21,29</sup>

As cognitive and behavioural issues worsen, people with MND may need extra support and different interventions to manage dysphagia. It is essential to consider both their swallowing abilities and broader mealtime issues.<sup>19,30</sup>

Cognitive difficulties can affect the person's ability to start eating, maintain attention or recognise food and cutlery. This may lead to taking a long time to finish meals and not eating or drinking enough. They might also struggle with following or remembering instructions about safe swallowing techniques, positions or exercises, which may increase the risk of choking episodes, aspiration and related chest infections.<sup>30</sup> Finally, people may develop unusual behaviours during meals, such as cramming food, eating more than necessary or preferring sweet foods.<sup>31</sup>

It is crucial to properly inform and train carers and care workers on how to adjust diets and ensure safety while helping the person with MND. For example, ask them to:<sup>30</sup>

- sit with the person while they eat to assist and encourage them to finish their meal
- supervise their eating closely to monitor their behaviour and prevent aspiration or choking
- ensure that mealtimes are free from any distractions and maintain a quiet and calm environment
- use pointers and cues to encourage the person to focus on eating
- repeat reminders about swallowing techniques and safety tips
- offer multiple small meals to prevent cramming.

Working with a dietitian can ensure the person receives the right nutrition and that any specific cravings are addressed. It is also important to assess if modified texture diet, including thickened drinks, is appropriate. If the person struggles to follow the diet or swallow safely, enteral feeding might be an option. However, the benefits of gastrostomy for people with severe dementia can be uncertain.<sup>6,21</sup>

## **Eating and drinking with acknowledged risks**

A person may make a decision that their clinicians, carers or family think is unwise. For example, they might choose to continue to eat their favourite food, despite the risk of choking, because it's important for their quality of life. Making an unwise decision does not mean that they lack mental capacity.

The Royal College of Speech and Language Therapists advises that the MDT should talk with the person with MND to ensure that they are aware and understand the risks. Professionals, along with the person with MND and their carers, should then work together to reduce those risks, including creating clear guidance for emergency situations. Assessment by the SLT is vital to offer adequate strategies.

Any decisions, discussions and protocols about eating and drinking with acknowledged risks must be documented in the care plan. It's also crucial to follow any local policies. If someone has capacity to make a decision and the decision has been agreed with professionals and properly documented, following the relevant policies, the person feeding them is not responsible for any risks.

For more information, visit [rcslt.org/members/clinical-guidance/eating-and-drinking-with-acknowledged-risks-risk-feeding/](https://www.rcslt.org/members/clinical-guidance/eating-and-drinking-with-acknowledged-risks-risk-feeding/)



### **Information to share with people with or affected by MND:**

Booklet – Changes to thinking and behaviour  
Information sheet 14A – Advance decision to refuse treatment and advance care planning

### **Information for professionals:**

Booklet – Cognitive change, FTD and MND  
Booklet – Advance care planning for MND  
Infographic – FTD

**See page 22 to order publications.**

## **Medication**

Some people will have problems swallowing tablets, so a GP or a pharmacist can suggest alternative forms of medications, such as syrups or patches. They may also consider stopping any non-essential medications.

Crushing or dispersing medicines that are not meant to be given this way can make them unsafe or ineffective. This includes riluzole tablets, the only disease-modifying drug available to people with MND in the UK.<sup>1</sup> People with dysphagia can be prescribed riluzole in a liquid form.<sup>32,33</sup> Riluzole is also available as a film that slowly melts on the tongue (orodispersible film). This could cause mouth numbness, known as oral hypoesthesia, which can last for an average of around 40 minutes.<sup>34</sup> Keep in mind that adding thickeners to medicines can delay absorption and reduce effectiveness.<sup>4</sup>

Many medications can be administered through a gastrostomy tube. Even if they are in liquid forms, medicines that are not licensed for enteral feeding can cause blockages or adhere to the tube's surface. A pharmacist can advise which medicines are safe to use with a gastrostomy.<sup>35</sup>

Where medicines are given through a feeding tube, it's crucial to flush the tube between each medication.<sup>35</sup> Research has shown that people with dysphagia are more likely to experience medication administration errors than the general population, so it is important to be vigilant and provide appropriate training.<sup>36</sup>



### **Information to share with people with or affected by MND:**

Information sheet 5A – Riluzole

**See page 22 to order publications.**

## Laryngeal spasm<sup>9</sup>

Some people may experience uncontrolled and involuntary contractions of the laryngeal muscles or vocal cords due to swallowing problems. These can often follow acid reflux or food and saliva sticking in the airway.

This condition is known as laryngospasm, but it can also be referred to as inducible laryngeal obstruction or ILO. It can be very distressing as it can briefly stop someone from breathing or speaking. If this happens, encourage the person to tilt their neck back, take a slow breath in and a quick breath out. They might also make a loud, high-pitched sound known as stridor.

Sitting up straight after eating can also help prevent acid reflux.<sup>4</sup> A healthcare provider may consider prescribing lorazepam to help with laryngeal spasms.<sup>6</sup>

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## How we can support you and your team

Our MND Connect helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. They can also provide further information about our services mentioned below.

Email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

Tel: **0808 8026262**

### MND Association website

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

[mndassociation.org/professionals](https://mndassociation.org/professionals)

Stay updated on events, publications and opportunities for professionals.

[mndassociation.org/educationupdate](https://mndassociation.org/educationupdate)

X: [mndeducation](#)

Bluesky: [mndeducation.bsky.social](#)

### Information resources

We produce high quality information for people with MND, carers, families and professionals, available in multiple formats and languages.

[mndassociation.org/pro-info-finder](https://mndassociation.org/pro-info-finder)

[mndassociation.org/careinfinder](https://mndassociation.org/careinfinder)

### Education

Our education programme aims to improve standards of care and quality of life. Opportunities include webinars and face to face equipment training.

[mndassociation.org/education](https://mndassociation.org/education)

### MND Professionals' Community of Practice

A peer led group supporting cross disciplinary learning in MND care. Membership can contribute to CPD and offers access to networking and learning events.

[mndassociation.org/cop](https://mndassociation.org/cop)

### Local support

We offer online and local peer support, plus trained volunteers who provide practical help by phone, email or visits.

[mndassociation.org/local-support](https://mndassociation.org/local-support)

We fund and develop specialist care centres and networks across England, Wales and Northern Ireland, offering multidisciplinary care.

[mndassociation.org/care-centres](https://mndassociation.org/care-centres)

### Financial support

We offer a range of grants to support people living with MND, their families and unpaid carers. These are not in place of any statutory funding that should be available.

[mndassociation.org/getting-support](https://mndassociation.org/getting-support)

### MND register

The Register aims to collect information about everyone with MND in England, Wales and Northern Ireland to support care planning and research.

[mndregister.ac.uk](https://mndregister.ac.uk)

### Research into MND

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND. We also produce information sheets on MND research for people with or affected by MND.

[mndassociation.org/research](https://mndassociation.org/research)

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## 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 [smartsurvey.co.uk/s/mndprofessionals](https://smartsurvey.co.uk/s/mndprofessionals) or email your comments to [education@mndassociation.org](mailto:education@mndassociation.org).

If you would like to help us by reviewing future versions of our information resources, please email us at [education@mndassociation.org](mailto:education@mndassociation.org).

## How to order our publications

Our publications are free for anyone with or affected by MND or Kennedy's disease, including professionals. Health and social care professionals can also order items on behalf of someone with or affected by MND or Kennedy's disease.

Download from [mndassociation.org/publications](https://mndassociation.org/publications) or contact MND Connect to order hard copies. Call 0808 8026262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org).

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**Every day we support people affected  
by Motor Neurone Disease.  
Because with MND, every day matters.**