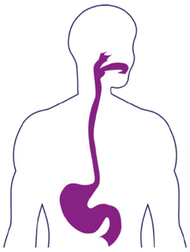

Managing dysphagia in motor neurone disease

Motor neurone disease (MND) is a progressive and life-shortening disease that causes the degeneration of the motor neurones, or nerves, in the brain and spinal cord.[1]

Around 80% of people with MND will experience swallowing problems, known as dysphagia.[1] These issues can make eating and drinking difficult and seriously affect the health and quality of life of people with MND. Dysphagia should be assessed and treated early and regularly to prevent complications.[1,2]

This information provides practical suggestions and medication options for health and social care professionals. It also includes information they can share with people in their care.

It's important to remember that everyone with MND has a different experience. Not everyone will develop symptoms in the same way or order. Support should be based on a personalised assessment and a care plan tailored to the individual, with regular reviews to adapt to their changing needs.

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.[2] About a third of people experience the first symptoms of MND in these muscles. These people usually show signs of dysphagia at an earlier stage than those with other types of MND.[1] Weak bulbar muscles also make speaking difficult.[3]

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).[2] People with MND have the most trouble during the oral and pharyngeal phases when they chew and swallow food or drinks.

Signs of dysphagia:[4,5]

- eating/drinking becoming tiring and taking longer due to weak chewing
- food or drink leaking out of the mouth due to poor lip or tongue control
- drooling due to reduced/impaired swallowing – this is known as sialorrhea
- weight loss - recognisable signs include clothes fitting looser or more visible cheekbones
- difficulty moving the tongue in the mouth or food/liquid backwards to trigger the swallow reflex
- needing several swallows for each mouthful of food
- coughing or choking when eating and/or drinking
- wet or muffled sounding voice or hoarseness
- pain and discomfort when swallowing
- problems co-ordinating breathing and swallowing, especially once the person requires non-invasive ventilation more often
- changes in eating behaviours eg avoiding eating or drinking, not enjoying eating or drinking, leaving food or eating slowly.

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.[5] People with dysphagia also have trouble swallowing saliva, leading to drooling.[2]

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.[2]

Respiratory issues also make it challenging to protect the airway. An ineffective cough, resulting from weakened respiratory muscles, makes it more difficult to clear the throat and remove the irritant.[6,7] Aspiration increases the risk of chest infections, including pneumonia, which can be fatal.[6,8]

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. Medications can help manage these spasms, known as laryngospasm (See page 12).[9] People with dysphagia might have trouble swallowing tablets. See page 12 to learn more about what to consider when prescribing and administering medications.

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.[10] 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.[10] Carers may also worry about choking and ensuring the person's safety, or feel frustrated by the inability to stop weight loss.[11]

Information to share with people with or affected by MND:

Information sheet 7A – *Swallowing difficulties* contains information for people with MND and their carers on how to manage episodes of choking.

Our guide *Eating and drinking with MND* helps people adapt how they eat and drink, if needed. It includes information, tips and easy-swallow recipes. A web app of the guide is also available.

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

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.[12] Keep in mind that there are various reasons why a person with MND might lose weight or have trouble eating, including: [6,12]

- swallowing difficulties
- low mood causing loss of appetite and weight loss
- fatigue and limb weakness, making eating and preparing meals tiring and slow
- 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 aspired, contributing to chest infections. Good oral hygiene helps prevent this risk and increase comfort, however people with MND may need help with it
- gastrointestinal problems like nausea or constipation.

Respiratory issues also contribute to making eating and drinking more difficult, so it is important to regularly assess respiratory function, including the efficacy of coughing and throat clearing.[1]

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, instrumental assessment using videofluoroscopy and/or fibreoptic endoscopic evaluation of swallowing (FEES).[2,3,12] It is important to assess swallowing periodically, as some people do not report symptoms of dysphagia.[1]
- looking at factors that contribute to swallowing issues eg positioning, fear of choking, food and drinks consistency[12]
- assessing the need for tube feeding options, including gastrostomy.[12] These options should be discussed with the person with MND early on and regularly (see page 7)
- working with other professionals to manage dysphagia and educate the person with MND, their family, carers and care workers eg teaching feeding techniques and advising on how to deal with social situations.[12]

A **dietitian** will collaborate closely with the SLT to develop a diet that optimises nutritional and fluids intake. An **occupational therapist** can recommend strategies and equipment for mobility issues and limb weakness. A **physiotherapist** can also help by teaching techniques to clear secretions and cough. Together with the occupational therapist, they can suggest head supports and positions to make swallowing easier and safer, too.

The **specialist respiratory team** can assess whether the person with MND has breathing issues contributing to swallowing or eating difficulties. A **neurologist** and **gastroenterology services** should be involved to evaluate the need for tube feeding. **GPs** and **pharmacists** can prescribe appropriate medications, while **dentists and dental hygienists** can advise on good oral health, which helps reduce pain, discomfort and the risk of infections.

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.

Information to share with people with or affected by MND:

Our guide *Eating and drinking with MND* helps people adapt how they eat and drink, if needed. It includes information, tips and easy-swallow recipes. A web app of the guide is also available.

Our guide *Personal care for people with MND or Kennedy's disease* include information on mouthcare.

Information for professionals:

Our guide *Occupational therapy for MND* covers ways OTs can support people with MND to eat/drink

Our booklet *Caring for a person with MND: a guide for care workers* includes information for care workers assisting people to eat and drink

Information sheet P3 - *Managing saliva problems in MND* includes strategies and treatment options

Information sheet P6 - *Evaluation and management of respiratory symptoms in MND*

Information sheet P9 - *Oral suction* includes information on secretion management

Information sheet P12 - *MND information for dental teams* gives an overview of potential issues people with MND face with oral health

Infographic - *Dietetics and nutrition*

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Effective interventions include:[2]

- changing the consistency of food and drinks
- providing nutrition support eg with high-calorie and protein diets and nutritional supplements[13]
- 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.[13] However, not everyone will want to choose this option (see page 7).

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.[4]

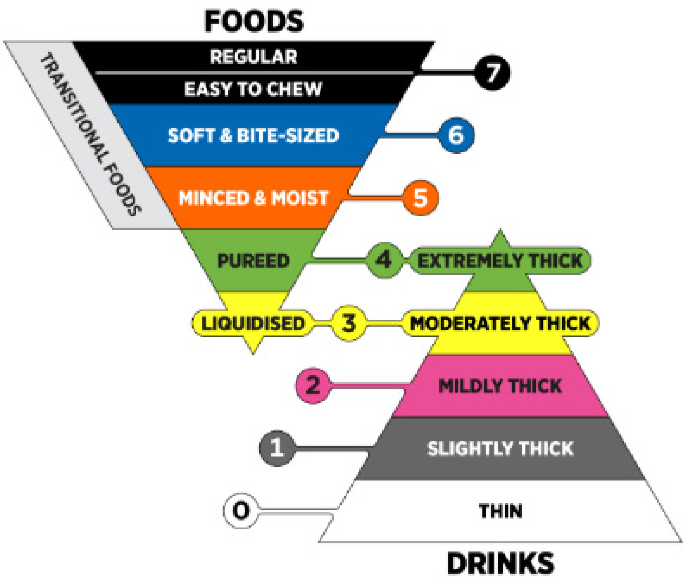
When suggesting modifications, they should consider:[4]

- 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 enjoying certain food/drinks despite the risks (page 11). 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.[10,11]

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

Everyone's ability to swallow is different. It's always best to seek advice from a SLT, who can recommend which food and drink consistencies are appropriate and which ones to avoid.

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 8 levels (0 - 7), where drink thickness is measured from Levels 0 – 4, while food texture from Levels 3 – 7.[16]



Visit **www.iddsi.org** to learn more.

It is important to document the recommended levels of food and drinks in the individual's care plan and explain them to both paid and unpaid carers, who might be preparing food for the person with MND.

The SLT might suggest adding a thickening powder to drinks, which is available on prescription.[17] 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:[4]

- 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 can all contribute to poor treatment adherence, worsening emotional wellbeing and may reduce quality of life.

The Royal College of Speech and Language Therapists (RCSLT) has developed a position statement and a paper on the use of thickened fluids. It advises that determining whether to use thickened fluids should involve a process of informed consent based on a comprehensive assessment that includes the best available evidence of risks and benefits of thickened fluids, 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.[18] Any decision to trial thickened fluids should always be reviewed.

Visit **www.rcslt.org/news/our-statement-on-thickened-fluids** and **www.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.[14,19] For example, avoiding risky food such as bread and fibrous fruits and vegetables might result in insufficient fibre intake and cause constipation. Pureed diets can also be less nutrient-dense compared to regular diets.[14]

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

They can suggest:[11,14]

- high energy food

- ways to add flavour and taste to food
- how to maximise calorie intake and fortify food eg with butter, yogurt or full cream milk
- supplements available on prescription - these 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.[11] 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 the next page, 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.[6]

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).[6,12,22]

Eating and drinking aids[10,14,20,21]

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.
- It's important to make puréed or minced food 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. Nicely decorated plates 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 to provide carers with clear instructions and training on oral health and regularly go to the dentist.
- 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 10).

The following equipment 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	Things to try	Who can help?
Posture	Sitting upright in a firm, high-backed chair. Sitting straight after eating can also help prevent acid reflux.	Occupational therapist, 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.	Orthotics, occupational therapist
Weakened grip and limited wrist movement	Specially designed plates, cups and cutlery.	Occupational therapist
	Attaching cutlery to splints.	
Difficulties in lifting food/drink to mouth	An adjustable cantilever table.	Occupational therapist, 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.	

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.[3,6]

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 Gastrostomy placement in the next page).[12]

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.[23]

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-making.

Information to share with people with or affected by MND:

Information sheet 7B – *Tube feeding* contains information for people with MND and their carers on how to manage episodes of choking.

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

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.[24]

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.[2]

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 gastrostomy 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 (PIG), 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.[5] 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.[6]

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.[6] Possible risks of a late gastrostomy include:[12]

- continued weight loss
- respiratory complications
- dehydration
- failed insertion
- a higher risk of mortality 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.[25]

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

- 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.[12]

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.

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. Search **www.gastrostomychoice.co.uk**

MyTube is a useful online resource containing short videos and information about tube feeding for people with MND. Search **mytube.mymnd.org.uk/**

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:[23]

- 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 the most to that person
- any possible side effects, including discomfort, pain 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 10)
- current or potential future cognitive problems and how they might impact their ability to decide on a gastrostomy (see pages 10-11). It is crucial to assess the capacity of the person to make a decision as per the Mental Capacity Act.[12]
  Visit **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[6]. Professionals should assess whether the person is likely to cope with the intervention. To ensure the person makes an informed decision, they should also consider that:[5,12,23]

- 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 in advance information 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.

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.[5]

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.[21,24,26] 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 to reach out to in case of medical complications. The contacts should include professionals who understand the needs and problems of people on home enteral feeding.[5]

Using the tube may cause changes in bowel habits.[24] A dietitian or MND specialist should be consulted about these issues.

Refusing or withdrawing a feeding tube[21]

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.

Other issues related to dysphagia

Cognitive change

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

Information to share with people with or affected by MND:

Changes to thinking and behaviour

Information sheet 14A - *Advance Decision to Refuse Treatment and advance care planning* contains relevant documentations, completed with sample forms

Information for professionals:

Cognitive change, FTD and MND

Infographic - *FTD* is a brief overview of what to take in consideration when someone is affected by FTD.

Our guide *Advance care planning for MND* covers practical strategies to facilitate care planning.

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

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.[21,29]

As cognitive and behavioural issues worsen, people with MND may need extra support and different interventions to manage dysphagia. It is crucial to consider both their swallowing abilities and broader mealtime issues.[19,30]

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.[30] Finally, people may develop unusual behaviours during meals, such as cramming food, eating more than necessary or preferring sweet foods.[31]

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:[30]

- 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.[6,21]

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 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 any decisions have 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 the RCSLT website: **www.rcslt.org/members/clinical-guidance/eating-and-drinking-with-acknowledged-risks-risk-feeding/**

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.[1] People with dysphagia can be prescribed with Riluzole in a liquid form.[32,33] 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.[34] Keep in mind that adding thickeners to medicines can delay absorption and reduce effectiveness.[4]

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.[35]

Where medicines are given through a feeding tube, it's crucial to flush the tube between each medication.[35] 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.[36]

Information to share with people with or affected by MND:

Information sheet 5A - *Riluzole*

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

Laryngeal spasm[9]

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.[4] A healthcare provider may consider prescribing lorazepam to help with laryngeal spasms.[6]

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MND Professionals' Community of Practice

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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