

Managing dysphagia in motor neurone disease

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

Many people with MND will experience dysphagia (swallowing problems), which can make eating and drinking difficult.² Dysphagia can also be detrimental to health overall and can lead to malnutrition and dehydration. This can cause anxiety for people with MND and their carers/family, who may have concerns about choking on food and liquids.³

This information provides suggestions, medication options and practical tips for health and social care professionals working with people with MND.

Everyone with MND has a different experience of the disease. There is no standard rate of progression.⁴ Not all symptoms affect everyone, and it is unlikely that they will develop at the same time or in any specific order. Therefore, each person should have an individual assessment for treatment.

What is dysphagia?

Dysphagia is the medical term for difficulty with swallowing. Swallowing is a complex process involving many muscles and nerves coordinating at the right time. Difficulties can occur in the mouth, pharynx (throat) or oesophagus (gullet). It affects many people over the course of MND.⁵

People with MND may have swallowing problems caused by weak muscles in the bulbar region (face, mouth, tongue and throat). Those whose first symptoms affect this region (bulbar onset) usually experience dysphagia at an earlier stage than those with other types of MND.²

Information for professionals

Information sheet P3 – *Managing saliva problems in motor neurone disease*

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.

We also have two relevant information sheets for people affected by MND:

Information sheet 7A – *Swallowing difficulties*

Information sheet 7B – *Tube feeding*

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

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

Signs of dysphagia: ⁶	Dysphagia can lead to: ⁶
<ul style="list-style-type: none"> • eating and drinking is tiring • poor lip control meaning food or fluid may leak out of the mouth • weak chewing, which takes more effort • difficulty moving the tongue around in the mouth • difficulty moving food or fluid backwards in the mouth to trigger the swallow reflex • several swallows needed for each mouthful of food due to weakness in pharyngeal muscles • coughing or choking when eating and/or drinking • reduced ability to cough to clear anything which goes the wrong way • wet or muffled sounding voice after eating • Difficulty coordinating breathing and swallowing, particularly as the person becomes more reliant on NIV • sialorrhoea – drooling due to reduced/ impaired swallowing rather than excess saliva production. 	<ul style="list-style-type: none"> • dehydration and weight loss – because the person is unable to take in the food and fluids they need to maintain nutrition and hydration • aspiration, where food, drink or saliva go into the lungs – this can cause aspiration pneumonia which can be life threatening • recurrent chest infections – often caused by aspiration • loss of strength • tiredness and fatigue • constipation • loose, dry and flaky skin, and poor skin integrity • reduced enjoyment of meals and drinks, which can lead to a reduced quality of life • lengthy mealtimes, with food going cold • feeling unable to take part in family mealtimes • loss of social opportunities, such as eating out at restaurants • burden and stress for carer or family members, who may eat separately and prepare food that may not be eaten. <p>Note: Dysphagia is also associated with impaired respiratory function.</p>

Referrals to other professionals

As this symptom will get worse, it is crucial that referrals are made to the appropriate professionals as soon as a problem is identified. Referrals should be made by whichever professional first notices a problem.

Specialists at MND care centres or networks, or through multidisciplinary teams (see below), can advise on dysphagia management and refer to appropriate services. Unregistered professionals have a responsibility to report concerns or deterioration immediately to their line manager.

Referral to a **speech and language therapist (SLT)** should be a priority. They can assess the ability to eat, drink and swallow and will put together a plan of action, which may include teaching swallowing techniques and altering the consistency of diet, for example by introducing a puréed diet. This may include instrumental assessment of swallow using videofluoroscopy and/or fibreoptic endoscopic evaluation of swallowing (FEES).¹⁹ Weak bulbar muscles will also affect communication.⁷ The SLT can also assess speech problems and whether any aids or equipment might be needed to help the person with MND to communicate.

Usually the person with dysphagia will also require advice from a **dietitian** and these two professionals will work closely together. The dietitian can assess diet, nutritional and fluid intake and weight. Weight loss is often related to dysphagia, but it can also be affected by a person with MND not having the strength to feed themselves because of extreme fatigue or weakness in their upper limbs. Low mood or changes in bowel habit are other possible causes. A dietitian can suggest ways to optimise the person's diet and nutritional intake.

The person may be referred for an assessment for **enteral feeding** to determine whether alternative ways of feeding are needed. Enteral feeding should be discussed regularly and the person should be supported to make an informed decision as to whether they wish to have this intervention. See Alternative Feeding Methods on page 7. Be aware that some people will not want to have a gastrostomy.

A **physiotherapist** can advise on head supports and positioning and teach simple cough assist techniques to help with secretion management.

An **occupational therapist** may also advise on head supports, seating and positioning, food and drink preparation, and may recommend strategies and equipment to help with eating and drinking, such as adapted cutlery.

The **specialist respiratory team** can determine whether the person with MND has respiratory involvement and can help the person with MND determine the course of action.

Managing dysphagia

When eating and swallowing become difficult the following may help:

Eating

- Choose softer food which is easier to chew.
- Cut the food finely on the plate or mash it well with a fork so it requires less effort to chew.
- Add extra sauce or gravy, as moist food is easier to swallow.

As mealtimes become more difficult, people with dysphagia usually find that blended or puréed food is easier to swallow. It is often preferable to blend the different foods separately to retain the flavours, rather than blending the entire meal together.

In general, when someone has a swallowing problem, they should avoid:

- mixed textured foods and liquid with 'bits', eg minestrone soup
- foods that need a lot of chewing, eg fresh bread or some meats
- stringy food, eg celery or some green beans
- coarse, hard food, eg well done toast, or crumbly, dry food, eg biscuits or flaky pastry
- some vegetable skins which can be difficult to clear in the mouth, eg tomato or sweetcorn
- foods that become sticky in the mouth, eg bread or mashed potato.

It is best to always seek advice from an SLT, as everyone's ability to swallow is different.

The SLT will recommend levels of diet and fluids as defined by the IDDSI guidelines (International Dysphagia Diet Standardisation Initiative). The IDDSI framework consists of a continuum of 8 levels (0 - 7), where drinks are measured from Levels 0 – 4, while foods are measured from Levels 3 – 7. The IDDSI Framework provides a common terminology to describe food textures and drink thickness. It is important that these levels are documented in care plans when professional care is in place. Visit www.iddsi.org for further information.

Drinking

People with MND sometimes cough when drinking. This may be due to weakness and lack of co-ordination of the muscles used to swallow. It may be a sign of aspiration (drink going down towards the lungs). Thicker drinks tend to move more slowly and are therefore may be less likely to cause aspiration, as they may allow people more time to coordinate their muscle movements.

The person's SLT might recommend a thickening powder,⁸ available on prescription, which can be added to drinks. A potential downside of thickened fluids can be reduced fluid intake due to not liking the taste or consistency of the liquid. It is important that the person with MND discusses the pros and cons of thickening fluid with the SLT to make a decision that is right for them. Not everyone will choose to accept thickened fluids.

If drinking is difficult, an individual may gradually reduce their fluid intake. Choosing moist foods with a high fluid content, eg soups, casseroles, stewed fruit, ice cream and custard, helps to prevent dehydration and associated symptoms.

Assessment and management by the dietitian

When someone has swallowing problems and can take in less food, the nutritional content of meals is particularly important. A dietitian can recommend a diet based around advice from the SLT. They will suggest different types of food and ways to fortify food to improve the nutritional content. They may recommend food supplements which are available on prescription. As part of the management of a swallowing difficulty, alternative methods of feeding may also be discussed and considered (see page 7).

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.

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

Tips for mealtimes

These tips may help if you're involved in the preparation and serving of food for someone with MND, at home or in a care setting.

- Serve several small meals rather than one large one: this can be less tiring for the person eating.
- Offer the main meal at lunch time when fatigue is less likely.
- Use garnishes and attractive colours to make pureed food more appetising, and make sure they can see and smell the food.
- Allow plenty of time for the meal.
- Keep food warm and reheat if necessary. Using a keep-warm plate may help.
- Let the person concentrate on what they're doing – allow them to swallow before asking questions.
- Leave a gap between courses if eating is slow and tiring.
- Sipping an iced drink or consuming anything cold or frozen before eating and between mouthfuls can stimulate a stronger swallowing reflex.
- A relaxed, quiet environment may help the person to feel less anxious.
- The person with MND may feel unable to eat with their family or friends because of dysphagia. They may instead join the family for social reasons and take a few spoonfuls, while eating most of their meal before or afterwards.
- Encourage good mouth hygiene before and after meals, including swilling the mouth, brushing teeth and/or using a suction unit to clear away food debris.

Equipment that may help

Potential problem	Things to try	Who can help?
Posture	Sitting upright in a firm, high-backed chair	Occupational therapist
	Keeping head erect with chin tucked in	
	Adequate support for arms	
Weak neck muscles	A collar or chin support may help – although this 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. An SLT must be involved in this decision, as straw drinking often encourages large mouthfuls to be taken, and the mouthfuls arrive further back on the tongue than when drinking from a cup. Aspiration can occur if oral control is not sufficient to manage these variables.	

Fear of choking

Swallowing will get more difficult over time and there may be times when a person with dysphagia will have episodes of coughing, sensations of choking or actual choking. An ineffective cough, resulting from weakened respiratory muscles, will make it more difficult to remove the irritant, whether it is food, drink or saliva.³

This can be very distressing for both the person with MND and those close to them, and it is common for people with MND to worry that they will die by choking. However, it is important to explain and reassure them that this is very rarely a direct cause of death in MND.¹

A small number of people with MND may occasionally experience unexpected coughing or choking episodes brought on by spasms in stiff throat muscles. Medication can reduce the impact if this does occur, which can be prescribed for the person in the MND Just in Case Kit. The MND Just in Case kit is designed to hold a range of medications to relieve distressing symptoms, including anxiety and

breathlessness.

Once the need for a kit has been discussed and agreed with the person with MND and their carer, the GP can order a kit from MND Connect by emailing mndconnect@mndassociation.org or calling 0808 802 6262.

Read more about cough management in Information sheet P6 – *Evaluation and management of respiratory symptoms in MND*. Download at www.mndassociation.org/publications or contact MND Connect. Call 0808 802 6262 or email mndconnect@mndassociation.org

Our information sheet 7A - *Swallowing difficulties* has guidance on managing choking. Download at www.mndassociation.org/publications or contact MND Connect. Call 0808 802 6262 or email mndconnect@mndassociation.org

Other issues related to dysphagia

Laryngeal spasm²⁰

Uncontrolled/involuntary muscular contractions of the laryngeal (vocal) cords may be experienced due to an impaired swallow. This is often preceded by acid reflux.⁷

Laryngeal spasm can be extremely distressing as it can temporarily stop someone from breathing or speaking. The person affected should be encouraged to extend their neck backwards, take a slow breath in and a quick breath out. It can be accompanied by stridor: a loud, high-pitched respiratory sound.

A prescribing professional may consider lorazepam for laryngeal spasm.⁹

Taking medication

Some people will have problems swallowing tablets, so speak to a GP or pharmacist about alternative forms of any medications needed, for example syrups or patches. Many drugs can be taken via a gastrostomy tube.¹⁰ Always check with the pharmacist before crushing tablets as not all are suitable. Sometimes an alternative medication that does the same job may be a better option.

Cognitive change

About half of all people with MND experience some degree of cognitive and/or behaviour change.¹ This increases to 80% in the final stages of the disease.¹¹ Additional support will be needed for people with dysphagia and cognitive impairment.

- Supervise the person's eating more closely.
- People with more severe cognitive or behaviour changes may place too much food in their mouth at one time and cram food. Others may eat more food than they need, or they may have a preference for sweet food.¹²
- Limit the amount of food on the plate at any one time.
- Ask the carer to model eating at an appropriate pace.
- If food cravings are noticeable, question how much of a problem the behaviour is causing. It may be helpful to discuss with a dietitian.
- Those with poor swallowing may have trouble following SLT advice to modify consistency or to thicken drinks.
- Refer to an SLT for assessment and advice about how to encourage safe eating, eg using the chin-tuck technique.
- Repeated reminders about swallow safety tips may be necessary.
- Ensure that mealtimes are protected from any distractions.

Enteral feeding methods

Enteral feeding methods should be discussed at an early stage and revisited regularly before oral intake becomes difficult. Introducing the option of a feeding tube early will give the patient time to make an informed decision. Severe weight loss before having a feeding tube fitted may increase the risks during and after the procedure, so it is best to consider various options early, before a person with MND has lost a substantial amount of weight. Respiratory function must also be considered, as surgery can become increasingly difficult as respiratory symptoms progress.

The NICE Guideline on MND recommends explaining the benefits of early placement of a gastrostomy, and the possible risks of a late gastrostomy (for example, low critical body mass, respiratory complications, risk of dehydration, different methods of insertion, and a higher risk of mortality and procedural complications).¹⁶

Information you can share

Information sheet 7B – *Tube feeding*

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

Alternative feeding may be provided via or a stoma (hole) from the skin of the abdomen into the stomach, allowing a tube to be placed and feed passed through (gastrostomy), or a tube inserted through the nose into the stomach (nasogastric tube). Nasogastric tubes are usually used as a short-term solution.

Once the feeding system has been inserted, liquid feed may be delivered by:

- syringe
- gravity – a bag of liquid food is hung from a stand and allowed to drip through a tube
- pump method – a measured quantity is pumped into the tube, generally over some hours.

Having a gastrostomy tube in place does not prevent the person from continuing to eat and drink orally. Often the tube will have been inserted pre-emptively whilst the person is well and will not need to be used for nutrition and hydration at that point. The tube will need to be flushed daily to ensure it is kept clean and in working order. Any carers or care workers supporting the person should be trained in how to do this.

Later, when swallowing is more difficult, if they choose to do so, the person may continue to take some food and liquid by mouth, for pleasure or quality of life, and use the feeding tube to supplement nutrition. The quantity fed through the tube may increase as swallowing becomes more difficult. The SLT and the dietitian, along with other members of the MDT, will help a person to decide how they want to manage the balance of oral intake and gastrostomy feeding.

Some people may choose not to have enteral feeding at all, and it is important that their decision making is supported by the MDT.

Types of enteral feeding

The following may be used to 'top up' oral intake, to meet full nutrition and hydration needs and to administer medications:¹³

- Percutaneous Endoscopic Gastrostomy (PEG)
- Radiologically Inserted Gastrostomy (RIG)
- Per-oral Image-guided Gastrostomy (PIG)
- Nasogastric tube (NGT)

With RIG, the feeding tube is inserted under x-ray guidance. PIG is a hybrid of PEG and RIG but at present is not widely available.

Gastrostomy placement

PEG is the preferred method of gastrostomy, when someone has good respiratory function, or PIG/RIG when there is significant compromise of respiratory function.

The optimal timing of gastrostomy is not entirely clear but is likely to be when someone has lost around 5% of their body weight (from measurement taken at diagnosis).¹⁵ Earlier placement of a gastrostomy tube is recommended, even if it isn't used straight away, as when needed, it can improve/maintain quality of life.¹⁵

Possible risks of a late gastrostomy include, continued weight loss, respiratory complications, dehydration, failed insertion, and a higher risk of mortality and procedural complications.¹⁶ Therefore, the conversation about alternative feeding should happen early, before a crisis is reached, and revisited regularly. Additionally, discussions may be triggered by these indicators:

- aspiration of food
- anxiety when eating
- fear of choking
- inadequate food or fluid intake
- length of time and effort taken over meals
- weight loss or dehydration
- fatigue from eating.

Nasogastric tube

This is a tube inserted through the nose, allowing food to be passed directly into the stomach. It is usually a short-term option which may be appropriate for someone who is malnourished or dehydrated, while waiting for gastrostomy placement, or where gastrostomy placement is not possible. It is more often used in a hospital setting.

This method may be used in people for whom other types of gastrostomy are not appropriate, or may be preferred by some. As with other types of gastrostomy, this method can improve quality of life, but it is often considered less comfortable than gastrostomy tube placement.¹⁴

Making the decision

It is important to recognise that, while early placement of a feeding tube is recommended, insertion of gastrostomy is an elective procedure which people with MND delay due to personal perceptions and concerns. It may not be an option where support to manage the tube is not available locally.

Discussions about the need for a tube can be distressing, especially soon after diagnosis, and should be handled sensitively. Referral to psychological support services may be helpful. The pros and cons of this option should be discussed to enable the individual to make an informed choice. Understanding the factors that influence decision making about artificial feeding can help professionals to support people to decide whether gastrostomy is for them.¹⁷

Any discussion the person with MND has about gastrostomy should cover:

- how alternative feeding can affect quality of life
- any possible side effects, including discomfort or pain
- how gastrostomy may be included in an Advance Decision to Refuse Treatment (ADRT).

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. It is also important to recognise that it may be too late to undergo the procedure after a certain point in disease progression.

Careful assessment is also needed of:

- the level of support required to manage living with this intervention. The person with MND or their carer will need to understand what is involved and how often feeds should be administered, to ensure they can manage physically. If care support is required, arrangements need to be made at an early stage
- the capacity of the person with MND to make the decision as per the Mental Capacity Act. If the person lacks capacity, and has not documented their wishes in an Advance Care Plan prior to losing capacity, a best interests meeting may be needed to determine whether the procedure is right for that person
- any possible physical restrictions imposed by the time required for feeds or trips to the toilet at night if the feed runs through overnight.

Maintenance and potential problems

Disadvantages of gastrostomy include having to keep the placement site very clean, the potential for infection, bleeding or leakage from this site, and for the tube to be displaced. Practicalities around the maintenance of the tube (eg cleaning and flushing through) and administration of feed should also be considered.

People with MND and carers need adequate information and training both before and after feeding tube insertion to help them make the decision, but also to help with the transition from oral to gastrostomy feeding. They should know where to go and who to contact in case of any clinical complications.¹⁸

Possible problems that may arise with use of the tube include bloating and changes in bowel habits. A dietitian or MND specialist should be consulted about these issues.

Refusing or withdrawing a feeding tube

Someone with MND may make an Advance Decision to Refuse Treatment (ADRT) in which they refuse particular treatments. This could include instructions about initiating or withdrawing artificial nutrition and hydration by any means, including by feeding tube. A person with a gastrostomy can choose to stop using it at any time, and this should form part of the discussions when the person is deciding whether to have the intervention.

If someone decides against a gastrostomy or it is withdrawn, they may need symptom control for hunger and thirst. As the disease progresses, these desires usually decline naturally, but any discomfort may be minimised with the use of medication. Consult the specialist palliative care team.

Cognitive change and decision making

The potential for cognitive impairment highlights the importance of early planning. If someone experiences cognitive change, their ability to tolerate and understand the need for particular interventions may be affected.¹⁶ Advance care planning should include a person's preferences in relation to alternative feeding.

The person should have the chance to discuss whether they would want to make an ADRT before they lose the ability to communicate or experience possible cognitive change. If this has not been done and the person is unable to make an informed decision, consult the person's relatives and the specialist palliative care team if appropriate in your area.

If the person lacks capacity and has not documented their wishes in an Advance care plan, a best interests meeting may be needed to determine whether any procedure is right for that person.

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How we can support you and your team

MND Connect

Our helpline offers help, information and support, and signposting to people living with MND, carers, family and health and social care professionals.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

Information resources

We produce high quality information resources for people living with MND, carers, family members and health and social care professionals.

www.mndassociation.org/publications

MND Association website

We have a wide range of information to support health and social care professionals working with people affected by MND.

www.mndassociation.org/professionals

Education

Our education programme is designed to improve standards of care and quality of life for people living with and affected by MND. Opportunities include online modules and face-to-face training.

www.mndassociation.org/education

Support grants and equipment loan

Where statutory provision is not available, we may be able to offer a support grant or loan equipment.

www.mndassociation.org/getting-support

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 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

Regional staff

We have a network of regional staff with specialist knowledge of MND. They work closely with local statutory services and community care providers. Contact MND Connect for further information.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

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

Branches and groups

We have volunteer-led branches and groups nationwide providing local support and practical help to people with MND and their carers.

www.mndassociation.org/branchesandgroups

Association visitors (AVs)

AVs are trained volunteers who provide one-to-one local support to people affected by MND. They can support people affected by MND in person, by telephone or by email or through support groups.

www.mndassociation.org/associationvisitors

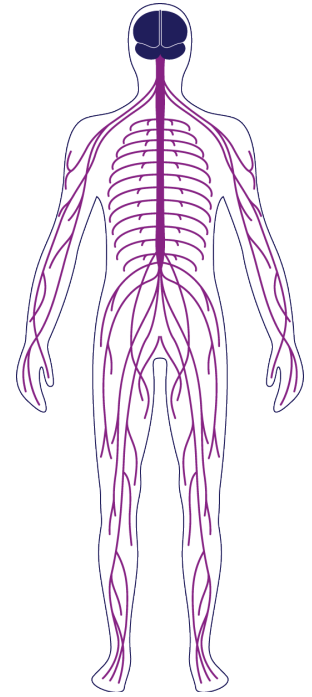
We value your feedback

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

About MND

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work. MND does not usually affect sight, hearing or sensation.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- It affects people from all communities.
- Some people may experience changes in thinking and behaviour, with some experiencing a rare form of dementia.
- MND kills a third of people within a year and more than half within two years of diagnosis.
- A person's lifetime risk of developing MND is up to 1 in 300.
- Six people per day are diagnosed with MND in the UK.
- MND kills six people per day in the UK.
- It has no cure.



Would you like to find out more?

Contact our helpline if you have any questions about MND or want more information about anything in this publication.

mndconnect
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www.mndassociation.org/professionals