

P8

Dysphagia in motor neurone disease (MND)

Information for health and social care professionals

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

Many people with MND will experience problems with dysphagia (swallowing problems), which can make eating and drinking difficult.² 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 is for health and social care professionals working with people with MND and provides suggestions, medication options and practical tips.

Everyone with MND has a different experience of the disease, and is unlikely to have the same symptoms or experience them in the same order. There is no standard rate of progression.⁴ Therefore, each person should have an individual assessment for treatment.

Find out more

See our information sheet for health and social care professionals:

- *Managing saliva problems in motor neurone disease* – information sheet P3

Information you can share

We have two relevant information sheets for people affected by MND, both endorsed by the British Dietetic Association:

- 7A – *Swallowing difficulties*
- 7B – *Tube feeding*

Download from our website at www.mndassociation.org/publications or see page 9 for details of how to order copies.

What is dysphagia?

Dysphagia is a disruption of the normal eating and swallowing process and affects many people during 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

Signs of dysphagia ⁶	Dysphagia can lead to: ⁶
<ul style="list-style-type: none"> • coughing or choking when eating or drinking • poor lip control • reduced ability to cough • problems swallowing medication • several swallows needed for each mouthful of food • weak chewing, which takes more effort • eating and drinking is tiring • food may not move to the back of the mouth • food may not disappear down the throat because of a poor or absent swallow reflex, or because of an uncoordinated swallow caused by weak pharyngeal muscles • wet or muffled sounding voice after eating • muscle spasms • drooling due to poor control of saliva. 	<ul style="list-style-type: none"> • dehydration and weight loss – because the person is unable to take in the food and fluids they need • aspiration – where food or drink goes into the lungs – which can be life threatening • recurrent chest infections (often caused by aspiration) • loose, dry and flaky skin, and poor skin integrity • loss of strength • tiredness • constipation • loss of wellbeing and reduced quality of life • lengthy mealtimes, with food going cold • feeling unable to take part in family mealtimes • burden and stress for carer or family members, who may eat separately and prepare food that may not be eaten. <p>Dysphagia is also associated with impaired respiratory function.</p>

Referrals to other professionals

As this symptom will get worse over time, 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. Unregistered professionals have a responsibility to report concerns or deterioration immediately to their line manager.

The **specialist respiratory team** can determine whether the person with MND has respiratory involvement and risk of aspiration and/or choking and can help the person with MND to determine the course of action.

Referral to a **speech and language therapist (SLT)** should be a priority. They can assess the ability to eat 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 purée diet. Often, the SLT will indicate whether the person needs to see a dietitian and these two professionals will work closely together.

Weak bulbar muscles will also affect communication.⁷ The SLT can assess speech problems and whether any aids or equipment might be needed to help the person with MND to communicate.

A **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 (see page 3).

A **physiotherapist** can advise on head supports and positioning.

An **occupational therapist** may 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 person may be referred to the **enteral feeding team** for assessment to determine whether alternative ways of feeding are needed.

Managing dysphagia

A speech and language therapist can provide advice on swallowing techniques, or on experimenting with different textures, such as a softer diet. They may also suggest a change in meal patterns, such as eating 'little and often' rather than three meals a day.

Alternative methods of feeding may also be considered (see page 5).⁶

Softer diets

As eating becomes more difficult, the diet should be changed to softer foods. However, it shouldn't include only mashed or puréed food until necessary: before someone is no longer able to swallow safely without undue risk of aspiration or choking. Without practice, the action of chewing and swallowing will be lost sooner than it would be otherwise.⁸

- Food should be bulky enough to be felt in the mouth but not so large that it is difficult to swallow all at once.
- Consistency is important when food is puréed or liquidised. People may find their preferred consistency varies from day to day.
- If food needs to be liquidised, process items separately so that they keep their individual colours and flavours.

Increasing fluid intake

Thin liquids can become difficult to control and swallow, so fluid intake may be reduced. Choosing soft, sloppy foods with a high fluid content such as sauces, soups, liquidised stews and casseroles can help to prevent dehydration and associated symptoms. A speech and language therapist may suggest using products such as flour, cornflour or yoghurt in cooking to improve the texture.

Thicker drinks are sometimes easier to swallow. Thickening powders are available on prescription, which can be used to thicken drinks.⁹ Cold foods, such as yoghurt and mousse, can stimulate the swallow.

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 implement a diet based around the recommendations from the speech and language therapist. They will suggest types of food and ways to fortify food to improve the nutritional content.

When someone has swallowing problems, foods to be avoided include:

- mixed textured foods, eg minestrone soup
- foods that need a lot of chewing, eg grilled meat
- stringy food, eg bacon or celery
- coarse, hard food, eg nuts or hard toast
- foods that become sticky in the mouth, eg bread or mashed potato.

Sharp or spicy foods can increase the flow of saliva, although some people find the strong stimulation of these foods can help with swallowing.

Information you can share

Information sheet 7A – *Swallowing difficulties* has information for people with MND and their carers on how to manage episodes of choking. You can download a copy of this sheet from www.mndassociation.org/publications or see page 9 for details of how to order.

The *MND Just in Case Kit* is designed to contain medication for the relief of anxiety and breathlessness. It also includes guidance on symptom management. The kit is supplied at the request of a GP for a named person. See page 9 for more information.

Tips for meal times

If you're involved in the preparation and serving of food for someone with MND, perhaps in a care setting, these tips may help. Alternatively, they may be offered to people with MND and carers.

- Serve several small meals rather than one large one: this can be less tiring for the person eating.
- Use garnishes and attractive colours to make 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 (eg ice cream) 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		

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 and 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 Read more about cough management in Information sheet P6 – *Evaluation and management of respiratory symptoms in MND* (see page 9 for how to order resources).

Other issues related to dysphagia

Laryngeal spasm

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.¹⁰

Taking medication

Some people will have problems swallowing tablets, so speak to a pharmacist about alternative forms of any medications needed, for example syrups or patches. Some drugs can be taken via a gastrostomy tube.¹¹

Cognitive change

Up to half of all people with MND will experience some degree of cognitive change.¹ Additional support will be needed for people with dysphagia and cognitive impairment.

- Supervise the person's eating more closely.
- People with more severe changes may place too much food in their mouth at one time and cram food, while others may eat more food than they need.
- Limit the amount of food on the plate at 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 medical advice to modify consistency or to thicken drinks.
- Refer to speech and language therapy for assessment and advice about how to encourage safe eating, eg using the chin-tuck technique, counting to 10 when swallowing.
- Repeated reminders about swallow safety tips may be necessary.
- Ensure that mealtimes are protected from any distractions.

Alternative feeding methods

If dysphagia is present, alternative feeding methods should be discussed with the person with MND. Alternative feeding may be provided via a tube inserted through the nose into the stomach (nasogastric tube) or a stoma (hole) from the skin of the abdomen into the stomach, allowing a tube to be placed and feed passed through (gastrostomy).

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

- syringe
- gravity – a bag of feed 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.

If it is safe to do so, the person may continue to take some food and liquid by mouth, using the feeding tube to supplement nutrition, or for pleasure or quality of life. The quantity fed through the tube may increase as swallowing becomes more difficult.

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:¹²

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

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.

Nasogastric tubes

This is a tube that is inserted through the nose, allowing food to be passed directly into the stomach. A nasogastric tube can be used in the short-term to build up someone who is malnourished or dehydrated, and who wants to proceed with gastrostomy, or it may be used for a longer period.⁶

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.¹³

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 likely to be when someone has lost around 5% of their body weight (from measurement taken at diagnosis).¹⁴ 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.¹⁴

Possible risks of a late gastrostomy include, for example, low critical body mass, respiratory complications, risk of dehydration, a higher risk of mortality and procedural complications.¹⁵

Therefore, the conversation about alternative feeding should happen early, before a crisis is reached. The discussion 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.

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 and people with MND often delay the procedure due to personal perceptions and concerns.

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 with MND to decide whether gastrostomy is for them.¹⁶

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

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

The person should also have the opportunity to meet with the palliative care team, and other people with MND who are using gastrostomy.

Not everyone with MND will choose this type of intervention and their decision should be respected. However, as problems progress, they may change their mind.

Careful assessment is also needed of:

- the ability of the person with MND or their carer to manage the feeding process and the level of support needed to manage living with this intervention. For example, the level of community support and who will manage feeds in the community. If it is a family member, this person will need to understand what is involved and how often feeds should be administered, to ensure they can physically manage. If care support is needed, arrangements need to be made at an early stage
- the understanding by the person with MND of the need for the procedure, so they can make an informed choice about whether or not to have the tube
- 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 at 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 their 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.¹⁷

Possible problems that may arise with the use of the tube include bloating and changes in bowel habits. A dietitian 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.

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

Advance care planning should include a person's preferences related 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 specialist palliative care team and the person's relatives. If someone experiences cognitive change, this may affect their ability to tolerate and understand the need for particular interventions.¹⁵

Information you can share

Information sheet 7B – *Tube feeding*. Download this sheet from www.mndassociation.org/publications or see page 9 for details of how to order copies.

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Further Reading

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How the MND Association can support you and your team

We support health and social care professionals to provide the best possible care for people living with MND, their carers and families. We do this in a number of ways:

MND Connect

Our helpline offers help, information and support, and signposting to other services and agencies. The service is for people living with MND, carers, family members, health and social care professionals and Association staff and volunteers who directly support people with MND.

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Please contact MND Connect if you have any questions about the information in this publication.

MND Association website

Access information for health and social care professionals on our website at **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, such as conferences and masterclasses. Find out more at www.mndassociation.org/education

Information resources

We produce high quality information resources for health and social care professionals who work with people with MND. The range includes:

- *Managing saliva problems in motor neurone disease* (information sheet P3)
- *Evaluation and management of respiratory problems in MND* (information sheet P6)

We also have a wide range of resources for people living with and affected by MND, including:

- *Living with MND* booklet
- *MND Recipes Collection: easy to swallow meals*
- Information sheet 7A – *Swallowing difficulties*
- Information sheet 7B – *Tube feeding*
- *End of life: a guide for people with motor neurone disease*
- Information sheet 14A – *Advance Decision to Refuse Treatment (ADRT)*

Downloads of all our information sheets and most of our publications are available from our website at www.mndassociation.org/publications. You can also order our publications directly from the MND Connect team.

The MND Just In Case Kit

The MND Just in Case Kit is designed to hold medication for the relief of choking, breathlessness or related anxiety. Its presence in the home provides tangible evidence for people with MND and carers that fears have been addressed and practical help is at hand. For the GP and district or community nurse it provides guidance on symptom management and medication and storage for the prescribed medications. A GP can request a kit for a person with MND from MND Connect (**0808 802 6262** or mndconnect@mndassociation.org).

Find out more at www.mndassociation.org/justincase

MND support grants and equipment loan

Where statutory funding or provision has been explored and is not available, we may be able to provide a support grant or equipment loan.

Our support grant service consists of providing care and quality of life grants for people with MND. This service is supported by MND Association branch and group funds, and by the Association's central fund.

Our equipment loan service is focused on three core items of equipment to help people with day-to-day tasks and communication:

- riser-recliner chairs
- specialist communication aids
- portable suction units.

For suction units, a small charge is made to statutory services for carriage, maintenance and cleaning.

Referrals for support grants or equipment loan need to be made by an occupational therapist, speech and language therapist or other relevant health or social care professional. For enquiries about MND support grants or equipment loan, call the MND Support Services team on **01604 611802**, email support.services@mndassociation.org or visit www.mndassociation.org/getting-support

Wheelchair service

If you are seeking information on wheelchairs, or if there are delays in assessment or provision of an appropriate wheelchair for someone with MND, our wheelchair service may be able to help, through training, joint assessments, advice or support. For our wheelchair service, call MND Connect on **0808 802 6262** or email wheelchairs@mndassociation.org

Communication aids service

This service helps people affected by MND and health and social care professionals with queries about communication aids. The service provides limited financial support for communication aids or some items on loan, if unavailable or delayed through health and social care services. Our aim is to improve provision and information on a local and national level, through collaboration with professionals. Call **01604 611767** or email communicationaids@mndassociation.org

Research into MND

We fund and promote research that leads to new understanding and treatment and brings us closer to a cure. Contact the Research Development team on **01604 611880** or research@mndassociation.org. Alternatively, visit www.mndassociation.org/research for more information. For the latest research news, visit our research blog at www.mndresearch.wordpress.com

Our peer-to-peer research and care community blog (RECCOB) has a number of reporters who write updates on MND-related workshops and events around the world. Subscribe for email alerts at www.reccob.wordpress.com

International Symposium on ALS/MND

Each year we organise the world's largest clinical and biomedical research conference on MND. It is the premier event in the MND research calendar for discussion on the latest advances in research and clinical management, attracting more than 800 delegates from at least 30 countries. Find out more at www.mndassociation.org/symposium

MND Association membership

Join us now and help fight MND. Membership costs £12 for individuals. It is free for people with MND and for carers, spouses or partners of people living with MND. Call **01604 611855** or email membership@mndassociation.org

Local support

Regional care development advisers

We have a network of regional care development advisers (RCDAs) covering England, Wales and Northern Ireland. RCDAs have specialist knowledge of the care and management of MND. They work closely with local statutory services and community care providers to ensure effective support for people affected by MND. RCDAs provide education for health and social care professionals in MND, and are champions at influencing care services in their respective areas.

MND care centres and networks

Care centres and networks are teams of professionals who are specialists in MND. We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist clinical expertise from diagnosis onwards.

Branches and groups

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

Association visitors (AVs)

Association visitors provide one-to-one local support to people affected by MND. Managed by regional care development advisers, they are volunteers with experience of MND who can visit people affected by MND within their homes or contact them by telephone, email or through local support groups. They can also provide a link with health and social care professionals. You may be in contact with Association visitors following up on queries from the families they support.

Please send us your feedback on
Managing dysphagia in motor neurone disease (MND)

Thank you for taking the time to provide your feedback on one of our information resources.

This questionnaire can be accessed online if preferred, using the following link:
www.surveymonkey.com/s/professionalinformation

What is your profession or specialism?

Did you find this resource useful?

Yes Somewhat Not really No Please explain your answer

Will this information resource help you to provide people affected by MND with any of the following?
(tick all that apply)

- | | |
|---|--|
| <input type="checkbox"/> an increased understanding of their symptoms | <input type="checkbox"/> more confidence |
| <input type="checkbox"/> an increased understanding of their condition | <input type="checkbox"/> improved quality of life |
| <input type="checkbox"/> more independence | <input type="checkbox"/> a greater ability to maintain dignity |
| <input type="checkbox"/> an increased ability to raise awareness of their needs | |

Were there any particular topics that were useful to you?

Was there any information that you didn't find useful or relevant?

Are there any other MND-related topics that you'd like more information about?

Do you have any other feedback about this resource or our other information for professionals?

Would you be happy to help us improve our information by becoming an expert reviewer?

Yes (please include your email address below) No

Do you have any experiences of working with people with MND you could share as an anonymous quote or case study for future resources?

Yes (please include your email address below) No

Please return your completed form to:

Education and information team
MND Association
PO Box 246
Northampton NN1 2PR

Name: _____

Email: _____

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MND Association

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About us

The MND Association was founded in 1979 by a group of volunteers with experience of living with or caring for someone with MND.

Since then, we have grown significantly, with an ever-increasing community of volunteers, supporters and staff, all sharing the same goal – to support people with MND and everyone who cares for them, both now and in the future.

We are the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.

Our mission

We improve care and support for people with MND, their families and carers.

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND.

We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

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 the senses such as sight, sound and feeling.
- 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 a proportion 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.



mndconnect
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