

# 7A

## Swallowing difficulties

**Information for people with Motor Neurone Disease (MND) or Kennedy's disease, and their carers.**

With MND or Kennedy's disease, you may experience changes to the way you swallow. You may also experience problems with managing your saliva and a weakened ability to cough. This information sheet covers what may happen, with guidance for carers if they need to provide support for coughing or choking. The content includes:

- 1. How does MND affect swallowing?**
- 2. How can I manage problems with saliva?**
- 3. How can a suction unit help?**
- 4. How can I manage coughing?**
- 5. How can I manage choking?**
- 6. How do I find out more?**



**This content has been evidenced, user tested and reviewed by experts. See: [piftick.org.uk](http://piftick.org.uk)**



This symbol highlights quotes from people living with or affected by MND or Kennedy's disease.



### **How do I download or order your information resources?**

To help you explore further, you will see our information resources mentioned throughout this booklet, as relevant to a subject.

## **1. How does MND or Kennedy's disease affect swallowing?**

When we swallow, it happens partly under our control and partly as an automatic reflex. In a normal swallow, your jaw, lips and tongue keep food, liquids and saliva in your mouth for chewing and to prepare for swallowing. An automatic reflex then moves the contents down to the stomach.

MND and Kennedy's disease can both affect nerves that carry messages to muscles in your jaw, lips, throat, face and tongue, causing the muscles to become weak. This can make it harder to swallow effectively and move saliva around in your mouth.

Health and social care professionals call these swallowing difficulties dysphagia. Weakness in these muscles can also affect the way you speak.



See information sheet **7C Speech and communication support**.

If you have a form of MND called progressive bulbar palsy, swallowing problems may start early in the disease. These problems can also occur with other forms of MND, but usually at a later stage.

### **What are the signs of swallowing difficulties?**

Some of the signs will be obvious, but some less so. Sometimes your family, friends or others may notice changes before you do.

You may already have adapted to the changes, but they will progress. Seek advice from your speech and language therapist, neurological specialist or GP if you notice any problems with swallowing.

Being aware of early signs can help you manage symptoms and avoid more serious problems, such as chest infections.

You may find the way you swallow changes through the day. For example, gradually becoming weaker.

General signs of swallowing difficulties may include:

- coughing when eating or drinking,
- more frequent swallowing to clear food, liquids or saliva, or feeling unable to clear your mouth or throat
- a wet or gurgly sounding voice
- needing extra time or effort to chew or swallow
- food or liquid leaking from the mouth, or drooling of saliva
- gagging, a sense of choking or feeling that food, liquids or medication get 'stuck' in your throat.

## **How might swallowing difficulties affect me?**

Swallowing difficulties can lead to:

- less enjoyment of eating or drinking
- nausea, loss of appetite and weight loss
- eating and drinking taking longer
- embarrassment or isolation in social situations involving eating or drinking
- not drinking enough, causing dehydration, constipation, thick stringy saliva and other issues
- anxiety, particularly if you are concerned about choking
- chest infections or aspiration pneumonia from saliva, food or drink getting into the lungs.

## **What tests are used to diagnose swallowing problems?**

Your speech and language therapist can assess your swallowing difficulties and examine your mouth. They may watch you taking small mouthfuls of food or drink to see which muscles are affected. You may be referred for more tests, if needed, which could include:

### **Fibreoptic Endoscopic Examination of Swallowing (FEES)**

A small flexible tube with a light at the end is passed through the nose into the back of your throat. This can see what happens as food and liquid pass over the back of your tongue.

### **Videofluoroscopy (VF)**

This scan uses video to record food and liquids as you swallow them. They are mixed with a substance that shows up on an X-ray. This helps pinpoint the swallowing problems and shows if anything is going into the lungs.

## How can I manage the emotional impact?

Any new symptoms, general worries or anxiety can cause concern and you may need time to adjust. Feeling tired and stressed can make swallowing more difficult.



**"It is a difficult subject to discuss – particularly with friends or colleagues, as it is something that none of us really want to think about."**

Without support, swallowing problems and anxiety can make each other worse. Your health and social care team can help you find ways to manage worries and treat these issues.



See our booklet: **Emotional and psychological support**.

You may find open conversations help with those close to you, particularly if a partner, family member or friend is your main carer. Agreeing on how to approach difficult situations in advance helps reduce tension.



**"I feel it could be very empowering for the person with MND to read and share this information sheet with their carers – any steps you can take to reduce the feelings of anxiety can only be positive."**

Swallowing difficulties can be a very sensitive issue. At first, you may find it hard to accept there is a problem, but symptoms will progress. Advice from a relevant professional is vital to help you and those supporting you.

## Why is there a risk of chest infection?

Your body tries to prevent anything entering your airway by coughing. If the muscles have weakened and your cough is not effective, saliva, food or liquids may enter the lungs. This is known as aspiration. If this happens without coughing or gagging, it is known as silent aspiration.

Our lungs cannot clear unwanted food or drink very easily. This can lead to chest infections, or a type of pneumonia known as aspiration pneumonia.

Get advice from your GP and your speech and language therapist if you notice any problems with swallowing or experience repeated chest infections.

## **Do I need a flu jab?**

We recommend having the flu jab, as you qualify as being at risk. Flu can lead to illnesses such as bronchitis and pneumonia, so it is worth having the vaccination. The flu jab will protect you for 12 months and is usually available from the beginning of October every year. You may also qualify for the vaccination if you are caring for someone with MND or Kennedy's disease, who may be at risk if you fall ill.

Vaccinations are also available to protect you from pneumonia infections. You may need a single one-off vaccination or five-yearly vaccinations depending on your health and age. Contact your GP surgery to arrange an appointment to discuss vaccinations.

## **Who can help if I have swallowing difficulties?**

You may meet a range of professionals for swallowing difficulties, including the following.

### **General practitioner (GP)**

Your GP is likely to be your first contact. They can advise, prescribe medications and refer you to specialist support, treatment or therapy.

### **Speech and language therapist**

Your main contact for swallowing assessment is your speech and language therapist. They help with eating and drinking techniques, as well as speech and communication. Following their assessment of your symptoms and needs, they can:

- advise on swallowing techniques, and consistencies of food and drink that are safer to swallow
- help you, your family and carers with guidance on how to manage swallowing and any anxiety
- provide guidance on tube feeding to help you get enough food and fluids
- review your needs at regular appointments (ask to be reassessed if any of your swallowing symptoms change)
- refer you to other professionals, as needed.

### **Dietitians**

A dietitian can advise on how to stay nourished and maintain weight. They often work closely with your speech and language therapist.

### **Specialist nurses**

These nurses have relevant experience with neurological conditions or relevant symptoms for monitoring and treatment.

### **Pharmacists**

Your pharmacist can give you guidance on medication to suit your needs. For example, many medications come in liquid form, for easy swallow.

### **Occupational therapists (OTs)**

Ask your OT for advice on posture and equipment to help you stay independent with eating and drinking, for as long as possible. This can help with management of swallowing difficulties and any weakness you may develop in your arms and hands.

### **Respiratory physiotherapists**

These physiotherapists specialise in breathing problems. They can advise on techniques to maintain your chest and respiratory muscle strength, which can help improve both your breathing and your coughing ability. This can support clearing of mucus and phlegm.

## **Is there anything I can do to make swallowing easier?**

Seek guidance from your health and social care team to manage any difficulties, but the following suggestions may help:

- sit as upright as possible when swallowing
- if it's difficult to clear your mouth, repeat a deliberate swallow several times
- ask your speech and language therapist about a 'swallow reminder' to swallow more frequently than normal (this can be done visually or with a device that beeps)
- have meals when less tired, such as eating more in the day than in the evening
- try different consistencies of food and drink
- eat smaller, but more frequent snacks, rather than large meals
- ask your occupational therapist about head supports if neck weakness is causing your head to drop.

Thickeners can help make fluids easier to swallow, but always have your needs assessed before using these. Your speech and language therapist can advise on how best to use thickeners in a safe way.

Ask your speech and language therapist and occupational therapist about helpful equipment.

For example, a valved straw is easier to suck by keeping fluid at the top of the straw, but be aware that any type of straw can increase the risk of aspiration with swallowing difficulties.

## **What can I do to make meal times easier?**

If you have swallowing problems, you may find meal times particularly frustrating. Not only can it take much longer to eat, but you may find that you no longer feel confident to eat and drink some of the food and liquids you really enjoy.

Your speech and language therapist can advise on texture and consistency, of food and drinks. This can help you swallow more safely, for as long as possible.

Using the right consistency of food and drink to help your swallow helps you maintain your calorie intake.

Your dietitian can also advise on how to get enough calories to meet your body's nutritional needs, including high-calorie drinks to supplement food intake and help maintain your weight (these are available on prescription, which the dietitian may recommend for you).

However, as the muscles involved in swallowing become weaker, you may be advised that you are at increased risk of aspiration. In these cases, your dietitian may discuss alternative ways of providing the nutrition your body needs.

Some people with MND or Kennedy's disease choose to have a feeding tube, usually known as a PEG, RIG or PIG tube, depending on the way it's fitted. This can help you receive fluids and specially prepared liquid feed straight into your stomach, through a tube in your abdomen.

The tube is the size of a small narrow straw and is usually inserted under local anaesthetic.

Severe weight loss before having a feeding tube fitted may increase the risks during and after the operation, so it is best to consider your options early, before you have lost a substantial amount of weight. Your speech and language therapist, dietitian, nutrition nurse or doctor can advise.

With a feeding tube, you can still eat and drink by mouth if you wish to and feel safe to do so. This is usually done with advice from your health and social care team.

Using a combined approach can help you feel full, but enable you to continue enjoying flavours.



See our guide **Eating and drinking with MND** for guidance on food preparation and easy swallow recipes.

At first, you may only use your feeding tube to top-up your food and drink, but you can get all your nutrients and fluids through the tube if necessary.

Tube feeding can also help your carer feel more confident that you are getting enough nutrition and reduce stress for you both.



See information sheet **7B Tube feeding**.

## 2. How can I manage problems with saliva?

With MND or Kennedy's disease, you may have problems with saliva. This is not caused by producing extra saliva, but through not being able to swallow effectively, breathing through your mouth or dehydration. Problems with saliva may include:

- pooling of thin, watery saliva that isn't being cleared and gathers in the mouth
- saliva dribbling out from the mouth if you are unable to close your lips fully
- discomfort if saliva collects at the back of the throat
- thick, sticky saliva which is difficult to clear from your mouth and throat (which can happen if you are dehydrated)
- dehydration, if the fluids you lose are not replaced (this can be made worse if you are drinking less due to swallowing difficulties).

### How do I cope with thin, watery saliva?

You may need to clear saliva that pools and leaks from the mouth by wiping it with a tissue or into a small container. This may make you self-conscious and affect your confidence in social situations. Ask your health and social care team for help, such as trying relevant prescription medications to find what suits you best. These may include:

#### **Glycopyrronium**

Normally used to treat excess sweating, but can also dry the mouth. Available in liquid form or by injection.

#### **Hyoscine hydrobromide**

Normally used to treat travel sickness, but can also dry the mouth, although it may cause drowsiness. Available in tablet form, as a skin patch or by injection.

#### **Hyoscine butylbromide**

Normally used to treat bowel cramps, but can also dry the mouth, but is less likely to make you drowsy than hyoscine hydrobromide. Taken in tablet form or by injection.

#### **Atropine**

Can be used to dry the mouth. In tablet form or, with medical recommendation, as eye drops used under the tongue for short term relief of reducing thin saliva.

#### **Amitriptyline**

Normally used as an antidepressant, but can also dry the mouth. Available in tablet form or as an oral solution.

#### **Botulinum toxin**

Also known as Botox and usually only used in severe cases for saliva control. It can only be administered by a specialist and is injected into the saliva glands. A single dose can last up to three months. Although considered relatively safe, it can cause side effects, such as swallowing problems and a very dry mouth.

## Clonidine

Normally used for high blood pressure but can reduce volume of saliva production. Available in tablet form.

## Radiation

Can suppress the saliva glands and may be helpful if the problem is severe.



See later heading in the section: **How can an oral suction unit help?**

## How do I cope with thick saliva or a dry mouth?

You may have thick and sticky saliva and a dry mouth. This can be caused by dehydration and evaporation of saliva, often by breathing through the mouth.

When thick saliva, mucus and phlegm build up in your mouth and the back of your throat, it can be very uncomfortable. Chest infections can also increase phlegm. Practical tips can help.

- Drink plenty of fluids to stay hydrated. If you have swallowing difficulties, your speech and language therapist can advise on different ways of getting fluids.
- if you can still swallow thin liquids safely, ice lollies or ice cubes on sticks can help relieve a dry mouth.
- It may be worth avoiding or reducing dairy products and citrus fruit, as these can sometimes make saliva and phlegm thicker. Check with your dietitian first, as reducing dairy intake may lead to weight loss.
- Try juices such as pineapple and papaya, as these contain an enzyme that can help break down thick saliva. Papain or bromelain supplements can also help.
- Inhaling steam may help to loosen and moisten thick secretions or using a nebuliser as prescribed. A nebuliser produces a fine mist for inhaling. Usually used to administer medications, it should only be used in consultation with your doctor or health and social care team.
- Saliva replacement gel or spray can help relieve a dry mouth and inhibit odour-causing bacteria. Regular sips of water may also relieve a dry mouth.
- If your mouth gets very dry when asleep, a spoonful of a good olive oil or ghee (clarified butter) may help. Ensure good oral hygiene if using this method.

Everyone will have different needs and preferences, but you may also find certain foods are more difficult to eat or unappealing with saliva problems.



**"Sticky saliva and broccoli don't make a good combination for me!"**

The following prescription medications may be helpful with thick saliva.

#### **Carbocisteine/Acetylcysteine**

This works by breaking down the mucus to make it less thick and sticky, and easier to cough up. It is available as a liquid or capsules, as well as an inhalation in a nebuliser.

#### **Guaifenesin**

This is a cough mixture that can help add moisture to thicker mucus secretions, so it's easier to cough up. It is available as a suspension medication, over the counter.

#### **Beta-blockers**

Normally used to treat various conditions including angina and high blood pressures, but can also thin mucus in the mouth.

Further remedies may be available, particularly if you have problems with phlegm. Consult your health care team for appropriate guidance on medication.

### **3. How can an oral suction unit help?**

Oral suction involves inserting a suction tube into the mouth to remove saliva, mucus or food particles. It may be suitable if you are unable to clear your mouth through swallowing. Depending on your symptoms, you may be able to use the suction unit yourself or need support from your carer or care worker. However, oral suction may not be suitable if you have:

- any broken bones in your face
- loose teeth
- blood clotting disorders
- cancer of the throat or mouth
- severe bronchospasm – which can feature in asthma, bronchitis or allergies
- stridor, when air flowing to or from the lungs makes a high-pitched breath noise caused by a narrowed airway
- restlessness or anxiety.

#### **How do I get a suction unit?**

Suction units should be available via your GP or district nurse. In some areas, suction units are only available through a local MND care centre or network.

If they are unable to get a unit, for example due to lack of funding, ask your GP or a member of your health and social care team to email our Support Services team for guidance: [support.services@mndassociation.org](mailto:support.services@mndassociation.org)

## How do I use a suction unit?

The professional who supplies the unit should give you training in how to use it safely. This may be your respiratory physiotherapist, speech and language therapist, nurse, or a member of your specialist healthcare team.

If training wasn't provided, ask them how to use the unit safely.

When using a suction unit, the following guidance should always be followed:

- An oral suction unit should only be used in the mouth. Do not use it on the back of the throat, past the back teeth or further into the mouth than you can see.
- Do not try to remove solid objects, food or an inhaled foreign body from the back of the mouth or throat, as this could force the object further into the airway.
- Do not lay flat on your back. Your respiratory physiotherapist or nurse can advise on positioning, but if you cannot sit up, you should lie on your side.
- Don't turn the dial too high. Start off on a low setting and increase slowly if needed. The appropriate healthcare professional will advise you on the ideal setting to use.
- Do not perform suctioning in the mouth for longer than 10 seconds at a time.
- Do not bring the suction tip in contact with the tongue or the soft skin inside of the cheeks, to avoid damage. Get advice from the professional who provided the equipment to ensure you use the tip in the right parts of the mouth.

## How do I take care of the suction unit?

Always follow any guidance given to you by the manufacturer or the professional who supplied the unit.

The following guidance may also help you maintain the unit correctly:

- Suction a small amount of cold, clean water before and after each use.
- Keep the suction tip and tubing as clean as possible to prevent build up of bacteria.
- Empty the canister as required.
- Follow the manufacturer's instructions for cleaning the equipment after use.
- The battery should be regularly charged as instructed.

If you have any queries about maintenance of the suction unit, refer to the instruction manual or contact the manufacturer for more information.

## 4. How can I manage coughing?

If you experience muscle weakness or pooling of saliva, sensations at the back of the throat can change. You may feel anxious that sudden coughing will affect your breathing, but even a severe coughing fit does not result in sudden loss of breathing.

A small number of people with MND or Kennedy's disease occasionally experience unexpected coughing or choking brought on by spasm in stiff throat muscles. This does not result in sudden loss of breathing and medication can reduce the impact.

If the tubes leading to our lungs are irritated, it's natural to cough to clear the airways. However, if your breathing muscles get weaker, you may not be able to cough as forcefully as before. You may need to cough more times, but if your cough isn't strong enough to clear the irritation, your risk of chest infection increases. Ask your speech and language therapist or a respiratory physiotherapist about the following.

### Breathing techniques

These techniques include breath stacking to add extra force to your cough (this works by placing additional air on top of air already in your lungs).

### A machine to help you cough

This machine is used with a face mask and simulates a natural cough to reduce the risk of repeated chest infections. Some people find it difficult to adjust to this, but it can be helpful. It's usually easier to get used to in the early stages of difficulty.

Your cough support machine is usually set up and monitored by a respiratory physiotherapist. Provision or loan of these cough support machines may vary by region and servicing can be tricky. If you do experience any problems in access or with servicing, contact our helpline, MND Connect to help us monitor these issues.



See section 6: **How do I find out more?** for MND Connect contact details.

### What can I do about coughing during eating?

When swallowing muscles get weaker, you may cough more when eating and drinking. In this case, seek advice from your speech and language therapist and dietitian. They will advise you on the best techniques, such as:

- chewing more thoroughly so that food is mixed well with saliva to make it easier to swallow
- using different consistencies of food or thickening thin liquids to make them easier to swallow (some thickeners are available on prescription but always take advice on how to use these safely).

## 5. How can I manage choking?

Choking happens when the airway is obstructed by a foreign object, such as food or liquid. This can feel frightening, but it usually clears without the need for extra help.

Coughing and choking when eating can happen to anyone, not just people with swallowing difficulties. If your swallowing muscles are weakened, you are slightly more at risk.

Most incidents are fairly minor, but there is a risk that choking can become an emergency, needing immediate first aid. Guidance is covered in this section, including for carers.

Those supporting you need to know what to do in the unlikely event that you have a serious choking episode. Advice from your speech and language therapist on this issue can help you and those around you to prevent and manage these events.

How to manage choking for people with MND or Kennedy's disease is exactly the same as for any other adult. Knowing how to deal with possible situations in advance can help reduce anxiety.

There is a difference between mild and severe choking.

### **Mild or partial choking**

This is where the airway is only partially blocked. It can happen when taking in food or liquid, or when trying to clear secretions coming up from the lungs.

Choking is mild if the person can:

- speak or make a sound (where speech has not been severely affected)
- still cough and breathe.

### **Severe choking**

This is where the airway is completely blocked and the person will be unable to speak or make a sound.

They may be able to make small wheezing sounds but any attempt to cough will be silent, as they will be unable to breathe in or out.

**Severe choking is an emergency and requires immediate action.**

If the person is unable to speak due to MND, they may be able to respond by nodding or shaking their head, or by gesture.

## Guidance on choking for your carer

Share this information with those who support you when you are eating and drinking. It may help to reassure you and your carer about any choking you might experience.

Feeling less anxious and more in control is important, as panic can make the situation worse.

**The following are guidelines and do not replace clinical advice. If you have any problems with swallowing, coughing or choking, see a speech and language therapist and a dietitian for assessment and advice. You may also find it helpful to see a physiotherapist with experience of neurological conditions.**

### Assisting someone with mild or partial choking

If the person can still cough, breathe or make a sound, this is mild or partial choking and they can usually clear the blockage themselves.

Encourage them to continue coughing until the airway is clear and the feeling subsides. Then give them time to rest.



**"I found that giving them a reassuring hug from the side, while the person with MND was seated, while saying 'Everything is going to be alright', had a relaxing and loosening effect, which helped to clear the choking... just giving this reassurance helped to reduce anxiety."**

Mild choking can be very distressing for the person and for those around them, but with patience and time the blockage will eventually clear.

If supporting, staying calm can help reduce anxiety for the person who is experiencing mild choking.

**With mild or partial choking, do not slap the person on the back as they may inhale deeply, forcing the food or liquid further down the airway.**

If at any time the person loses their ability to cough effectively, then this could become a severe choking episode.

## Assisting someone with severe choking

If the person is unable to cough, breathe, speak or make any sound except possibly a small wheezing sound, it is severe choking.

**WARNING: This is an emergency situation requiring immediate action.**

In this instance:

- stand slightly behind the person to one side (if you're right-handed, stand to the left, if you're left-handed, stand to the right)
- support their chest with one hand and lean the person forward, so the blockage will come out of their mouth rather than going further down
- provide up to five sharp blows between the person's shoulder blades with the heel of your hand (the heel is between the palm of your hand and your wrist)
- stop after each back blow to see if the blockage has been dislodged.

If five back blows fail to clear the obstruction, then provide up to five abdominal thrusts as follows:

- stand behind the person who is choking, even if they are in a chair or wheelchair (if the chair is too bulky to include, position yourself to one side and follow the procedure as closely as you can)
- place your arms around their waist and bend them well forward
- clench your fist and place it right above their belly button
- place your other hand on top and thrust both hands backwards into their stomach with a hard, upward movement
- repeat this five times until the blockage comes out of their mouth
- stop after each thrust to check if the blockage has cleared
- if the obstruction is still stuck, continue alternating back blows with abdominal thrusts.

If the person's airway is still blocked after three cycles of back blows and abdominal thrusts, then:

- call 999 or get someone else to do it and ask for an ambulance immediately
- continue with the cycles of back blows and abdominal thrusts until help arrives.

If you have to perform abdominal thrusts, the person should go to hospital afterwards.

## What if I become unconscious?

If you become unconscious, cardio pulmonary resuscitation (CPR) would normally be attempted.

Do not attempt cardio pulmonary resuscitation (DNACPR) can only be applied if previously agreed that CPR is not your wish and not medically in your best interests. This would usually have to include a specific instruction about choking.

CPR can cause injury and your carer should be trained before attempting to carry it out. See the NHS website at: [www.nhs.uk/conditions/first-aid/cpr](http://www.nhs.uk/conditions/first-aid/cpr)

If you do not wish for an attempt at resuscitation, you can write down your decisions to refuse or withdraw specific treatments and in which circumstances, on a form known as an Advance Decision to Refuse Treatment (ADRT).

If completely correctly and valid, an ADRT is legally binding in England and Wales under the Mental Capacity Act 2005.

An ADRT is also legally binding in Northern Ireland under common law.

Although not legally binding in Scotland, an ADRT can still be used to guide health and social care professionals there.

Inform all those involved in your care about your ADRT, as well as any other care documents. This includes your GP and any specialists.

Provide your GP with a copy of your ADRT for your medical records and ask how local systems work.

For example, some ambulance services hold copies of ADRTs or care guidance for people with life-shortening diseases, such as MND.

Wherever possible, paramedics and other emergency responders take medical history into consideration, but they may not be able to access your records in an emergency. Without seeing a valid ADRT form, they may have to make a swift clinical judgment about the treatment they provide.



See information sheet **14A Advance Decision to Refuse Treatment**.

## 6. How do I find out more?

### Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

#### **BDA - The Association of UK Dietitians**

Guidance for and about dietitians and others working in nutrition.

Email: [info@bda.uk.com](mailto:info@bda.uk.com)

Website: [bda.uk.com](http://bda.uk.com)

#### **The Royal College of Occupational Therapists**

Guidance for and about occupational therapists (OTs).

Email: [membership@rcot.co.uk](mailto:membership@rcot.co.uk)

Website: [rcot.co.uk](http://rcot.co.uk)

#### **Chartered Society of Physiotherapy (CSP)**

Guidance on physiotherapy and a search facility to find a local physiotherapist.

Email: through the website contact page

Website: [csp.org.uk](http://csp.org.uk)

#### **MND Scotland**

Care, information and research funding for people affected by MND in Scotland.

Tel: 0141 332 3903

Email: [info@mndscotland.org.uk](mailto:info@mndscotland.org.uk)

Website: [mndscotland.org.uk](http://mndscotland.org.uk)

#### **NHS and UK healthcare**

Information about NHS services and healthcare across the UK.

Website: [nhs.uk](http://nhs.uk)

Tel: 111 (for urgent medical advice in England, available 24/7)

Website: [111.nhs.uk](http://111.nhs.uk) (For England)

Tel: 111 (for urgent medical advice in Wales, available 24/7)

Website: [111.wales.nhs.uk](http://111.wales.nhs.uk) (For Wales)

Tel: Find individual trusts in Northern Ireland on website contact page

Website: [hscni.net](http://hscni.net) (For Northern Ireland)

Tel: 111 (for urgent medical advice, available 24/7)

Website: [nhs24.scot](http://nhs24.scot) (For Scotland)

#### **Royal College of Speech and Language Therapists (RCSLT)**

The RCSLT can help you find qualified speech and language therapists

Email: through the website contact page

Website: [rcslt.org](http://rcslt.org)

## **Acknowledgements**

With thanks to our User Review Group for kindly sharing their experiences.

Thank you also to the following for their kind review during the development or revision of this information sheet:

**Dr Emma Husbands**      Consultant Palliative Medicine, Gloucestershire Hospitals NHS Foundation Trust.

**Nina Squires**      Speech and Language Therapist, Nottingham University Hospitals Trust.

## **References**

References used to support this resource are available on request:

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

Or write to:

Information feedback,  
Motor Neurone Disease Association,  
Francis Crick House,  
6 Summerhouse Road,  
Moulton Park,  
Northampton, NN3 6BJ

## **Further information**

We offer a wide range of information about MND and Kennedy's disease. You may find the following resources helpful, relating to this sheet.

### **Information sheets**

7B Tube feeding  
8A Support for breathing problems  
14A Advance Decision to Refuse Treatment (ADRT)  
6A Physiotherapy

### **Booklets**

An introduction to motor neurone disease (MND)  
Kennedy's disease  
Caring and MND - quick guide

### **Large guides**

Living with MND  
Eating and drinking with MND  
Caring and MND - support for you

Search for information by need at: [mndassociation.org/careinfofinder](http://mndassociation.org/careinfofinder)

Find information for professionals at: [mndassociation.org/professionals](http://mndassociation.org/professionals)

Download our information at: [mndassociation.org/publications](http://mndassociation.org/publications)

Find information in other languages at: [mndassociation.org/languages](http://mndassociation.org/languages)

Order printed copies from our MND Connect helpline (see Our support next).

## **Our support**

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy's disease.

### **MND Connect**

Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: [mndassociation.org/mndconnect](http://mndassociation.org/mndconnect)

Tel: 0808 802 6262

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

### **Support services**

Find out about our support services at: [mndassociation.org/our-services](http://mndassociation.org/our-services)

### **Local and regional support**

Find out about our branches and groups at: [mndassociation.org/local-support](http://mndassociation.org/local-support)

### **MND Association Benefits Advice Service**

For help to identify claims and how to apply, visit: [mndassociation.org/benefitsadvice](http://mndassociation.org/benefitsadvice) or call our MND Connect helpline.

Tel: 0808 802 6262

### **MND Association website and online forum**

Website: [mndassociation.org](http://mndassociation.org)

Online forum: [forum.mndassociation.org](http://forum.mndassociation.org)

## We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with MND or Kennedy's disease, their families and carers.

Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns, and applications for funding.

To give feedback on this or any of our information sheets, access our online form at:  
**[smartsurvey.co.uk/s/infosheets\\_1-25](https://smartsurvey.co.uk/s/infosheets_1-25)**

You can request a paper version of the form or provide direct feedback by email:  
[infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)

Or write to:

Information feedback  
Motor Neurone Disease Association  
Francis Crick House,  
6 Summerhouse Road,  
Moulton Park  
Northampton NN3 6BJ

## Would you like to help with user review of our information?

If you are living with MND or Kennedy's disease, or you are a carer, contact us at:  
[infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)

© MND Association, 2026

Motor Neurone Disease Association  
Francis Crick House,  
6 Summerhouse Road,  
Moulton Park  
Northampton, NN3 6BJ

Tel: 01604 250505  
Email: [enquiries@mndassociation.org](mailto:enquiries@mndassociation.org)  
Website: [mndassociation.org](http://mndassociation.org)

Registered Charity no. 294354

Revised: January 2026  
Next review: May 2026  
Version: 1

