

7A

## Swallowing difficulties

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### Information for people with or affected by motor neurone disease


With MND, 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 looks at issues you may face and why they happen, with suggestions on what can be done to help. It also includes guidance to help carers feel more confident if they need to assist during an episode of mild or severe choking.

The content includes the following sections:

- 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?**

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 This symbol is used to highlight **our other publications**. To find out how to access these, see *Further information* at the end of this sheet.

 This symbol is used to highlight **quotes** from other people with or affected by MND.

# 1: How does MND affect swallowing?

Swallowing is a complex process, part of which happens under our voluntary control and part of which happens automatically. In a normal swallow, the 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 can affect the nerves that carry messages to muscles in your jaw, lips, throat, face and tongue, causing the muscles to become weak. This can make it more difficult to swallow effectively and handle saliva in your mouth. Health and social care professionals call these swallowing difficulties dysphagia.

Weakness in these muscles can also affect the way you speak.



For more information about speech and communication with MND, see: Information sheet 7C – *Speech and communication support*

If you have a form of MND called progressive bulbar palsy, swallowing problems may start at a fairly early stage in the disease. These problems can also occur with other types 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. You may have already adapted without really noticing and sometimes family, friends or others may notice changes before you do.

Being aware of signs as early as possible can help you manage symptoms and avoid more serious problems that might develop, such as chest infections. It is very important to get advice from your GP and your speech and language therapist if you notice any problems with swallowing.

You might find the way you swallow changes through the day, gradually becoming weaker. General signs of swallowing difficulties may include:

- coughing when eating or drinking
- more frequent swallowing to clear food, liquids or saliva
- feeling unable to clear your mouth or throat
- gagging or choking on food, liquids or saliva
- a wet or gurgly sounding voice
- needing extra time or effort to chew or swallow
- food or liquid leaking from the mouth

- drooling
- a sense of choking
- feeling that food or medication is 'stuck' in the throat.

## How might swallowing difficulties affect me?

Swallowing difficulties can lead to:

- less enjoyment of eating or drinking
- eating and drinking taking longer
- embarrassment or isolation in social situations involving eating or drinking
- weight loss
- dehydration, which can lead to constipation, thick stringy saliva and other issues
- anxiety, particularly if you are concerned about choking
- chest infections or aspiration pneumonia from food or drink getting into the lungs.

## What tests are used to diagnose swallowing problems?

Your speech and language therapist can discuss your swallowing difficulties to understand what is happening and the impact it is having. They may examine your mouth and observe you taking small mouthfuls of food or drink. This can help identify which muscles are affected. If necessary, you may be referred for further tests. These include:

**Fibreoptic Endoscopic Examination of Swallowing (FEES):** A small flexible tube with a light at the end is passed into the back of the throat via the nose, to observe food and liquid as it passes over the back of the 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 and become a vicious cycle. With support from your health and social care team, there may be ways to manage and treat these issues. See later heading in this section, *Who can help if I have swallowing difficulties?*



For more information about coping with the emotional challenges of MND, see our guide: *Emotional and psychological support*.

You may find it useful to have open conversations with those close to you, particularly if a partner, family member or friend is your main carer. Agreeing on how you will approach any difficult situations in advance can help to reduce any tension that may be felt.



*"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 early signs are likely to progress. Advice from a relevant professional may not feel easy at first, but it is vital to help you and those supporting you.

## **Why is there a risk of chest infection?**

The body's reaction to prevent anything entering our airway is to cough. If the muscles have weakened and your cough is not effective, food or liquids may enter the lungs. This is known as aspiration. If this happens without a reaction such as coughing or gagging, it is known as silent aspiration.

Aspiration or silent aspiration can lead to chest infections or a type of pneumonia known as aspiration pneumonia, as lungs cannot clear unwanted food or drink very easily. Get advice from your GP and your speech and language therapist if you notice any problems with swallowing, or if you experience repeated chest infections.

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

We recommend having the flu jab in all cases of MND, as you qualify as being at risk. Flu can lead to more serious illnesses including 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, who may be at risk if you fall ill.

Vaccinations are also available to protect you from serious 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?**

In most cases, your GP will refer you to a speech and language therapist, who can assist you, your family and your carers with practical guidance on how to manage swallowing and any anxiety you might feel. They are likely to be your main contact for swallowing difficulties, and can refer you to other professionals when needed.

Speech and language therapists are specialists in the function of the mouth and throat, including eating and drinking techniques as well as speech and communication. They can teach you techniques to help you swallow as safely as possible. Following a swallow assessment, they can advise on consistencies of food and drink that are safe to swallow.

Because your swallowing could change, you will need to be seen regularly by your speech and language therapist. They can monitor you and determine if any techniques that you use to manage the problem are still helping. If you think your needs have changed, ask for a reassessment.

The following professionals may also be involved if you have concerns about swallowing, saliva, coughing or choking:

**General practitioners (GPs):** are likely to be your first contact. They give medical advice, prescribe medication and treatments, and can refer you to other health and social care professionals for specialist support or therapy.

**Dietitians:** advise on the best foods to help you stay nourished. Ideally they will work closely with your speech and language therapist.

**Specialist nurses:** help with the monitoring and treatment of symptoms, eg specialist respiratory nurses for support with breathing and coughing.

**Pharmacists:** provide guidance on the best types of medication to suit individual needs, eg many medications can be dispensed in liquid form, which may be easier to swallow.

**Occupational therapists (OTs):** advise 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:** advise on techniques to maintain your chest and respiratory muscle strength, and to improve your breathing and coughing ability. This can also help with the clearing of mucus and phlegm.

## Is there anything I can do?

We recommend you follow guidance from your health and social care team to help manage any difficulties you may encounter. However, the following suggestions may also help:

- sit as upright as possible when swallowing
- try lowering your chin towards your chest before swallowing, which reduces the risk of saliva, food or drink, entering your airways
- repeat a deliberate swallow several times if you have difficulty clearing your mouth
- ask your speech and language therapist about a 'swallow reminder' which prompts you to swallow more frequently than normal (this can be done with a visual reminder or a device that beeps)
- ask your speech and language therapist or occupational therapist about other pieces of equipment to help with eating and drinking – for example, if sucking is difficult, a valved straw can reduce the effort required by keeping fluid at the top of the straw (please note that with swallowing difficulties, using any kind of straw may increase the risk of aspiration)
- have meals when you feel less tired, which may mean eating more during the day rather than in the evening
- try different consistencies of food and drink, or drink thickeners if needed, to find what suits you best – your speech and language therapist can advise
- choose 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.


## What can I do about difficulty eating and drinking?

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, to help you continue to swallow safely for as long as possible, to maintain your calorie intake.


As well as advising on suitable foods, your dietitian can advise you 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.

 For easier to swallow meal ideas, see our guide:  
*Eating and drinking with MND*

Some people with MND choose to have a feeding tube known as a PEG, RIG or PIG tube. 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, nutrition nurse, dietitian or doctor can advise.

 For more information about tube feeding, see:  
*Information sheet 7B – Tube feeding*

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.

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.

## **2: How can I manage problems with saliva?**

With MND, you may find that you have problems with your saliva. This is not caused by producing extra saliva, but by the inability to swallow it effectively, breathing through your mouth or dehydration.

Problems with saliva may include:

- pooling of thin, watery saliva because it is not 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?

Sometimes the only way to clear saliva that pools or leaks from the mouth is to wipe it with a tissue or into a small container. This may make you feel self-conscious and affect your confidence in public and in social situations. However, there are a number of methods to help, so ask your health and social care team for advice.

If you have thin saliva pooling in your mouth, or drooling, this can be treated using prescription medications. These may include:

**Hyoscine hydrobromide:** normally used to treat travel sickness, but can also dry the mouth, although it may cause drowsiness. It is available in tablet form, as a skin patch and by injection.

**Hyoscine butylbromide:** normally used to treat bowel cramps, but can also dry the mouth. It is less likely to cause drowsiness than hyoscine hydrobromide. It is available in tablet form, but can also be administered as an injection.

**Atropine:** can be used to dry the mouth. It is available in tablet form or, with medical recommendation, atropine eye drops can be used under the tongue for short term relief of reducing thin saliva.

**Amitriptyline:** normally used as an antidepressant, but can also dry the mouth. It is available in tablet form or as an oral solution.

**Glycopyrronium:** normally used to treat excess sweating, but can also dry the mouth. It is available in liquid form, but can also be administered as an injection.

**Botulinum toxin:** also known as Botox. This is 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 for up to three months. Although considered relatively safe, it can cause side effects, such as swallowing problems and a very dry mouth.



**Radiation:** this can suppress the saliva glands and may be helpful if the problem is severe.

Ask your GP or wider health and social care team what would be suitable for you. You may have to try different medications to find what suits you best.

See also section 3: *How can an oral suction unit help?*

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

You may find that you have the opposite of thin saliva, where your saliva becomes thick and sticky.

Dehydration and evaporation of saliva caused by breathing through the mouth can cause thick saliva, mucus and phlegm to build up in the mouth and at the back of the throat. This can feel very uncomfortable. Your mouth may also feel very dry. Chest infections are likely to increase the production of phlegm.

Practical tips can help:

- Drink plenty of fluids to help avoid dehydration. Your speech and language therapist can advise on drinking techniques, thickeners or different ways of getting fluids, if you have problems with your swallow.
- Ice lollies or ice cubes on sticks can help to relieve a dry mouth if swallowing is still safe with thin liquids.
- It may be worth avoiding or reducing your intake of dairy products and citrus fruit, as some people find these can make saliva and phlegm thicker. Check with your dietitian, as reducing your dairy intake may lead to weight loss.
- Try juices such as pineapple and papaya, as these contain an enzyme which helps to break down thick saliva. Also papain or bromelain supplements can help.
- Inhaling steam may help to loosen and moisten thick secretions.
- Sterile water can be given via a nebuliser to help loosen chest secretions. A nebuliser produces a fine mist for inhaling into the lungs. It is usually used to administer medications, and should only be used in consultation with your doctor or health and social care team.
- Saliva replacement gel or spray can help to relieve a dry mouth and inhibit odour-causing bacteria. Regular sips of water may also relieve a dry mouth.
- If the mouth is very dry during periods of sleep – using a good olive oil or a spoonful of ghee (clarified butter) to ‘lubricate’ the mouth may give a slightly longer period of relief. Ensure good oral hygiene in between use of 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:

**Carbocisteine/Acetylcysteine:** 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 a form which can be inhaled in a nebuliser.

**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 for you if you are unable to clear your mouth through swallowing.

Depending on how MND affects you, you may be able to use the suction unit yourself, or you may need support from a carer or care worker.

Oral suction may not be suitable for you 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 make a high-pitched breath noise, caused by a narrowed or obstructed 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 in your area, it may be possible to loan one from the MND Association. Ask your GP or a member of your health and social care team to contact the Support Services team on 01604 611802, or email: [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 the MND specialist team. If training wasn't provided, request it to ensure you 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 on the 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 can also help you to maintain the unit correctly:

- Suction a small amount of cold, clean water before and after each use. It is important to keep the suction tip and tubing as clean as possible to prevent the 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, you may find that sensations change at the back of the throat. This can cause anxiety that a sudden coughing fit will affect your breathing, but it is important to remember that even severe coughing episodes do not result in sudden loss of breathing.

A small number of people with MND may occasionally experience unexpected coughing or 'choking' episodes brought on by spasm in stiff throat muscles, but again this does not result in sudden loss of breathing. Medication can reduce the impact if this does occur, which can be prescribed for you in the *MND Just in Case Kit*. See next heading for further information about the kit.

When the tubes leading to the lungs are irritated, we cough as a natural reflex to clear the airways. If you have respiratory muscle weakness, you may not be able to cough as forcefully as you once could.

This may mean you need to cough more to clear an irritation. However, if your cough is not strong enough to clear the irritation, you may be at increased risk of chest infection. Your speech and language therapist and a respiratory physiotherapist can help you manage this through:

**Breathing techniques:** such as breath stacking (which places additional air on top of air already in the lungs) to add extra force to your cough.

**A machine to help you cough:** which is used with a face mask and often referred to as 'cough assist'. This simulates a natural cough and can help to reduce the risk of recurring chest infections. Some people find it difficult to adjust to this, but it can be beneficial. It is usually easier to get used to the technique in the early stages of difficulty. The machine is set up and monitored by a respiratory physiotherapist.

The provision or loan of 'cough assist' machines may vary from region to region and sometimes servicing and maintenance can be problematic. If you experience any problems in accessing one, or with servicing, please contact our helpline, MND Connect to help us monitor these issues. See *Further information* in section 6: *How do I find out more?* for contact details.

### What is the MND Just in Case Kit?

The *MND Just in Case Kit* is a small box that can store specific medications to alleviate any feelings of breathlessness and panic you may experience, including those due to coughing and choking.

The kit holds information and prescribed medication for your carer to administer in certain situations. It also holds information and additional medication for health professionals to use, so they can take immediate and appropriate action if they are called in an emergency.

The **empty** box is supplied directly to your GP, free of charge. They can prescribe the required medicines and supply you with the complete kit to keep at home.

Advice and instructions are provided inside the kit for your carer, but additional guidance should be given to you and your carer when the kit is supplied, usually by your community nurse or your GP. This is because the medications will have been prescribed according to your individual needs. If the contents of the kit are not explained, then ask for clarification.

Although most people never need to use the medications in the box, having these close at hand can bring confidence and reassurance. Ask your GP about obtaining a kit if you feel it would be useful. They can contact MND Connect to order a kit for you. See *Further information* in section 6: *How do I find out more?* for contact details.

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

When the muscles involved in swallowing are affected, you may find that you 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 safely (some thickeners are available on prescription).

## **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 requiring immediate first aid. See next heading *Guidance on choking for your carer*.

Advice from your speech and language therapist on this issue is important to help prevent and manage these events. It is also important for those around you to know what to do in the unlikely event that you have a serious choking episode.

The treatment of choking for people with MND is exactly the same as treatment of choking for any other adult. To reduce feelings of anxiety about choking, it is helpful to know beforehand how to deal with situations that may arise.

It is important to know the difference between mild and severe choking:

**Mild or partial choking:** happens if the airway is only partially blocked. This might be through taking in food or liquid, or trying to get rid of secretions coming up from the lungs. Choking is mild if the person can:

- answer a question or make a sound (where speech has not been severely affected by MND)
- still cough and breathe.

**Severe choking:** the person will be unable to speak or make a sound. 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. If they are unable to do this, there will be other signs that the choking is severe. If the airway is completely blocked, they may only be able to make small wheezing sounds and 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.** See the next page for further information.

## Guidance on choking for your carer

Whether your main carer is a partner, family member or friend, or you access support from paid carers, you may wish to 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. See earlier heading, *What is the MND Just in Case Kit?*



*“Not panicking is important... the person caring and the person with MND have to trust in each other’s capabilities.”*

The following are guidelines only and should not be viewed as a replacement for clinical advice on choking. If you are experiencing any problems with swallowing, coughing or choking, see a speech and language therapist and a dietitian for advice. You may also find it helpful to discuss this with 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. In this situation they can usually clear the blockage themselves. Encourage them to continue coughing until the airway is clear and the feeling subsides.

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

**WARNING:** 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.



*"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."*

If at any time the person loses their ability to cough effectively, then this could become a severe choking episode. See next heading *Assisting someone with severe choking*.

## 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 that 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. If they are in a chair or wheelchair, you may have to position yourself behind it. 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 had 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, unless it had been previously agreed this is not your wish and not medically in your best interests.

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/Accidents-and-first-aid](http://www.nhs.uk/Conditions/Accidents-and-first-aid)

If you do not wish for an attempt at resuscitation, you can write down your decisions to refuse or withdraw specific treatments on a form known as an Advance Decision to Refuse Treatment (ADRT). It is only legally binding in England and Wales, but can still be used to guide health and social care professionals in Northern Ireland.



For more information about ADRT, see:  
Information sheet 14A – *Advance Decision to Refuse Treatment (ADRT)*

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

## 6: How do I find out more?

### Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information. The contact details are correct at the time of print, but may change between revisions. If you need help to find an organisation, contact our MND Connect helpline (see *Further information* at the end of this sheet for details).

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

An organisation representing dietitians and providing those working in nutrition with advice about how they work.

Address: 3rd Floor, Interchange Place, 151-165 Edmund Street,  
Birmingham B3 2TA

Telephone: 0121 2008080

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

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

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

The professional body for all occupational therapy staff in the United Kingdom with information on how to find an OT.

Address: 106-114 Borough High Street, Southwark, London SE1 1LB

Telephone: 020 3141 4600

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

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

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

A professional body working to achieve and promote excellence in physiotherapy. They have search engine for you to find a local physiotherapist.

Address: 14 Bedford Row, London, WC1R 4ED

Telephone: 020 7306 6666

Email: through the website contact page

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

### **Health and Care Professions Council (HCPC)**

A regulatory body who keep a register of health professionals who meet their standards of practice.

Address: Park House, 184 Kennington Park Road, London, SE11 4BU

Telephone: 0300 500 6184

Website: **[www.hpc-uk.org](http://www.hpc-uk.org)**

### **MND Scotland**

They have published a leaflet called Getting the Best from Physiotherapy.

Address: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA

Telephone: 0141 332 3903

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

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

### **NHS Website**

Online information to help you make informed choices about health.

Telephone: 111

Email: through the website contact page

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

### **NHS Direct Wales**

Health advice and information service for Wales.

Telephone: 111

Website: **[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)**

### **NHS Northern Ireland**

Information on NHS services in Northern Ireland. This is an online service.

Email: through the website contact page

Website: **[www.hscni.net](http://www.hscni.net)**

### **Royal College of Speech and Language Therapists**

The main professional body for speech and language therapists, who can help you to contact qualified therapists.

Address: 2 White Hart, London SE1 1NX

Telephone: 020 7378 1200

Email: through the website contact page

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

## **References**

References used to support this document are available on request from:

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

Or write to:

Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd,  
Moulton Park Industrial Estate, Moulton Park, Northampton NN3 6BJ

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## Further information

You may find some of our other information sheets useful in relation to this sheet:

*7B – Tube feeding*

*8A – Support for breathing problems*

*14A – Advance Decision to Refuse Treatment (ADRT)*

*6A – Physiotherapy*

We also produce the following publications:

*Living with motor neurone disease* – our guide to MND and how to manage its impact, including guidance about eating and drinking, and speech and communication

*Eating and drinking with MND* - guidance and a range of easy swallow recipes

*Caring and MND: support for you* – comprehensive information for family carers, who are supporting someone living with MND

*Caring and MND: quick guide* – the summary version of our information for carers

You can download most of our publications from our website at:

**[www.mndassociation.org/publications](http://www.mndassociation.org/publications)** or order in print from the MND Connect team, who can provide additional information and support:

### **MND Connect**

Telephone: 0808 808 6262

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

MND Association, Francis Crick House, 6 Summerhouse Rd,

Moulton Park Industrial Estate, Moulton Park,

Northampton NN3 6BJ

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

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

Online forum: **<https://forum.mndassociation.org/>** or through the website

## **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 or affected by MND, or Kennedy's disease. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

To feedback on any of our information sheets, access our online form at:  
**[www.surveymonkey.com/s/infosheets\\_1-25](http://www.surveymonkey.com/s/infosheets_1-25)**

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

Or write to:

Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd,  
Moulton Park Industrial Estate, Moulton Park, Northampton NN3 6BJ

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