motor neurone disease association

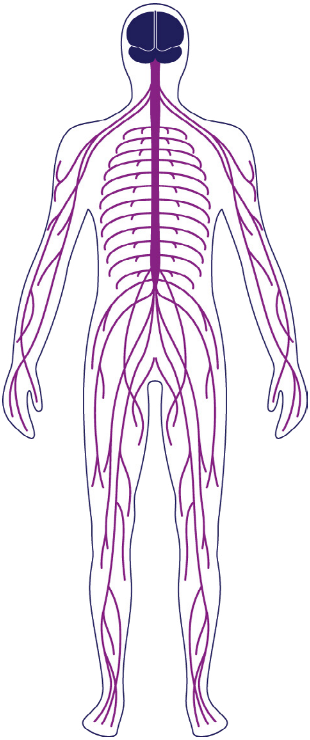
MND Professionals' Community of Practice

Caring for a person with MND: A guide for care workers

For health and social care professionals

About MND

- MND is a fatal, rapidly progressing disease that affects the brain and the spinal cord.
- It attacks the nerves that control movement so muscles no longer work.
- It can leave people locked in a failing body, unable to move, talk or breathe.
- It affects people from all communities.
- Some people may experience changes in thinking and behaviour, with some experiencing a rare form of dementia.
- MND kills a third of people within a year and more than half within two years.
- A person's lifetime risk of developing MND is up to 1 in 300.
- Six people per day are diagnosed with MND in the UK.
- MND kills six people per day in the UK.
- It has no cure.



Would you like to find out more?

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

mndconnect
0808 802 6262
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Content

Section 1: Caring for a person with MND

Section 2: A care worker's toolkit

Section 3: Supporting resources

MND Professionals' Community of Practice

This guide has been endorsed by the MND Professionals' Community of Practice.

Introduction

Motor neurone disease (MND) is a progressive, fatal disease that attacks the motor neurones, or nerves, in the brain and spinal cord. About two people in every 100,000 of the general population will develop MND each year.

MND can affect how people walk, talk, eat, drink, breathe and think. Not all symptoms affect everyone, and it is unlikely they will all develop at the same time or in any specific order. There is no cure for MND, but symptoms can be managed to help improve quality of life.

As MND is a progressive condition, a person's care needs will greatly increase over time and they will need more support from others. Some people with MND will have a carer who is a family member or friend, but may have extra help from care workers at certain times. Others will have all their care needs met by paid care workers.

About this guide

This booklet is for you if you are a care worker – someone who is paid to provide care for people who are unable to look after their own care needs.

You may be providing this care within a person's home, in a care home or in a hospice. You may be employed by an agency, a care or nursing home, or directly by the person with MND. Either way, this booklet will help you find out more about MND and provide the best possible care.

This guide is split into three sections:

- **Section 1: Caring for a person with MND** introduces MND and how it is managed. It also outlines your role in the care team.
- **Section 2: A care worker's toolkit** includes practical tips to monitor the condition of the person with MND, and provide them with appropriate care as their needs change.
- **Section 3: Supporting resources** includes an appendix of sample documents that you might find helpful, as well as a list of the ways the MND Association can help health and social care professionals in providing optimal MND care.

Section one: Caring for a person with MND

The care worker's role

Individuals with MND have many different needs, so various people help with their care. As a care worker, you play an important role in helping them maintain a good quality of life.

It can be hard to predict what support someone with MND might need. Compared to other professionals, you may see the person with MND more often. This will give you a good insight into how they are doing daily, any changes they go through, and what extra support they need.

That's why it's essential to understand the symptoms of MND, how to assist someone with this condition, and who else will be involved in their care.

Information to help you support someone with MND

To provide good care for someone with MND, you will need training in:

- the symptoms and progression of MND
- communicating and understanding the needs of a person who may have trouble speaking
- safely moving and handling a person with mobility issues
- giving medication and helping someone who uses specialist equipment for breathing, eating and talking
- recognising changes in cognition and behaviour
- ensuring safety and dignity while providing care.

While care agencies usually offer training in basic skills, they generally do not cover the specific needs of people with MND.

Relevant professionals should train you in specific areas eg assisting with specialist equipment. The MND Association offers a free online course for care workers, which covers MND, its symptoms, and how you can support those with the condition. The course is divided into seven parts, so you can complete it over several sessions at your own pace.

Visit **www.mndassociation.org/careworkermodule** to access.

On our website, you can find various information resources and training opportunities that can help you learn more about the topics outlined in this booklet. For more details, see page 51.

We also offer an extensive range of helpful resources for people living with and affected by MND. You can use these yourself or share them with the person with MND, their family, and other caregivers. Remember to share this information sensitively and at the right time for the person and their family.

Below we have included some introductory information. You can use our info finders to explore our resources:

- for professionals **www.mndassociation.org/pro-info-finder**
- for people with MND **www.mndassociation.org/careinfofinder.**

All of our resources can be downloaded from the website. You can contact MND Connect to order printed copies (See page 51).

Information to share with people affected by MND

Living with MND - our main guide to help people manage daily life.

Living alone with MND or Kennedy's disease - offers resources to help people living alone with either condition.

Making the most of life with MND – focuses on how people can adapt their approach to continue doing the things they want to.

Understanding my needs - a form that enables them to record their needs and to share them with their care workers or hospital staff.

What you should expect from your care - our booklet to support conversations with health and social care professionals.

Information for professionals

Understanding MND – training videos featuring people with MND sharing their experience.

An introduction to Kennedy's disease – our booklet designed to introduce you to Kennedy's disease.

Using our care information resources – a brief information sheet to help you navigate our provision of resources for people with MND.

Care planning

When you start working with someone with MND, you should receive a copy of their care plan. Whether you are caring for the person at home or in a care facility, you should always follow this plan. It's tailored to their unique needs, likes and dislikes, and it takes into account:

- their health
- personal and family situations
- social, economic and educational background
- mental wellbeing
- ethnic and cultural background.

A member of the care team will assess the person's needs and design a care plan with them. Care will involve various organisations and professionals working as a team led by a named key worker. This is usually the MND co-ordinator (see page 11).

As MND progresses, the person's needs will change. The care team should regularly reassess the needs and update the care plan accordingly. The assessments should happen monthly but may become more frequent as the condition advances.

As a care worker, you play a key role in helping ensure the care plan is reviewed when needed. To do this, talk with the person, monitor their condition, and immediately report any changes or concerns.

Communicating with someone with MND: Talking to someone with MND can be challenging and may require time and effort, but it's crucial.

- Spend time communicating with them to understand how the condition affects their life and how best to support them.
- Don't assume what someone thinks, feels, or prefers. Even in the advanced stages of MND, many people continue to experience a good quality of life.
- Be patient.
- Even if communicating is hard, do your best to understand their needs (see pages 20-21 and 30 for practical advice).

Record keeping: All care providers must keep accurate and timely records. This is crucial to deliver safe, effective, person-centred care. Good record keeping helps monitor any changes in the person's condition or environment that could affect their care, and highlight any support needed.

Safely store and regularly update documents, including:

- the care plan
- daily diary
- weekly body weight measurements
- a medication administration record
- important contact numbers (see also page 48)
- details of emergency procedures (see also page 33)
- checks for services eg fire alarm
- accident policies and report sheets
- updated risk assessment
- complaints procedures and report forms
- documents about capacity assessment, best interest decisions and advance care decisions (pages 27 and 32)
- policies and procedures related to death of a client.

Use the daily diary to record what is specified in the care plan, including:

- food and drink consumed
- emotional wellbeing, mood and health (including communication and mobility issues, equipment used and breathing problems)
- levels of fatigue eg when the person was most tired in the day
- skin pressure areas and treatments
- night-time care
- washing, bathing and dressing (done by themselves or with help)
- bowel habits (frequency, consistency and any signs of constipation or discomfort)
- any other significant events.

Reporting: When you first start caring for someone, find out who to contact if you notice something unusual or concerning. You can refer to the key contacts list on page 46 to help you with this.

- Before sharing something about the person in your care, talk to the them. Explain to them why you may need to report the issue and with whom you will share the information. If there are any safeguarding or urgent medical issues, tell your manager right away.
- Always document any changes, concerns or questions that you, or the person with MND, have. Report them to your manager, as they'll raise the issue with the care team and arrange any training for you.
- Encourage the person you care for to raise any questions or problems directly with their GP or MND co-ordinator. They will refer them to the appropriate support.

Remember to follow data protection laws when sharing personal information. Your manager can guide you on this, or you can learn more at: **www.gov.uk/government/publications/the-caldicott-principles**

Your place in the multidisciplinary team

The National Institute for Health and Care Excellence (NICE) Guideline *NG42 - Motor neuron disease: assessment and management* outlines how to improve care for people with this condition.

It recommends that all people involved in the care of someone with MND work together as a team. When different professionals co-ordinate their services, they can provide multidisciplinary care that meets physical, emotional and practical needs.

As a care worker, you are a fundamental part of this multidisciplinary team (MDT). The MDT should also include:

- occupational therapist
- respiratory specialist
- speech and language therapist
- counsellor or psychologist
- respiratory ventilation services
- wheelchair services
- palliative care specialists
- volunteer organisations
- community care teams
- neurologist
- specialist nurse
- dietitian
- physiotherapist
- MND co-ordinator
- adult social services
- communication services
- orthotics
- GP.

Other professionals may be involved at different stages of the disease.

Keeping detailed records of the person's condition and sharing them with the MDT helps everyone stay up-to-date and provide timely and effective care to the person.

Working with other carers

Ideally, the same person or the same team should care for a person with MND. Having the same care workers regularly helps build trust and develop a meaningful connection with the person with MND. It also helps the care worker develop a clearer understanding of the person's needs, preferences, and individual circumstances.

This consistency may be hard to achieve, however these steps can help maintain consistent care:

- When new care workers start, they should receive a detailed induction with clear instructions and information about what has been done before.
- The person with MND should be told about any changes in the care team and any information that has been shared.
- Care records and daily diaries should be shared with other team members to keep everyone informed and provide consistent care.
- Care workers should share key updates of the day with each other when they hand over care.

Working with the person's unpaid carers

The person with MND and their family are also part of the MDT. Some family members will often act as unpaid carers. They usually have a good understanding of how the condition affects the person in your care so it's crucial to communicate well with them.

Some of them might hesitate to ask for help, but getting support from care workers can give them more free time and a chance to rest. They may also step in to assist you at times. When handing over responsibilities, share any relevant updates with them.

Working with ambulance staff or paramedics

The person in your care may need emergency care and be taken to hospital. Ambulance staff might not know about MND, so it's important you give them essential information:

- Do not lay the person flat without support if they have breathing problems (see page 39 for more on safe positioning)
- Do not give the person oxygen, unless instructed by an MND specialist (see page 15-17).

See page 33 for more information on how to handle emergencies.

The symptoms of MND

MND leads to muscle weakness because the nerve cells in the brain and spinal cord that control movement (called motor neurons) stop sending signals to the muscles. This causes the muscles to waste, resulting in loss of strength and functions such as moving, swallowing, talking and breathing.

Most voluntary muscles (that you can control consciously) are affected. This makes everyday tasks like walking, eating or even sitting up and brushing teeth, challenging.

In this section, we summarise the effects of MND and what you should be aware of as a care worker. It's important to remember that not everyone will experience all the symptoms described here in the same way or order. Some people may also have other health issues.

Mobility and posture issues

MND weakens muscles in the arms, legs, neck and torso, which causes problems with movement, posture and co-ordination.

A person might have floppy arms or legs and a weak neck, affecting their balance and increasing the risk of falls and injuries. They may also feel tightness and stiffness in their muscles, which can lead to sudden, painful cramps and spasms.

Sometimes, muscle tightness causes twitching that feels like rippling sensations under the skin. These are called fasciculations and may be so obvious that other people see them. This twitching can become more pronounced when someone is stressed but usually gets better over time.

What to look for:

- Difficulty co-ordinating movements eg using a zip or opening a jar.
- Frequent trips and falls.
- Cramps and muscle twitching.
- As the muscles waste, legs, shoulders and hands may look thinner and asymmetrical, with fingers curling towards the palm.
- Bent posture that makes the person look shorter.

- Any changes in posture, including those that happen throughout the day and when a person is tired.
- Difficulty keeping the head up, sitting straight or standing tall for extended periods - this can affect the person's breathing, communication and eating and drinking.
- Pain in the back or neck.
- Getting tired quickly after moving or doing activities - eg weakness in the arm can make it tiring for a person to finish a meal or complete tasks like lifting a cup.

How a person can be supported: A **physiotherapist** can suggest aids, splints and collars to maintain posture. They can recommend ways to assist someone who has fallen, or to support their heads, neck and limbs when moving them.

They can also prescribe exercise programmes to maximise movement and reduce stiffness. While not reversing the effects of MND, exercise is still very important for both physical and mental wellbeing. They often suggest passive exercises, where someone moves the person's limbs.

An **occupational therapist** advises on strategies for daily activities like:

- aids and strategies for showering, dressing and sleeping
- equipment to move, like hoists and walking aids
- home adaptations such as a shower chair and a profiling bed
- environmental controls eg lights, TVs and computer switches that can be operated by any part of the body the person can still move.

Wheelchair services evaluate current and future mobility needs and the person's living situation to determine the best type of wheelchair needed.

Palliative care services may help with the pain caused, for example, by muscle stiffness. They can refer to **complementary therapies**, such as massages and acupuncture, which may be beneficial.

If a person says they are in pain, it's important to assess the cause of it, as it might not always be related to MND.

As a care worker: Stay alert for any signs of mobility or posture issues. Document and inform your manager of any changes.

You should also help the person as their ability to move changes. This might include assisting with (see section 2 for practical tips):

- their exercise program - this can be tiring, so the person might prefer short exercise sessions
- moving or getting to a comfortable position (see page 39)
- preventing pressure sores (page 40)
- getting dressed (pages 36-37)
- showering (pages 34-35)
- going to the toilet (pages 35)
- brushing their teeth (pages 37-38).

Breathing problems

As the muscles involved in breathing weaken, it becomes harder for the person to take in enough oxygen and remove carbon dioxide from the body. This is known as respiratory insufficiency and is usually the cause of death in people with MND. It also causes fatigue, daytime sleepiness, poor memory, and hallucinations in some cases. Breathlessness is common, especially when lying flat or during activities like eating or talking.

When the respiratory muscles weaken, some people start using other muscles, like those in the neck and shoulders, to help with breathing. People may have trouble co-ordinating breathing and swallowing, as well as coughing and clearing their lungs or airways. This can lead to food or liquids accidentally going down the wrong way, known as aspiration. It can increase the risk of chest infections.

People with MND may eventually need assistive equipment to breathe. Assisted ventilation does not stop the disease from getting worse, but it may help them live longer. There are two main types:

- Non-invasive ventilation (NIV) – where a machine helps the person breathe through a mask. The masks can range from a simple nasal tube to a full-face mask.

- Tracheostomy ventilation – where a machine takes over breathing through a tube inserted into the windpipe in the neck (see page 50).

Assisted ventilation uses regular room air instead of pure oxygen, as too much oxygen can lead to a build-up of carbon dioxide in people with MND. Oxygen may only be given if a specialist recommends it.

What to look for:

- Shortness of breath, especially when lying flat, eating, drinking or just talking.
- Fatigue and morning headaches.
- Disturbed sleep, including nightmares and daytime sleepiness.
- Poor concentration or memory, confusion and hallucinations.
- Weak cough and sniff.
- Quiet voice and difficulty completing long sentences.
- Unusual movements when breathing, like raising shoulders or pulling in the stomach.

How a person can be supported: A team of **respiratory specialists** will help manage breathing difficulties. The team typically includes a respiratory physiologist or healthcare professional who assesses respiratory function, including the need for assisted ventilation. Specialist nurses, ventilation services and respiratory physiotherapists can teach techniques to help with coughing or breathing.

An **occupational therapist** can offer advice on equipment to improve sleep, and postural support to help breathing. **Palliative care** and **complementary therapists** might help with relaxation strategies.

As a care worker: Breathing issues can be subtle, so they may be difficult for the person with MND to describe, especially if their mobility is limited. Changes that might seem insignificant, like asking for an extra pillow or feeling their socks are tight at the end of the day, could indicate declining respiratory function.

While it's not your job to diagnose an issue, it's crucial to monitor and document any of these signs, discuss them with the person with MND and report them to your manager.

You should assist with sitting or sleeping positions (see page 39) that can help reduce breathlessness.

It is also your responsibility to assist with any recommended equipment and techniques, once you have been properly trained. This includes:

- helping with breathing and coughing techniques
- assisting with putting on and taking off the ventilation mask, making sure it fits well to avoid pressure sores and leaks, which could make the ventilation less effective and lead to poor oxygenation and sleep problems
- operating and cleaning the ventilation machine, including filling the humidifier tank with water when needed
- checking that the machine is in good condition and knowing who to contact if there's a problem
- making sure spare equipment is available if needed.

If someone with MND wants to stop assisted ventilation, a qualified member of the care team will manage this process. You will not be responsible for it.

Swallowing issues

Swallowing difficulties, called dysphagia, happen when the muscles in the face, mouth and throat, known as bulbar muscles, weaken. This can make it hard to eat and drink, or swallow saliva.

Saliva building up in the mouth or throat may lead to drooling, especially if it's watery - this is known as sialorrhea. Thicker saliva, as well as food and drinks, might also get stuck in the throat or be inhaled and go down the airway. This can cause coughing episodes, a sensation of choking or actual choking, and increase the risk of chest infections.

This situation can be frightening for both the person with MND and those around them. However, dying from choking is rare. If someone is choking, it's important to stay calm. Changing their position might help (page 39).

Aspiration happens because weaker muscles make it harder to co-ordinate breathing and swallowing, and to cough effectively to clear the food/liquids from their throat.

Sometimes people don't realise that food/drink went down the airway. This is called silent aspiration and it might happen without any coughing.

Eating and drinking issues can cause weight loss, muscle wasting, malnutrition, dehydration, loss of strength, fatigue and poor skin health.

Eating can become stressful, having a significant social and psychological impact. For example, people may stop enjoying their meals or feel uncomfortable eating out or with others.

People may need to use different feeding options to maintain a good nutritional status and stay hydrated, including:

- a nasogastric (NG) tube which goes through the nose into the stomach (often a short-term intervention)
- a gastrostomy tube that is inserted into the stomach through a hole in the abdomen. The most common type of gastrostomy is PEG.

In some cases, even if people use a feeding tube, they may also want to keep eating by mouth for pleasure.

What to look for:

- weight loss - this could be visible only after some time. Look for other signs of muscle weakness (see page 13 and below), clothes fitting looser and more visible cheekbones
- eating/drinking becoming tiring
- people wanting to eat less, avoiding food or being frustrated
- needing extra time or effort to chew or swallow
- difficulty moving the tongue or food/drinks around the mouth
- a wet or gurgly sounding voice
- coughing, choking or sensations of choking while eating or drinking
- food/liquid leaking from the mouth and drooling.

How a person can be supported: A **speech and language therapist** can assess the ability to eat, drink and swallow, and create a plan. This includes safe swallowing techniques and feeding options.

They also collaborate with a **dietitian** to develop a diet that includes easy-to-swallow foods and prevents weight loss.

Other professionals involved include:

- **physiotherapists** - for guidance on the best positions for eating and how to handle coughing and choking episodes
- **respiratory specialists** - for managing breathing issues that affect swallowing, including saliva problems
- **occupational therapists** - for advice on easy-to-swallow food and drink preparations and equipment like adapted cutlery.

Saliva issues can be managed with dietary changes, medications and, in some cases, radiotherapy. Suction units can help remove excess saliva. Mechanical Insufflation-Exsufflation (MI:E) machine (Cough Assist) may help with weak coughs. These interventions may cause a dry mouth, which can be uncomfortable and make swallowing harder.

As a care worker: You should help the person follow the advice from dietitians and speech and language therapists to prevent malnutrition.

- Look out for any signs of weight loss, swallowing issues or changes in eating behaviour and report them immediately to your manager.
- Ensure the person eats and drinks enough. If they have a dry mouth, ensure they drink enough water and help them moisturise their lips.
- Create a comfortable space for eating. Allow plenty of time for meals, help them sit upright, and prepare tasty, easy-to-chew food. See page 43 for practical tips to follow.

If a person has a feeding tube, you might need to help with cleaning around the area where the tube is inserted, replacing any dressings and flushing the tube daily (even if it hasn't been used yet) to avoid infections.

Working with feeding tubes or suction units can be risky. Before using any equipment, make sure you have completed proper training and competency checks.

Speech problems

Speech difficulties, known as dysarthria, are common in people with MND. Over 80% of them experience slurred, quiet speech and many loses the ability to speak entirely. This happens because respiratory and bulbar muscles weaken, making it hard for people to say words clearly or have enough breath to speak loudly. Tracheostomies (pages 15-17) can also make speaking more difficult for some people.

It can take a great effort for people to express themselves, be understood or participate in conversations. As a result, they may feel isolated, frustrated or embarrassed.

To communicate, many people use Augmentative and Alternative Communication (AAC) systems. These can be simple tools, like gestures and a notepad, or more advanced options, such as tablets that speak typed words out loud. Each person will choose the options that work best for them, based on their preferences and abilities.

What to look for:

- a quiet voice and difficulty completing long sentences
- shortness of breath and struggling while talking.

How a person can be supported: A **speech and language therapist** can assess the person's needs and recommend suitable communication techniques and aids. An **occupational therapist** can assist in integrating environmental controls (such as light and TV switches) with the AAC technologies. **Clinical engineers** and **IT technicians** can help with adapting and using AAC equipment.

A member of the **specialist respiratory team** can teach breathing techniques, such as breath stacking. These can help those with weak respiratory muscles to cough more effectively and produce a stronger voice. An **orthotist** can advise on how to support the head and neck, which might be necessary to effectively use certain communication aids.

As a care worker:

- Take the time to learn about the person's preferred communication methods and any tools they use.
- Remember that non-verbal communication is important: sit facing them, focus on them, and pay attention to their body language.
- Be patient, create a relaxed setting and make communication as easy as possible. See page 30 for practical tips.
- Support the person with any breathing or communication techniques that have been recommended. If the person has a tracheostomy, they may have a "speaking valve" and need your help to use this.
- Share what you know with other caregivers who are new to working with the person with MND
- Advocate for the individual with MND, helping them to communicate with others if they wish
- The person's voice may vary from day to day. At the start of your shift, check in with them on how they are feeling and adjust your support.

Changes in thinking, reasoning and behaviour

Around half of people with MND experience changes in how they think and behave. A few of them also develop frontotemporal dementia (FTD), which involves severe cognitive change.

When someone experiences cognitive changes, they may find it harder to think, focus, interact with others or plan like they used to. They may show a lack of empathy, which can make them seem selfish. Sometimes, they might act in socially inappropriate ways. These changes can be difficult also for the people around them, including care workers, and may lead to needing more support.

People with MND might also experience emotional lability, known as pseudobulbar effect. It results in uncontrollable laughter or crying at inappropriate times. These reactions are involuntary and do not reflect what the person is actually feeling. For example, if the person in your care laughs when you move them, they might actually be in pain.

Recognising any changes in thinking and behaviour early on is crucial, as these can affect the person's quality of life and ability to make decisions about their care (pages 31-32), as well as symptoms management.

What to look for:

- the person is easily distracted and can not stay focused
- they find it hard to organise, start or finish tasks
- they have trouble responding to others in social situations
- they struggle to understand complex sentences or ideas
- they become stubborn or repeat the same things or activities
- they forget words they used to know
- changes in behaviour, including becoming aggressive, withdrawn, acting inappropriately or impulsively
- they seem careless or indifferent to others' feelings
- they feel or act restless
- they suddenly start cramming food or preferring sweet food.

How a person can be supported: It's important to monitor any cognitive and behavioural changes.

A **neuropsychologist** can assesses symptoms. However, it is essential to inform all the MDT if changes are detected so they can plan for future care while the person can participate in making decisions.

Occupational and speech and language therapists can help create strategies to manage daily activities, while a **dietitian** can help if the person shows any new food habits.

The **GP, palliative care specialists and mental health services** may provide home support. If someone has emotional lability, a **neurologist** can discuss possible medications.

As a care worker: Sometimes it's hard to understand if a person is acting strangely because of cognitive changes or because they are upset by their condition (see next page "Psychological and emotional needs"). Record any signs you notice and report them to your manager.

Talk to other carers, family members and friends who know the person. They might realise something is different because they knew the person before. Remember that these changes might be hard for them too. If the person seems not to care about their feelings or acts inappropriately, reassure them it's not personal. If they seem very upset by these behaviours, consider telling your manager as they may need some respite.

It's helpful to keep a calm atmosphere around the person with MND so that they don't become more confused or upset. Remember they can not just "try harder" in these situations, so patience is key.

Psychological and emotional needs

Being diagnosed and living with MND is very challenging and can be overwhelming. As the disease progresses, people have to make difficult choices about their care and end of life. Losing the ability to move, speak or think clearly can make someone feel like they are losing their sense of self or becoming a burden.

These problems impact both them and their relationships. It can lead the person to feel frustrated or lonely, especially if they think they can no longer join family meals and outings, or connect intimately with their loved one. The increasing need for assistive equipment or home adaptations can also cause financial worries.

As a result, both the person with MND and those around them may feel many strong emotions, including anxiety, fear, anger, sadness, depression and disbelief.

Sometimes, a person with severe cognitive decline or FTD (pages 22-23) may not fully understand the changes they are going through. In some cases, people are well aware and may need additional emotional support as the condition progresses. Support is also helpful to family, carers and the professionals helping them, including you (see page 46).

What to look for:

- sadness and low mood, anxiety, anger or frustration
- denial about their condition, what it means and, in general, difficulties accepting living with MND
- withdrawing or showing little interest in things they once enjoyed
- being dismissive or unengaged on topics around their care
- complaining about difficulty sleeping at night, including any worries
- refusing to eat, drink or keep up personal care.

How a person can be supported: **GPs** can refer the person to psychological services. They can also prescribe medication, if needed. **Counselling** and **palliative services** can provide support eg talking therapy. **Local organisations**, including the MND Association, offer peer-support groups for those living with and affected by MND.

Our helpline **MND Connect** is available for emotional and practical support at **0808 802 6262** or **mndconnect@mndassociation.org.**

! **For urgent mental health help, call the NHS helpline 111. If someone's life is at risk, call 999. The Samaritans offer a 24-hour support service calling 116 123.**

As a care worker: You may see the most emotional side of the people in your care. This can be hard, but being a trusted support can help.

- Be mindful that the person may need time to process their feelings about MND. They may grieve for the loss of their life as it has been and as they expected it to be in the future.
- Encourage them to express their worries and listen to them.
- Suggest they talk to their care team or reach out to someone they trust, like friends and family.
- Signpost them to the available support, for example joining support groups or contacting the MND Association's helpline.
- Share information to help them and their family understand their situation. Do this gently and at a time that feels right for them, without overwhelming them. See also page 51.
- Talk with the family and those close to the person in your care. They can share their thoughts about how the person feels. They can also suggest what kind of support the whole household may need.
- If the person, their family or carers have any questions, report them to your manager. Also, make sure to report any concerns that you or they may have, as they can refer to specialist mental health support to help cope with the situation.

! **If you are worried that the person may have any suicidal thoughts, or that there are any safeguarding issues, eg self-neglect or self-harm, alert your manager immediately and call NHS services for support (page 29).**

Medications for MND

Riluzole is the only drug currently licensed for the treatment of MND in the UK and approved for use by the NHS. It is thought to extend survival by three to six months. However, it does not reverse the effects of the disease. A neurologist will assess whether someone can take it.

Riluzole comes in tablet form, as a liquid, or as a film that slowly melts on the tongue (a orodispersible film). The liquid form might be easier to swallow for some people and can be given through the feeding tube.

Some people will take other medicines for specific symptoms, for example pain. Like riluzole, these medications may be available in alternative forms, and be given through the feeding tube if someone has problems swallowing tablets or syrups.

Medicines can leave a sediment, blocking the tube. For each medication, check with the pharmacist if it is safe to give this way and follow their instructions. You will need training to give medicines via the feeding tube.

End of life

When someone is diagnosed with MND, it often brings to light the challenges they will face and the time they have left. Talking about end of life is important: it is about living well and not just dying.

People with MND should be encouraged to discuss their preferences and care options before the need is urgent or before they find it too difficult or tiring to communicate. Having these conversations can help them plan for themselves and their loved ones and get their wishes recorded. It can also help them address their concerns, and think about positive experiences they can continue to have.

What to look for: A person is unlikely to start the conversation with "I want to talk about the end of my life". Instead, they may talk about:

- how long they should expect to live eg "Will I be able to go on holiday this summer?" or "I won't be here for my son's next birthday"
- MND progression eg "How will I say I don't want an appointment once I won't be able to speak?"

- financial or practical concerns eg who will walk their dog
- wishes, such as places they'd like to visit before they are unable to.

As a care worker: it is not your job to help them plan ahead for the end of life. However, as a trusted person in close contact, they might feel comfortable discussing it with you.

It's important to recognise when someone is trying to talk about end of life issues and ensure they feel they are listened. Do not avoid or dismiss the topic. Instead, acknowledge their difficulties and reassure them that it is okay to talk and express any worries whenever they need to.

If possible, offer practical suggestions, but do not give them false hope or lie. If you do not know the answer to a question, it's important to be honest and find out who can help. The MND co-ordinator of the person with MND and your line manager will often be the best point of contact.

It can also be useful to know about the following documents.

Advance care plan is a document where the person can outline their care preferences for the future so that everyone involved is clear about what they want. On top of care options, it can cover all future needs, including, for example, who will look after pets.

Advance statements may be included in the advance care plan or stand alone. They address choices about care, such as where a person wishes to be cared for or die. They are designed to guide caregivers if the person has lost the ability to make decisions. While these statements are not legally binding, professionals should respect them as much as possible.

Advance Decision to Refuse Treatment (ADRT) is a legally binding form where the person can specify treatments they do not want and under what circumstances. It's also known as a "Living Will" or an "Advance Directive".

It allows someone to refuse treatments that might prolong their life (eg artificial feeding or antibiotics). The ADRT must include a section where the person clearly states the refusal, even if life is at risk. The person will still have the right to primary care and comfort.

It is valid only if the person has lost the ability to make decisions. It should be updated regularly to reflect any changes in wishes. An updated copy should be kept with the person's medical records.

Section two:

A care worker's toolkit

Safeguarding

Safeguarding means preventing abuse or neglect of everyone, especially adults who are at risk of harm. It also involves promoting their wellbeing and respecting their views, feelings and beliefs when making decisions or taking action.

In England and Wales, adults that may be at risk of harm are those who have care and support needs and may struggle to protect themselves from abuse because of those needs. These can include needing help with eating, personal hygiene, keeping their home clean, using the toilet, getting dressed, maintaining relationships, or using public transport. People who have difficulty communicating might be at higher risk because they may not be able to tell others when something is wrong.

Many of these needs may apply to people with MND. It is everyone's responsibility, including yours, to ensure their safety and wellbeing. This means recognising and reporting to your manager any signs of abuse or neglect. Understanding the person's needs and how to assist them with respect and dignity are also key to safeguarding.

There are many forms of abuse, including:

- physical abuse eg rough handling, making someone uncomfortable (like removing a blanket when it's cold), misusing medication, or not giving food
- sexual abuse and domestic violence
- psychological or emotional abuse eg isolating someone, taking away their mobility aids or not allowing them to express their opinions
- financial abuse eg stopping someone from getting their benefits or misusing their money in a care home
- organisational abuse eg not respecting a person's dignity or privacy, not helping them eat, or ignoring their complaints.

If someone is at risk of abuse, report it in line with your organisation's policy. If you believe someone is in immediate danger or at serious risk of harm, call 999 without delay.

Communicating with someone with MND

Even if the person in your care has communication difficulties, you should try your best to understand their needs. The following tips can help (see also pages 20-21):

Do:

- find out if the person has a simple code for yes and no eg eye blinking or moving a finger. Make sure that the person can reliably use this method. For example, at one point they may not be able to move their finger anymore
- ask closed questions that only need simple, or yes and no answers
- make sure any necessary communication aids are ready and easy for them to reach
- keep pen and paper handy so they can write down any tough words, if they are able to
- encourage them to speak slowly and over-emphasise words to help clarity
- check back with them on what you think they said and admit it when you don't understand. Pay attention to avoid making them repeat themselves unnecessarily as this might be tiring and frustrating.
- make it easier for them to reach you. If speaking on the phone is hard for them, they might prefer to use email or text messages.

Do not:

- change how fast or loud you speak, unless the person with MND has asked you to, or their doctor suggested it
- finish their sentences, unless they've asked you to
- interrupt them: if the person uses assisted ventilation, they may have to speak in rhythm with the machine. Pauses while they are speaking won't always be natural pauses
- use family members or caregivers to translate for them unless that's what the person in your care wants.

Caring for a person with cognitive changes or FTD

Changes in thinking or behaviour, especially when they are severe, can increase the need for support and make caring for someone harder. This might mean that a new care plan should be developed. The following tips can help you support a person experiencing these changes:

- Use clear language and questions that require simple answers.
- Encourage a structured daily routine and find out if there is a time when it's easiest to do certain tasks. This can help if the person is confused, agitated or become fixated on one activity.
- If decision making is a problem: break information into smaller parts to make each step easier to understand. Check that the person understands the consequences of each action/decision.
- When introducing new equipment or routines, or if a person struggles with concentration: focus on one task at a time, break the task into smaller steps and use reminders to help them stay focused.
- Keep items in the same spot so the person can find them easily.
- If they struggle to remember the names of things they used to know, encourage them to use gestures, like pointing (if they are able to do so)
- If they act impulsively or show aggression: remain calm and try to distract them. Avoid getting involved in an argument.
- Be aware of triggers for aggression, such as tiredness, and keep a safe distance until they calm down. If their behaviour becomes really difficult, inform your manager, as they may need extra support.
- If they act impulsively, they could find themselves in unsafe situations. For example, you might need to remove sharp objects or lock a door that leads to a busy road. Putting up visual reminders, eg a poster saying "Do not open the door", may help with impulsivity.
- If they are cramming food, try giving multiple smaller portions. Supervise them during mealtime as they might forget techniques to swallow safely and could be at risk of choking. Always report any concerns to your manager.

Mental capacity

People with MND with cognitive changes or FTD might not be able to make a decision (lacking mental capacity). The Mental Capacity Act 2005 empowers anyone in England and Wales to make their own decisions: **www.gov.uk/government/collections/mental-capacity-act-making-decisions**

- Everybody should be assumed to have the capacity to make decisions. If there's evidence that someone finds making a decision hard (eg not understanding, in a conversation, the options of a decision) a trained professional can do a mental capacity assessment.
- Just because someone lacks capacity to make one decision, it does not mean they can not make other decisions.
- Whenever possible, people must be helped to make a decision on their own. This includes helping with using communication aids.
- If someone lacks capacity, professionals can make a decision in the person's best interest. They should always prioritise the wishes of the person with MND and involve anyone advocating for them eg their family. Best interest decisions should be recorded in the care plan.
- If a person with MND makes a decision you think is unwise, eg eating foods that could cause choking, it does not mean they lack capacity.

For many, enjoying their favourite food is important for their quality of life. The MDT must talk with them and anyone involved in their care. They must ensure the person with MND understands and is aware of the risks. The team should work together to reduce those risks, creating guidance for different situations, including emergencies.

- Any decisions, discussions and protocols about eating and drinking with acknowledged risks must be documented in the care plan.
- Always check local policies. If these have been followed and the decisions have been agreed on and documented, you are not responsible for the risks while helping someone eat or drink.
- If you ever feel unsure or uncomfortable, speak to your manager.

Find out more: **www.rcslt.org/members/clinical-guidance/eating-and-drinking-with-acknowledged-risks-risk-feeding/**

Handling emergencies

As a care worker, you might face some emergency situations, such as the person with MND falling. First aid training is essential. Ask your manager to arrange training if you have not had it yet.

You should know if the person has an ADRT (see page 27) and understand the specific treatments they want to refuse to ensure that those wishes are respected. Make sure you know where the ADRT is kept and how to find it quickly in an emergency. Be aware of any related documents, such as a Do Not Resuscitate (DNR). This is also known as a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR).

The person might also have a ReSPECT form. This stands for Recommended Summary Plan for Emergency Care and Treatment. It includes personalised recommendations for clinical care in emergencies in which they are not able to make decisions or express their wishes.

In an emergency:

- stay calm and try reassure the person with MND to help keep them as calm as possible
- call for help immediately by dialling 999
- stay with the person until emergency help arrives
- use your first aid training to keep the person as stable and comfortable as possible. Remember to not lay them flat, and avoid any actions that go against their ADRT
- inform the emergency services about the person's ADRT and related documents. See also page 12 for *Working with ambulance staff*
- afterward, write a full report and inform your manager. Inform other professionals, carers or family members who need to know.

If the person is choking, behave as you would in any choking situation. If they become unconscious due to choking, you should begin cardiopulmonary resuscitation (CPR), unless a valid DNACPR order explicitly states otherwise.

When you start working with a person with MND, ensure you are familiar with their DNR, stated wishes and care documents. Ask your manager to provide CPR training, if you don't have that already.

Providing personal care with dignity

For people with MND, everyday tasks like washing, dressing, using the toilet or brushing teeth can take a long time and they may need help.

This can make them feel a loss of dignity, especially when their abilities change suddenly because of the rapid progression of MND.

As a care worker, your support is crucial in helping them feel dignified and respected. To do this, it is vital to:

- ensure they have privacy and personal space
- acknowledge their abilities and wishes without undermining them
- respect who they are and the life they've lived.

When it comes to personal care, some individuals might still be able to manage tasks on their own without becoming too tired. This can improve their morale. Others may need or choose to rely on support to save energy for the activities that matter most to them.

Make sure you complete any necessary training to deliver appropriate care. It might be useful to also share with the person with MND our booklet *Personal care for people with MND and their carers* (see page 51).

Bathing and showering

A person may need help with:

- gripping things like soap, bottles and shower heads
- getting in and out of the bathroom, bath or shower
- maintaining balance and avoiding falls
- washing themselves or drying off.

An occupational therapist can suggest useful equipment and home adaptations eg shower seats, a wet room, grab rails or non-slip mats.

The following tips may also be helpful:

- Try strip washing using different coloured towels for the top half, the bottom half, and the face.

- Using environmentally friendly cleaning wipes can also help.
- Soft shower curtains can provide privacy, and a shorter fixed screen can help keep water contained and you dry.
- When assisting with bathing, use a lightweight jug to pour water.
- A towelling dressing gown can help dry them off while they lay down to rest after bathing or showering.
- Hair washing trays can help you wash their hair while they are sitting. Inflatable ones can be used while the person is lying down in bed.
- Dry shampoo can refresh hair but, if they are an aerosol type, they may not be suitable for people with breathing issues.

Toileting

Although MND does not usually affect bowel and bladder functions, mobility problems can make it more difficult to access and use the toilet. People may also worry about not getting to the toilet in time and therefore think drinking less will help with this.

However, not drinking enough can irritate their bladder. This can cause urine infections and actually make them feel that they need to go to the toilet more often. Dehydration can also cause constipation, which may make emptying the bladder and bowels hard.

Medications, changes in eating, poor mobility or breathing issues can also cause constipation. If persistent, it can cause diarrhoea. A GP and a continence nurse can help.

As a care worker, you may need to help someone with getting to the toilet, cleaning up, or managing their periods or constipation. Remember that maintaining their dignity is essential.

Where possible and appropriate, allow people their privacy when using the toilet. For example, you could help the person get to the toilet and then go do another task until they are finished, so they don’t feel pressured by someone waiting outside the bathroom.

An occupational therapist can advise on aids to support independence. The following tips might also be helpful:

- Encourage wearing loose, light clothing that's easy to remove.
- Consider incontinence products such as disposable pads and mattress protectors if needed.
- A wash and dry toilet seat and a long handled bottom wiper can ease cleaning.
- Grab rails and toileting slings can help with accessing the toilet. Some wheelchair cushions have a wedge that can be removed to enable toileting. Otherwise, commodes and bed pans can be used as portable toilets or at night.
- Establishing a routine, like sitting on the toilet 15-20 minutes after breakfast, can also facilitate regular bowel function.
- In case of any incontinence accidents, cleaning foams and barrier creams can help prevent skin problems and discomfort.
- Period pants are washable and can help manage menstrual needs.
- If periods are causing difficulties, a GP can discuss various medical options to stop or lighten periods, including contraceptives. You might need to help with administering those eg contraceptive pills.

Getting dressed and grooming

As a person loses movement control, they might need help with:

- dressing and undressing, including fastening clothes and shoes
- staying comfortable and warm
- grooming and oral hygiene.

An occupational therapist can recommend ways to make dressing easier. For example, they may suggest dressing aids eg leg lifters, button hooks or shoehorns, or wearing clothes with no fastening eg sport bras. It's also helpful to dress in layers that are easy to remove and keep clothes warm before wearing them.

When you help someone get dressed, consider also:

- the material: is it comfortable to sit for a long time? Satin and silk clothes may ease movement in bed, but can also cause sliding, affecting posture. If clothes ride up while on the wheelchair, keep a blanket or another layer handy to cover the person up

- safety: check that clothes, coats, blankets, or scarves are short enough to avoid getting caught in wheelchairs or hoists
- if drooling is an issue: dark tops or scarves can help hide saliva spills
- swollen feet or circulation problems: shoes may need to be larger than usual. Do not use heated products like socks or foot warmers without consulting a doctor
- movement restriction: loose sleeves or poncho style capes, instead of heavy coats, are comfortable and do not restrict mobility.

When helping a person with MND getting dressed, be careful as their hands and legs may be stiff. Be gentle to avoid causing pain, discomfort or losing balance.

Remember that dressing and keeping personal style can help the person maintain a sense of themselves and improve their wellbeing.

- Ask the person what they want to wear. They may want to dress according to their cultural or religious beliefs.
- If they ask for support with grooming, help with nail trimming or shaving. They may also prefer to see professionals for haircuts and makeup.

Oral hygiene

People with MND may have difficulties keeping good oral hygiene due to muscle weakness or swallowing issues. As part of their high-calorie diet, they may eat a lot of sugar which could also impact oral health.

So regular dental visits are crucial. Some people may also get oral thrush (known as oral candidiasis). This is a non-contagious fungal infection that can cause an unpleasant taste in the mouth, difficulties eating or drinking and pain. If you notice a coated tongue or white patches in the mouth, report it immediately.

Dental therapists and dentists can refer people to Special Care Dentistry or to community dental services for home visits. They can also provide strategies to maintain good oral health at home.

As a care worker, you should receive training to support mouth care. Our guide *Personal care for people with MND* (see page 51) include useful tips and services to share with the person you are supporting.

It can also be helpful to keep in mind the following:

- Some people are reluctant to brush their teeth because of their gag reflex or concerns about choking. It is crucial to brush their teeth at least twice a day using fluoride toothpaste.
- Non-foaming toothpaste can reduce the risk of aspiration. An oral suction unit can also be used to remove toothpaste, excessive saliva or water. It's important that the person keeps an upright seated position, with the head turned slightly to one side.
- If they brush their teeth on their own, suggest using a lightweight electric toothbrush to reduce fatigue. A polystyrene ball can be pushed onto toothbrushes' handles to help with gripping.
- If they have limited arm movement, suggest propping the arm up on the side of a chair or table, and gently moving the head side to side instead of the toothbrush.

If you brush their teeth:

- Introduce toothbrushes and other mouth cleaning items into the mouth gently and use slow movements.
- Try a softer toothbrush (eg a child-sized toothbrush).
- Pressing gently on the chin below the bottom lip may help open the mouth more easily.
- A bite block or mouth rest can be placed on the side of the mouth to keep the jaw open.
- If you use a water flosser, tilt the person's head forward and spray away from the throat to avoid aspiration. Use the flosser in short bursts, letting the mouth drain in-between.
- Non-alcoholic fluoride mouthwash might be beneficial. Consult a healthcare professional before using it regularly, especially if the person has swallowing difficulties.
- Use finger protectors.

If a person with MND uses a feeding tube, remember that oral hygiene is still necessary, even if they are not eating or drinking through their mouth.

Movement and handling

When someone has muscle loss, their joints can become stiff and painful. It's important to be careful when lifting or moving them to avoid causing more pain or injury. A physiotherapist and an occupational therapist can help you understand how best to help the person with MND. They can:

- train you on safe techniques for moving them gently without forcing the muscles or joints
- explain how to support their limbs, head, and neck when moving them
- show safe ways to lift or handle someone if they have fallen
- suggest useful equipment such as sliding sheets, hoists, profiling beds, mattress elevators, riser recliner chairs and turning tables
- advice on the use of heat and massages to improve comfort.

Seated posture and positions to help breathe

As MND progresses, the person will likely spend more time sitting and may struggle to stay upright or change position on their own. This can lead to issues like bone deformity and pressure sores (see page 40).

As a care worker, you should help the person adjust their position when needed. The ideal position is usually sitting upright or slightly reclined, with the arms, back, head and neck supported. This helps them keep a good head position and makes swallowing easier. It also helps them breathe more easily.

If the person has trouble breathing, lying flat can make them feel breathless, which can be uncomfortable and even dangerous. In bed, a semi-reclined position is likely to be more comfortable than the seated position described above. The head can be raised with some extra pillows, a pillow lifter or a profiling bed, which may reduce night-time problems.

If breathing is difficult, some people find that an electric fan blowing air into their face can help them feel better. Air conditioning may also help.

Pressure care

People with MND can have problems with their skin breaking down. Factors that contribute to this include:

- difficulty moving to relieve pressure while sitting or lying down
- poor seated posture that puts pressure on a small area
- issues with head position and saliva that cause moisture sores on the chin, chest, and ears
- limited bed mobility eg difficulty turning around
- not drinking enough or eating well enough.

To help prevent these issues it's essential to take good care of their skin and manage pressure. An occupational therapist can recommend the right tools to help relieve pressure (eg a pressure-relieving mattress). They can also train you on how to help the person move and change positions. Using lightweight bedding and clothing, along with barrier creams, can help prevent skin sores.

Keep in mind that masks used for non-invasive ventilation can cause sores on the nose and may also not fit well as the person's face shape changes with muscle loss.

Night time care

People with MND might have trouble sleeping due to limited movement, muscle cramps, difficulty swallowing and feelings of anxiety. If they have breathing issues, they might also be afraid to sleep and not wake up.

Sleep issues can lower quality of life and make them feel fatigued. Not sleeping well can also be an early sign of breathing problems, so it's important to report it. An occupational therapist can help with sleep habits and tips for better rest.

They might suggest using a profiling bed, which allows the person to sleep with their head and chest raised up, making breathing easier. As a care worker, you can help the person find a comfortable sleeping position and change positions at regular intervals (page 39).

Overnight, people may worry about not being able to get out of bed to go to the toilet or wetting the bed. You should assist them with accessing or using the toilet (page 35). Make sure there is a clear path to the bathroom and keep any toileting aids such as bed pans or portable toilets within reach from the bed. Going to the toilet before going to sleep can also help the person feel reassured and more comfortable.

If they use assisted ventilation, they may need your help with it eg with putting on and removing their NIV mask. Remember to check for leakage around the mask and adjust the fit as necessary.

Monitor sleep and breathing patterns, and check for any signs of discomfort, choking or aspiration. If you notice difficulties breathing, gurgling sounds or mucus, you can use suction units to clear the airways.

Fatigue management

Many people with MND feel very tired, which can affect their quality of life. Fatigue can show up in different ways, often feeling like extreme tiredness that can hit suddenly or build up over time. It might not be proportionate to how much they've done during the day.

Fatigue, and worrying about becoming tired, can make someone less motivated to do everyday activities. Stress can make this worse, especially if they want to stay active but find it hard to do so.

If fatigue is not recognised, a person may go through ups and downs in how well they can function. For example, when someone feels well, they might do a lot but then feel so tired that they need days of rest to recover.

An occupational therapist can offer advice on managing fatigue. The following tips can help you provide effective support:

- Encourage the person to keep track of how they feel after different activities. For example, record in the diary when the person was most tired or if any tasks were cut short or missed. This can help identify which tasks leave them tired and plan their schedule based on that.
- Help them create flexible routines that take advantage of their more energetic times and include enough time to rest.
- Encourage them to save their energy for activities they enjoy and mean the most to them. You could complete the tasks that are less important for them, so they have the energy to do the rest.
- Suggest doing activities differently eg doing chores while sitting.
- Encourage them to take their time with tasks rather than trying to complete everything quickly.
- Be mindful of little things that can help save energy eg keeping frequently used items within easy reach, placing chairs around the place to rest, and avoiding extreme temperatures, as they can contribute to tiredness.

Eating and drinking

A dietitian and a speech and language therapist should help monitor the weight and nutrition of someone with MND as their condition changes. They can also give advice on which foods are recommended and which ones to avoid while the person can still eat by mouth.

If the person with MND has problems swallowing, their clinicians will create a diet that makes sure they get enough nutrition and hydration from what they eat and drink.

When eating, it's best for the person to sit upright to lower the risk of food or drinks going down into the airway. An occupational therapist can give advice on equipment that may help at mealtimes.

These tips may be useful:

- Serve multiple small meals instead of one big one: this can be less tiring for the person eating.
- Follow any advice from the speech and language therapist on food's consistencies/textures that are easier to swallow. A speech and language therapist might prescribe thickeners for drinks.
- Make food appetising with colourful garnishes, and make sure the person that eats it can see and smell the food. This is especially important if the food is mashed or puréed.
- Find out whether the person likes particular comfort foods, such as puddings. Introduce small portions of these foods to make eating more interesting and enjoyable.
- Allow plenty of time for meals, and keep food warm or reheat it if needed. A warming plate can be helpful. Reheat small portions at a time to prevent the food from becoming soggy.
- Create a calm, quiet atmosphere to reduce anxiety and let the person focus on eating – wait for them to swallow before asking questions.
- If they eat slowly and get tired, take breaks between courses.
- Serve meals when they feel less tired, which might mean eating more during the day rather than in the evening.
- Sipping a hot or cold drink before meals and between bites can help stimulate the swallowing reflex.

People may go against medical advice and choose to eat food that could increase their risk of choking.

Make sure you follow the protocols set by the MDT and agreed by the person with MND to eat and drink with acknowledged risks and handle emergencies.

See page 32 to find more guidance and talk with your manager if you are uncomfortable or feel unsure of what to do.

People with MND might feel uncomfortable eating around others because of swallowing problems. They could join others to socialise by eating a few bites with them, while eating most of their meal afterwards.

If the person uses a suction unit, a professional should train you on how to use it and clean it. The following tips may be helpful:

- Use it only for suction from the mouth.
- Do not put the suction tip past the person's back teeth to prevent gagging and avoid touching soft tissue in the mouth to prevent any damage.
- Do not turn the suction dial too high and limit suctioning to 10 seconds at a time.
- Clean the device regularly following the manufacturer's instructions to prevent infections.

Nasal suctioning is sometimes required if the person has trouble clearing up the mucus from their nasal passages. This should be done with care to avoid discomfort or pain. You should use a soft, flexible suction tip that is specifically designed for the nose.

As with oral suctioning, use it for 5-10 seconds at a time, do not insert it too deep and clean it regularly. The person should be in a comfortable, upright position, with their head tilted forward to prevent the mucus from going down the throat.

End of life care

For some people with MND, death can be very sudden, before an obvious end stage is reached. Others experience a longer final stage, which can last many weeks.

If it's thought that the person is approaching end of life, it's important to review their care plans to provide the right support. For most people with MND, death will be peaceful. They very rarely die from choking.

Managing symptoms: As a person is dying, they may tolerate their symptoms less well. They might be given medication to help ease the discomfort. These medicines may make them feel sleepy. Feeling like that can also be part of the dying process.

Eating and drinking: In the last days of life, most people stop eating and drinking. The end of life care team will provide guidance on how to keep hydrated by mouth or through feeding tube.

Mouth care: During the final days, breathing through the mouth and not drinking much can dry out the mouth and lead to cracked lips. It's important to keep the mouth clean and moist. Some people find ice lollies refreshing.

Terminal restlessness: Sometimes, people may become restless and agitated just before death. This is usually associated with a reduced level of consciousness. Now and again, or all the time, they might seem disoriented, anxious, fidgeting, scared or distressed. In these moments, reassuring them and speaking in a gentle way can help. Ensure their environment is calm and that they feel as safe as possible.

Communicating: This can become extremely difficult as the person with MND reaches end of life. Even if they are unresponsive, try to keep communication. Simple questions with yes or no answers (eg "Do you want to listen to the radio?") eye movements and communication tools like picture boards can be useful.

Hearing and touch are thought to be the last senses we feel, so talking reassuringly and touching someone is the most natural and human expression of compassion that we can show.

Respecting people's preferences and cultural or religious needs: Some people may have specific wishes about end of life care, such as what objects they would like in the room, or any religious needs.

Even two people with the same religion may have different beliefs and wishes, so always check with the individual and ideally get their wishes documented in the care plan.

Talking with their family is also crucial to ensure the person's needs and wishes are respected. You can learn more with these resources:

- the *Culturally sensitive end of life care toolkit* created by NHS Birmingham and Solihull: **www.birminghamsolihull.icb.nhs.uk**
- the *Faith at end of Life* guide by Public Health England: **www.gov.uk/government/organisations/public-health-england**

Caring for yourself

Caring for a person with MND can be hard work, both physically and emotionally. Sometimes it can be difficult to think about your own needs. It is vital to look after yourself, eat properly and find moments to rest.

Seeing the condition of someone in your care getting worse, or having challenging conversations around end of life might be distressing. You may also be upset when they die. This is not unusual: many professionals feel this way after forming a connection with a person in their care.

Do not hesitate to look for support where you can. Talking about your experiences and sharing feelings with colleagues may be beneficial. Ideally you should have regular check-ins with your manager to discuss any concerns or any additional mental health support you may need.

Our MND Connect helpline offers emotional support to professionals, people with MND and their carers. You can contact MND Connect by calling **0808 802 6262** or emailing **mndconnect@mndassociation.org**.

Section three: Supporting resources

Key contacts

Having important numbers to contact in case of necessity can help the person with MND, you and your manager. Remember to keep an updated copy among the records of the person in your care. The table below is just a template.

Professional	Name	Contact number
Family carer		
MND co-ordinator		
MDT co-ordinator (if different from MND co-ordinator)		
MND care centre		
Care agency		
GP		
District or community nurse		
Pharmacist		
Hospice		
MND Connect helpline		
Local support groups		
Emergency services		

Words you might hear

Advance Decision to Refuse Treatment (ADRT)
A legal document outlining the person's choice to refuse specific treatments in certain circumstances in the future.

Aspiration
When food, drink or saliva enters the windpipe, often causing choking or coughing episodes.

Cognitive changes
Changes to thinking, reasoning and behaviours.

Dysarthria
Problems with speech

Dysphagia
Problems with swallowing

Emotional lability
A symptom of MND, also known as pseudobulbar effect, where a person laugh or cry at inappropriate times. It is an involuntary reaction that does not match the person's feelings.

Fasciculations
Muscle twitching and rippling sensations under the skin. May be visible to others.

Forced Vital Capacity (FVC)
This is the amount of air that can be breathed out from the lungs after taking the deepest breath possible. It is used to measure the progress of breathing problems in people with MND.

Frontotemporal dementia (FTD)
A type of dementia that can affect some people with MND. It can cause serious problems with thinking, reasoning, personality and behaviour.

Gastrostomy
An alternative method of feeding, which uses a tube inserted directly into the stomach through the abdomen.

Words you might hear

Invasive ventilation (IV)
One type of invasive ventilation is a tracheostomy, where a tube is inserted into the windpipe through the neck. This may be attached to a machine that takes over breathing.

LVR bag
A Lung Volume Recruitment bag is a flexible plastic bag that can be used with a one-way valve, filter, and a mask to help with breath stacking.

Mechanical Insufflator-Exsufflator (MI:E)
This is a machine that can be used to clear secretions in the throat. It does this by gradually applying a positive pressure to the airway, then rapidly shifting to negative pressure. It is also known as Cough Assist.

NIPPY
This is a trade name for a non-invasive ventilation system, but it is also used by some people as a term to describe non-invasive ventilation. It stands for Non-Invasive Positive Pressure ventilation.

Non-invasive ventilation (NIV)
A type of breathing support, where a portable machine is used to provide extra air through a mask.

Peak cough flow
This is a measurement of the strength of a person's cough. It can be used to measure the progress of breathing problems, including weak cough, in people with MND.

Riluzole
The only drug currently licensed for the treatment of MND in the UK and approved for use by the NHS. It does not reverse damage done by the disease, but may extend survival by three to six months.

Sialorrhea
Excessive drooling.

How we can support you

Motor neurone disease affects people from all backgrounds, and the needs of those living with MND are varied and complex. As a health and social care professional, it's crucial to provide the best care possible.

This involves tailoring support to the specific needs of people with MND, signposting relevant information, and working closely with specialist services.

The MND Association offers several resources to help you do that, as well as various services to which you can refer the people with MND you support. Find out more through:

MND Connect

Our helpline offers help to people living with MND, carers, family and health and social care professionals. Our advisers can provide emotional and practical support, including social and financial information, and refer to local support and MND Association's services.

Email: **mndconnect@mndassociation.org**
Phone: **0808 802 6262**

MND Association website

Our website offers supporting information on MND and our work, including the research we fund, the services we provide and how to get involved.

www.mndassociation.org/professionals - discover all resources for health and social care professionals

www.mndassociation.org/support-and-information - discover all help available for people with or affected by MND

Support for health and social care professionals

Professional information resources

We have a wide range of information resources available to support professionals from different disciplines, including booklets, infographic and online courses. Our professional information finder can help navigate them according to profession and topic.

www.mndassociation.org/pro-info-finder

MND Professionals' Community of Practice

A peer led group of health and social care professionals supporting cross disciplinary learning, knowledge exchange and the development of good care for people living with, or affected by, MND. You can join to participate in unique networking and learning events. Being an active member could count towards your professional CPD requirements.

www.mndassociation.org/cop

Education

Our education programme is designed to improve standards of care and quality of life for people living with and affected by MND. We regularly organise webinars, workshops, international lectures and networking events. We also offer a free online course for care workers.

www.mndassociation.org/education

www.mndassociation.org/careworkermodule

Social media

You can remain updated on all MND information for professionals through our newsletter or social media channels.

www.mndassociation.org/educationupdate

X: **mndeducation**

Bluesky: **mndeducation.bsky.social**

Support for people with or affected by MND

Care information resources

We produce high quality information resources for people with MND, carers and family members. Our publications are available in different formats and languages.

They can help people understand MND, plan ahead, and talk about MND to other people, including children.

Professionals can use this information to signpost people, or to open conversations.

www.mndassociation.org/careinfofinder

Benefits Advice Service

Qualified advisers can help identify benefits the person with MND and carers may be entitled to and advise on how to claim. This service is confidential, impartial and free.

www.mndassociation.org/benefits

Financial support

Where statutory provision is not available, we may be able to offer financial support to help with:

- funding for children and carers
- cost of living expenses
- equipment loans and services, including communication aids and wheelchair support, upon referral from a professional.

www.mndassociation.org/our-services

Online forum

Our online forum is accessible to anyone and can offer first-hand experience of MND, and practical and emotional support.

forum.mndassociation.org/

Local support

The MND Association offers a range of options for support in your local area:

- We fund and develop MND care centres and networks across England, Wales, and Northern Ireland, which offer specialist MND care.
- We run almost 150 online and face-to-face support groups.
- We have trained volunteers and volunteers-led groups that offer practical help and support for people with MND, via phone, email or visiting their own home.

www.mndassociation.org/local-support

Research

Research into MND

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

www.mndassociation.org/research

MND Register

The MND Register aims to collect information about every person with MND to help researchers focus their knowledge and expertise in the right areas.

mndregister.ac.uk

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We value your feedback

We would greatly appreciate your feedback on this guide. Please visit **www.smartsurvey.co.uk/s/mndprofessionals** or email your comments to **infofeedback@mndassociation.org**

Visit our webpages for health and social care professionals:

www.mndassociation.org/professionals

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