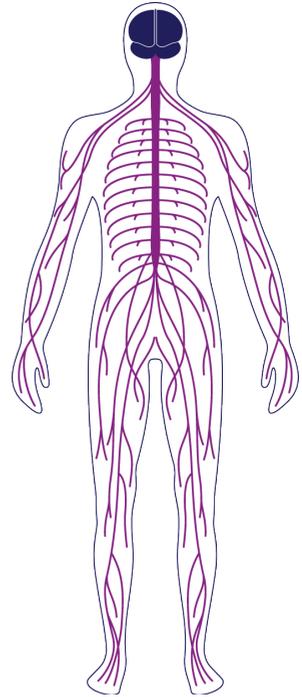




Caring for a person with MND: A guide for care workers

About MND

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work.
- It can leave people locked in a failing body, unable to move, talk and 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
mndconnect@mndassociation.org

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

Introduction

Motor neurone disease (MND) is a progressive and terminal disease that attacks the motor neurones, or nerves, in the brain and spinal cord. Around 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. However, 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 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 of their care needs met by professional care workers.

Who is this booklet for?

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 or in a care home or hospice. You may be employed as a care worker by a care agency, by a care or nursing home, or you may be employed directly by the person with MND, if they are using a personal budget to pay for care in this way.

This booklet has been designed to give you information and practical tips on the care of people with MND. It will help you find out more about MND, whether you care for a person with the condition now or in the future.

Information to share with people with MND

Throughout this booklet, we have included details of information resources on a range of topics that we produce for people with or affected by MND. This information should be shared in a sensitive way, when it's the right time for the person and their family.

Online module for care workers

Our free-to-access module introduces MND, its symptoms, and how a care worker can support a person with MND.

This introductory level module is split into seven units. Each unit can be studied individually, so the module can be completed over a number of sessions.

Access the module at www.mndassociation.org/careworkermodule

Information to share with people affected by MND

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

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

Personal care booklet - looks at how people with MND can adapt personal care tasks to prolong independence.

Caring and MND: support for you - Comprehensive information for unpaid/family carers supporting someone living with MND. This guide is designed to support individual needs during the caring role.

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

The care worker's role

As a care worker, you play a key role in maintaining quality of life for a person with MND.

You may be in more frequent contact with the person than other professionals involved in their care, so you will have a good overview of how they are day to day, and will become aware of changes in their condition, or any extra needs they have.

With MND, it can be difficult to predict what support may be needed. If you notice any early signs of change, alert the appropriate professionals (see page 47), and alert your manager. Give detailed, objective feedback on the person's condition and any changes. This can be very useful for other professionals who are providing care and may also help get support in place sooner.

Your place in the multidisciplinary team

There may be a range of professionals involved in the care of a person with MND. This is often called the multidisciplinary team. As a professional care worker, you are a key part of the team, which may also include:

- counsellor/psychologist
- dietitian
- district or community nurse
- GP and primary care team
- neurologist
- occupational therapist
- palliative care team
- MND co-ordinator
- physiotherapist
- gastroenterologist
- respiratory specialist
- adult social services
- specialist nurse
- speech and language therapist
- staff or volunteers from the MND Association and other voluntary organisations
- wheelchair services.

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

Further information for professionals

Multidisciplinary team working for MND booklet

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

Referrals to other services and sources of support

When you first start caring for someone, find out who you would need to contact if certain issues or queries come up. You can use the key contacts section on page 47 to help you with this.

If you think the person with MND would benefit from extra support:

- encourage the person to raise this with their GP or specialist team
- report the issue to your manager or supervisor
- speak to the person's GP or MND team if you have direct contact.

Ensure you comply with data protection legislation when sharing personal information. Your manager will be able to provide guidance on this, or you can find out more at:

www.gov.uk/government/publications/the-caldicott-principles

Working with the person's unpaid carers

The person with MND, and any unpaid carers they have, should also be seen as part of the multidisciplinary team. They will have expert knowledge of the condition and its effects. If the person has family around them, they will often be part of the care team. It is essential that you establish good communication, especially if you are working within their home.

While a professional carer may be involved to provide respite breaks for family carers, family carers may also step in to allow professional carers to have breaks from their caring duties. During the handover of responsibilities, they will need to be made aware of any developments or changes in procedures.

Alongside the person with MND, the family will also be very influential in executive decision-making, so precise communication with family members is very important.

Information to share with unpaid/family carers

Caring and MND: support for you - Comprehensive information for unpaid/family carers supporting someone living with MND. This guide is designed to support individual needs during the caring role.

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org



Working with ambulance staff or paramedics

If the person with MND needs to be taken to hospital in an emergency, don't be afraid to offer information that may help the ambulance staff or paramedics.

Ambulance staff may not know very much about MND and might not be aware, for example, that:

- they should not lie the person flat (see page 34 for more about posture and positioning)
- they should not automatically give the person oxygen, unless under guidance of an MND specialist (see page 15).

Training to help you care for a person with MND

To care effectively for a person with MND, you will need training in:

- MND, including how it progresses and important markers to look out for
- good communication skills – a care worker should know how to communicate with, and understand the needs of, a person who may have lost or has difficulty with their speech
- moving and handling
- safeguarding
- dignity in care provision
- cognitive change and dementia.

Further training may be needed in:

- administering medication
- helping a person who has a feeding tube
- using an assisted ventilation machine and other equipment.

The training given by care agencies will usually cover basic skills, but often will not cover specific information about the care of people with MND or how to use specialist pieces of equipment.

Training in specific areas of care should be provided by relevant members of the person's health and social care team.

MND Association education opportunities

The MND Association offers a wide range of educational opportunities for health and social care professionals, including study days, webinars and online courses. For further details, visit www.mndassociation.org/education

Visit www.mndassociation.org/careworkermodule to find out more about our online course for care workers.

Record keeping

All care should be supported by documentation that includes details of any actions taken, any issues, and monitoring of the person's condition.

Accurate records can help identify aspects of the environment or the person's condition that are positively or negatively affecting the care you provide.

These records can also help other care workers who you're working with, perhaps those who are doing different shifts, to help them provide the best possible care.

Records kept may include:

- a care plan
- a daily diary
- a medication sheet
- relevant contact numbers
- details of emergency procedures
- services check sheets (eg fire alarm)
- body weight measurements (taken every week)
- accident policies and report sheets
- an up-to-date risk assessment
- complaints procedures and report forms
- death of a client policies and procedures.

A daily diary should include:

- food and drink consumed
- health and mood
- skin pressure areas and any treatment
- night care
- washing, bathing and dressing (self or supported)
- bowel habits (to avoid constipation)
- any other significant events.

Continuity of care

Ideally, a person with MND should be cared for by the same person or team of people. We appreciate that this may be difficult in practice, but the number of different care workers should be kept to a minimum and the person with MND should be told about any changes. Providing a detailed induction and handover when staff change is essential.



What are the signs and symptoms of MND?

MND affects people differently. Not everyone will experience all the following symptoms, and they may not appear in the same order. Some may have symptoms that are not mentioned in this list due to other medical conditions that are not related to MND.

Muscle weakness

When the messages from the motor neurones reduce, the muscle they connect to is used less and tends to waste. This causes weakness and can affect balance and posture, with the risk of falls.

Exercise can't reverse muscle wasting, as the progression of the disease cannot be undone. However, appropriate exercise, on the advice of a physiotherapist, may be physically and psychologically important for a person with MND, especially in the earlier stages and before muscles become too weak.



Muscle tightness and/or cramping

Due to the breakdown of messages from the motor neurones, general muscle tightness or spasticity (stiffness, rigidity and spasms) can affect mobility, co-ordination of movement and may cause pain or increase the risk of falls. Physiotherapy or medication may help. Improving positioning when seated or lying down can also help the person with MND to feel more comfortable. See page 34 for information on positioning.

Twitching (fasciculations)

Twitching and rippling sensations under the skin, called fasciculations, are often among the first signs of MND. Some people feel the rippling effect in individual muscles, but this may spread. This rippling may be so obvious that it can be seen by other people. It can seem worse when a person is stressed, but usually eases over time.

Further information for professionals

Occupational therapy for MND

Information sheet P1 – *Head supports for people with MND*

Information sheet P2 – *Wheelchairs for people with MND*

Information sheet P11 – *Pain in MND*

Information to share with people affected by MND

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

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

Information sheet 6A – *Physiotherapy*

Information sheet 6C – *Managing pain*

Information sheet 11C – *Equipment and wheelchairs*

Information sheet 11E – *Environmental controls*

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

Breathing problems

Problems with breathing (respiratory problems) usually develop during the illness, because the muscles involved in the voluntary control of breathing can become impaired. If a person with MND experiences shortness of breath, fatigue, disturbed sleep, morning headaches or daytime sleepiness, it is crucial that these, or any sudden or unexpected changes, are reported to the person's healthcare team.

When a person starts to experience problems with breathing, they should also talk with their specialist team about tube feeding. Their respiratory function needs to be good enough to be able to have an operation to have some types of feeding tube fitted (see page 16).

Changes that may seem irrelevant, such as the person with MND asking for an additional pillow, or noticing that their socks are tight around the ankles towards the end of the day can highlight a decline in respiratory function. Noticing problems early means that action can be taken sooner.

Managing breathing problems

Depending on the needs and preferences of the person with MND, management of respiratory problems may include breathing exercises, physiotherapy, advice on careful positioning, guidance on effective coughing, medication and specialist equipment for assisted ventilation. See page 34 for more information on positioning and posture to help with breathing problems.

Assisted ventilation

Some people with MND will use a ventilation machine that helps them to breathe. There are two main options for ventilation support for people with MND:

Non-invasive ventilation (NIV) – where a machine detects when the person with MND tries to take a breath and gently assists them to breathe air in and out. A range of mask designs are available, from a nasal tube to a full head mask.

Tracheostomy ventilation – where a machine takes over breathing via a tube inserted into the windpipe through the neck. This is used by a small number of people with MND, but is not routinely available.

Assisted ventilation may help the person live longer, but other disabilities will continue to progress. Access to assisted ventilation will be via referral to a respiratory consultant who will arrange an assessment.

As a care worker, you may have to help with putting on or taking off a ventilation mask, cleaning it and operating the ventilation machine. Someone from the person's respiratory specialist team should be able to train you in how to do this.

Stopping assisted ventilation

The person with MND may wish to stop assisted ventilation when they become more dependent on others or when their symptoms reach a certain point. This conversation will usually take place with someone from the person's specialist or palliative care team, or with their GP.

An appropriate healthcare professional will be responsible for managing the process of stopping assisted ventilation in line with the wishes of the person with MND. A professional care worker will not have a role in this process. See pages 41-43 for more information about advance care planning.

Oxygen

When a person uses assisted ventilation, it may look as if they are using oxygen, but assisted ventilation makes use of air that's already in the room where it is used. Oxygen is not generally used in MND, as it can cause a build up of too much carbon dioxide. It may be used in a small number of cases where oxygen levels are low, but only when recommended by MND specialists.

Further information for professionals

Information sheet P5 - *Managing respiratory symptoms in MND*

Information to share with people affected by MND

Information sheet 8A – *Support for breathing problems*

Information sheet 8B – *Ventilation for MND*

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

Swallowing problems

If the face, mouth and throat muscles (bulbar muscles) get weaker, swallowing can be affected. Swallowing problems, known as dysphagia, make it difficult for someone to eat and drink. This can lead to weight loss, but loss of weight can also be due to muscle wasting.

It is very important that people with MND do not lose weight suddenly. If you are concerned, talk to your manager or the MND specialist team, if you have direct contact.

A speech and language therapist can assess the person's ability to swallow and how this may be affecting their weight. They may also suggest supplements or dietary changes to increase nutritional intake. A dietitian can use this advice to recommend a diet to suit the person with MND.

Tube feeding

Alternative feeding options, such as a nasogastric tube (inserted through the nose into the stomach, often a short-term intervention) or gastrostomy (a tube inserted into the stomach through a hole in the abdomen) can be used to supplement or replace meals. In some cases, food may still be eaten by mouth for pleasure. A dietitian or speech and language therapist will give advice on this.

As a care worker, you may have responsibility for giving feed or medication using a feeding tube. You may also have to clean the tube by flushing it through, clean around the area where it is inserted and replace any gauze or other dressings.

If the person you care for has a feeding tube, you should receive training from their dietitian or another healthcare professional on how to use and take care of the tube. It is important that the site where a feeding tube is inserted is kept clean to help avoid complications that may otherwise result in emergency hospital admission.

Not all medications can be given using the feeding tube, so it is important to follow the instructions provided by the person's doctor, nurse or pharmacist.

See pages 36-37 for more information about eating and drinking.

Choking

Swallowing will get more difficult over time, and there may be episodes when a person with swallowing problems will experience coughing, sensations of choking or actual choking.

A weak cough, caused by weakened respiratory muscles, will make it more difficult for the person to remove food, drink or saliva that has become stuck. This can be distressing for the person with MND and those around them, but it is a common misconception that people with MND often die from choking. Choking is very rarely a direct cause of death in MND.

If a person with MND chokes, or has sensations of choking, it is important to try to remain calm, as this can help the person not to panic. See if a change of position helps (see page 34).

A physiotherapist can give advice on ways to manage coughing and a speech and language therapist can give advice on avoiding choking.

The MND Just in Case Kit is designed to hold medication that can be used to reduce symptoms of breathlessness, sensations of choking and associated panic. Having the box can be reassuring to the person with MND and their family.

The kit must be ordered by the person's GP, who should contact MND Connect on 0808 802 6262.

Further information for professionals

Information sheet P8 – *Dysphagia in MND*

Information sheet P3 – *Managing saliva problems in MND*

Information sheet P9 – *Oral suction*

Information to share with people affected by MND

Information sheet 7A – *Swallowing difficulties*

Information sheet 7B – *Tube feeding*

Eating and drinking with MND – information on how to adapt food and drink, as well as easy-swallow recipes.

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

Saliva and mucus problems

Problems with swallowing can lead to saliva building up in the mouth and throat. If saliva is thin and watery, this can lead to drooling. If saliva is thick, it can be difficult to clear from the throat, especially if the person with MND has a weak cough.

The person's healthcare team can suggest various management options, including advice on diet and fluid intake, medication and, occasionally, suction (see below), injections of botulinum toxin (Botox) or radiotherapy to the salivary glands.

Some people with MND may have a dry mouth, from medication, dehydration or breathing through the mouth. Medication dosages should be checked by a prescribing professional, who may also suggest artificial saliva sprays or gels. The person should drink more fluid, or receive more through their feeding tube if they have one. Humidifiers can also be helpful.

Suction units and machines to help with coughing

A person with MND may use a suction unit, which removes secretions from the mouth, or a Mechanical Insufflation-Exsufflation (MI:E) machine. An MI:E machine helps to clear secretions when a person is unable to cough well enough to remove them themselves. It may be known as a CoughAssist machine.

As a care worker, you may have to help with the operation of these machines. Someone from the person's respiratory specialist team should be able to train you in how to do this.

Further information for professionals

Information sheet 7A – *Swallowing difficulties*

Information to share with people affected by MND

Information sheet P8 – *Dysphagia in MND*

Information sheet P3 – *Managing saliva problems in MND*

Information sheet P9 – *Oral suction*

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

Pain

Pain may be experienced due to muscle cramps, spasticity, stiff joints, muscle spasms or skin pressure. It is important that the cause of the pain is assessed, as it may not always be connected to MND.

Seek advice from the person's health and social care team on careful positioning, support and pressure care, and suitable medication. A palliative care or pain clinic may be able to help with persistent pain.

Further information for professionals

Information sheet 6C – *Managing pain*

Information to share with people affected by MND

Information sheet P11 – *Pain in MND*

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org



Fatigue

Loss of physical function can make everyday tasks more difficult and tiring. Fatigue can also be caused by breathing problems and breathlessness, sleep problems, depression, low calorie intake and some medications.

If you work in a residential care setting, help the person to develop flexible routines that make the most of the times they feel alert, and allow for rest. You may also have the opportunity to support such a routine if you're working in the person's home.

It can be helpful to encourage the person to save their energy to do things they enjoy. This can sometimes help the person to accept help from care workers. If the care worker completes certain tasks, the person with MND may have the energy to complete something else.

An occupational therapist can advise on fatigue management and aids to make daily tasks easier.

Information to share with people affected by MND

Information sheet 11D – *Managing fatigue*

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org



Psychological and emotional needs

A person with MND may experience a range of emotions. These may include anxiety, fear, anger, sadness, depression and disbelief.

If these emotions are persistent and extreme, the person's health and social care team may suggest options for treatment or management. In some instances medication, or referral to a counsellor or psychologist, may help.

Emotional lability (pseudobulbar affect)

A person with MND may experience inappropriate laughing and/or crying, which can be difficult to control and can be distressing to the person and those around them. This is an involuntary response and does not affect everyone with MND.

The emotions the person is showing might be very different to how they feel: for example, they may laugh if they are in pain or when they are sad. If you know the person is affected by emotional lability, consider this if the person laughs unexpectedly during activities such as being transferred, as the laugh may indicate pain.

It is important to reassure the person and anyone else caring for them that this is a feature of MND.

The person's health and social care team can provide support. They may provide medication to help relieve this symptom.

Information to share with people affected by MND

Emotional and psychological support: for people with or affected by MND

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

Changes in thinking, reasoning and behaviour

Some people with MND experience changes to thinking, reasoning and behaviour known as cognitive change. A person with cognitive change may find it harder to think, concentrate, interact with others and plan things as easily as they used to. A small percentage of people with MND develop frontotemporal dementia (FTD), which involves severe cognitive change.

Some people experience changes in behaviour that are difficult for the people around them, including care workers. For example, they may show lack of empathy which can make them seem selfish. They may lose their inhibitions or behave impulsively, leading them to do things that are socially unacceptable. This will increase their care needs, and may in some cases lead to a care plan breakdown, and a new plan will need to be developed.

As a care worker, you may pick up on some of the early signs of cognitive change, such as problems processing information, or difficulties with language or spelling. This should be reported to the person's specialist team. Support for people with cognitive change should involve a range of professionals, including mental health and psychological services. You can support a person experiencing cognitive change by:

- only asking questions that have two choices of answer, eg yes/no
- establishing a structured routine
- finding out if there is a best time of day to carry out certain tasks
- remembering that they can't just 'try harder' to do something
- helping them to practise or rehearse tasks before doing them
- keeping objects in the same place so they can be found easily.

Further information for professionals

Cognitive change, frontotemporal dementia and MND

Information to share with people affected by MND

Changes to thinking and behaviour: for people with MND

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

What is not affected by MND?

The following are usually unaffected by MND, although each individual has a different experience.

Sexual function – however, movement problems, medical equipment and low self-esteem may make sexual expression and intimacy difficult.

Eye muscles – although some people will experience problems, most people with MND retain the ability to move their eyes.

Taste, sight, smell, touch and hearing – senses are generally unaffected by MND, although some people report minor changes.

The heart muscle – also unaffected.

Continence – although bowel and bladder functions are not usually affected by MND, mobility problems can make it more difficult to access and use the toilet. Changes in eating, weakened breathing, dehydration, anxiety, medication and poor mobility can cause constipation. In order to prevent a person becoming constipated:

- encourage them to drink at least a litre of water or equivalent a day
- add fibre to the diet (if possible)
- establish a daily routine (if the person does not already have one), such as sitting on the toilet 15-20 minutes after breakfast.

Diarrhoea can occur due to persistent constipation. The GP or specialist team can provide advice and medication if the constipation is ongoing.

Changes to bladder and bowel function should be investigated by the GP, who can give advice, review any medications the person is on and refer the person to a continence nurse if needed.

Treatments and therapies for MND

Riluzole is the only drug available to treat MND, but it has moderate benefit: it is thought to extend survival by three to six months. Riluzole does not reverse the damage done by the disease. A neurologist will assess whether someone is suitable to take riluzole.

Riluzole is available in a tablet or a liquid form. The liquid form may be easier for some people with MND to swallow and can be given through a feeding tube.

Information to share with people affected by MND

Information sheet 5A - *Riluzole*

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

Symptom management

As there is no other treatment for MND, management of the condition focuses on support from a range of specialists.

The **MND specialist team**, including the neurologist, specialist nurses and MND co-ordinators, can advise on all aspects of care, including treatment of symptoms and referral to other professionals as needed.

Some people will be taking medication for specific symptoms, for example pain. Some people will have problems swallowing tablets or syrups, so they may take alternative forms of medication. If the person with MND is fed by a tube into their stomach, some medication may be given through this too. Some medications can leave a sediment, potentially blocking the tube, so check whether it is safe for each medication to be given in this way.

Physiotherapists can help a person with MND maximise their movement and mobility and help maintain good balance and posture. Where a person with MND can't move one or more parts of their body themselves, a physiotherapist can give advice on passive movements. These are exercises where someone else moves the person's limbs, for example, which can help to maintain range of movement in the joints.

A physiotherapist may also recommend appropriate walking aids, splints, exercise programmes and ways to manage falls. They can also give advice on moving and handling the person with MND.

A respiratory physiotherapist can help with management of respiratory symptoms and a weak cough.

Occupational therapists can help a person with MND continue daily routines and activities of daily living with as much independence as possible, for example with advice on posture and equipment to help with specific needs. They can also advise on fatigue management.

Wheelchair services will provide an assessment of the person's current posture and mobility and how this might change in the future. They will assess the person's living environment, whether the chair needs to be transported, and consider what activities the person is likely to undertake. This will determine if a wheelchair is needed and if so, which would be the most suitable.

Speech and language therapists can assess and advise on problems with speech and swallowing, and teach techniques to reduce their impact. A speech and language therapist can also give advice on communication aids.

Dietitians can assess nutritional intake and weight, suggest ways to optimise the person's nutritional intake, or suggest other ways to change the person's diet to maintain their weight (see pages 36-37).

Palliative care services aim to achieve the best possible quality of life for people with advanced progressive illness and their families by managing pain and other symptoms and providing psychological, social and spiritual support.

Complementary therapies will not reverse the damage done by MND, but many people find therapies such as aromatherapy, reflexology, massage, relaxation techniques or acupuncture can help relieve symptoms and reduce stress. It is important that the therapist has some knowledge of MND. They must ensure that the person with MND knows the treatment isn't a cure, but will not do harm.

Caring for a person with MND

MND affects every individual differently. People with MND should have a full assessment of their care needs, which includes their preferences, likes and dislikes.

Care planning

A detailed, personalised care plan and statements of preferences should result from a discussion with the person with MND about the whole picture of needs they have: health, personal, family, social, economic, educational, mental health, and ethnic and cultural background. It should draw on information from the person with MND and relevant health and social care professionals involved in their care.

A key member of the person's health and social care team will be responsible for having this conversation and designing the plan with the person with MND. The plan will involve a number of organisations and professionals who will be directed by a key worker.

Because of the progressive nature of MND, a care plan for a person with the condition should be regularly reviewed in order to respond to ongoing changes in needs. This review should be carried out by a professional who can support the person with MND and those around them through the process.

As a care worker, you should follow this plan and report back to your manager when needs are changing and a review is required.

Key pointers on care planning

Whether you are caring for a person with MND in their own home or in a residential care setting:

- Communication issues should not prevent an assessment of needs. Every effort should be made to understand the person's needs, even if they find it difficult to communicate (see the communication tips on pages 38-40).
- Take your time to understand the needs of the person with MND. If possible, talk to the person with MND and their family carer, if they have one. The knowledge they have about how the condition affects them will be useful to you.

- A care plan should be available for you to follow from the first point of caring for a person with MND. It should be updated in light of regular assessments (monthly in the early stages) of the physical and psychological needs of the person with MND and their family. More frequent assessments may be needed as MND progresses.
- Talk to the main carer/partner of the person with MND. They often know what works best.
- Be prepared to be patient. Activities such as eating, drinking, communication and dressing will take more time.
- Find out who to contact about particular issues. As you are likely to be in day-to-day contact with the person with MND, you are a key part of the multidisciplinary team and may notice changes or issues in between appointments.
- Keep a diary of all appointments with professionals and a list of their contact details. This is useful to have to hand to see when particular professionals last visited or are due to be seen again.
- Avoid making assumptions about the person's wishes. When someone has advanced MND it may be easy to assume they have little quality of life, but the person themselves may consider their quality of life is better than it is perceived by others. Ask the person for their thoughts and perceptions.
- Report any concerns about your client's condition to your manager, particularly if the person's care needs are increasing.

Understanding my needs

This form that enables someone with MND to record their needs and preferences. This can help care workers and other professionals to provide appropriate care according to the person's wishes. It can be ordered as a printed booklet, which can be filled out by hand by contacting MND Connect. Call 0808 802 6262 or email mndconnect@mndassociation.org

Alternatively, download an interactive PDF version from www.mndassociation.org/publications

Personal care

- For people with MND, washing, dressing and toileting can take a long time.
- People who need help to wash, dress or use the toilet often experience feelings of indignity. This can be even more of an issue if rapid progression of MND has brought sudden change.
- Privacy and personal space in these and all areas of personal care is vital wherever possible.
- If people are able to carry out tasks for themselves and do not fatigue easily, this can improve morale and dignity.
- Remember that the support a person receives from their professional team can help maintain dignity.
- An occupational therapist can recommend strategies and equipment to help with personal care.
- Some people may choose to take a more dependent role, despite being able to do things for themselves.

Further information for professionals

Occupational therapy for MND booklet

Information to share with people affected by MND

Personal care booklet

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

Bathing and showering

An occupational therapist may be able to provide equipment and access to home adaptations, such as:

- shower seats, and particularly tilt-in-space shower seats with head extensions for those with trunk weakness or respiratory problems
- grab rails and non-slip mats
- bath boards or a mechanical bath seat

- a powered or manual hoist to transfer in and out of the bath
- accessible, level access shower cubicles or a wet room
- commode and shower chair.

Getting dressed and grooming

As dexterity progressively reduces, these may help to maintain independence:

- leg lifters, sock aids and shoe horns
- button hooks and zip pullers
- long handled hairbrushes and hands free hair dryers
- alternative fastenings eg sew buttons on outside of shirt to give the appearance of buttons, but use Velcro to fasten the shirt
- dry shampoo or shampoo caps.



Clothing

With MND, comfort and ease of dressing can become an issue. People may experience difficulties managing fastenings or reaching parts of their body.

It may help the person with MND to consider:

- suppliers of adapted clothes and local services that can adapt clothes for ease and comfort
- temperature control, such as good fabric choices for keeping cool or warm, wearing layers of loose, lightweight clothing, warming clothes before dressing, and considering thermal skiwear ranges
- clothing with no or simpler fastenings, such as elastic shoelaces, large D-rings and Velcro to adapt belts and zips, front fastening bras or sports bras with no fastenings
- dressing aids, such as zip pulls, button hooks, dressing sticks and shoe or sock devices to maintain independence
- items for protection and warmth when outdoors (eg quilted bags, capes, covers, hand muffs etc to use with wheelchairs/scooters)
- large neck openings and loose sleeves
- styles that allow for easy access to go to the toilet
- styles that are suitable for sitting for long periods of time
- fingerless gloves that keep hands warm but allow grip
- silk or satin materials for movement in bed – but these may cause sliding, affecting posture and positioning
- clothes with pockets for keeping small items to hand
- adjusting current clothing, such as a Velcro strip down the back of a suit jacket can aid getting on and off if someone is seated
- poncho style capes instead of heavy coats
- appropriate length of clothing to reduce the risk of trips and falls.

Heavy or tight garments that can restrict movement and may make problems with mobility and arm function feel worse. Clothing in fabrics that are itchy or ride up easily can cause discomfort when seated for long periods.

If a person experiences drooling due to problems swallowing saliva, this may be managed with:

- neck scarves
- adult bibs and tabards
- clothing adapted to include waterproof panels
- dark coloured patterned tops.

Footwear

Shoes should be the correct width, supportive and fasten securely. If someone experiences foot drop, their MND team may be able to provide a foot-up device. If a person uses foot supports or experiences swollen feet, footwear may need to be wider or larger than usual.

Toileting

Maintenance of dignity and self-esteem are paramount. An occupational therapist can advise on aids to support independence such as:

Specialised equipment - such as a bottom wiper, with a long looped handle and a paper grip.

Adapted clothing - for ease of access during toileting. Specialist underwear and disposable pads may be considered if there are concerns around timely access to the toilet.

Wash and dry toilets - for those with reduced mobility, a toilet with wash and dry facility can help to maintain hygiene, independence and dignity. There are types to replace the existing toilet, or to fit over it.

Wheelchair toileting - some wheelchair cushions have a removable wedge that can be taken out to enable toileting with a female urinating device or urinal bottle.

Additional equipment - to aid transfers, a raised toilet seat, frames, grab rails and hoists, will ensure the toilet can be used for as long as possible.

Contenance equipment and aids - for use at home or when travelling, such as a urinary sheath or urinal bottles.

Oral hygiene

Muscle weakness, dysphagia and a high calorie diet can all affect maintenance of good oral hygiene. Strategies and equipment may help a person maintain their own oral hygiene for as long as they can functionally do so. Advice and equipment may be sought from dental hygienists and dental therapists.

A family carer or care worker may need to attend dental appointments to learn techniques for mouth care at home.

Access to the dentist can be challenging. Some dentists may have hoists and wheelchair recliners. Alternatively, any health or social care professional can refer a person with MND to a community dental service, which may offer home visits.

Refer to the person's GP or MND specialist team for management of saliva problems.

Some people experience oral thrush which often goes unnoticed for long periods. Reporting a coated tongue or white patches in the mouth can save time and ensure fast treatment.



If the person cannot tolerate a toothbrush in their mouth:

Some people may be reluctant to brush their teeth due to brisk gag reflex or concerns about choking.

- Encourage better positioning, with an upright, seated position, the chin level or downward, and the head turned slightly to one side.
- Introduce toothbrushes and other mouth cleaning items into the mouth gently, and use slow movements.
- Try a softer toothbrush (eg a child sized toothbrush).
- Consider a toothbrush attachment for an oral suction unit.

For limited arm strength or movement, suggest:

- propping elbows on supporting surface, placing the toothbrush on to the teeth and moving the head from side to side
- holding with two hands
- a lightweight cordless electric toothbrush
- long handled toothbrushes
- three sided toothbrushes that brush all sides of the tooth at once.

For problems gripping the toothbrush, try:

- large toothbrush handles
- a polystyrene foam ball pushed on to the handle of a toothbrush
- pipe lagging from a DIY store wrapped around the handle
- elastic bands on the handle to aid gripping.

For swallowing difficulties, suggest:

- non-foaming, dissolving, 'no rinse' toothpaste for those concerned about choking on standard toothpaste or mouthwash - the ingredient which causes foaming is called sodium laurel sulphate
- preventive treatment with fluoride gels (with cotton swabs) or mouthwash rinses.

If a person with MND has problems opening their mouth:

- pressing gently on the chin below the bottom lip may help the mouth to open more easily
- a bite block or mouth rest may be used to keep the mouth open
- finger protectors may be used when assisting with oral hygiene.

If a person with MND uses a feeding tube:

- advise that oral hygiene is still necessary even if food or drink is not taken by mouth.

If a person with MND uses a suction machine:

- this can be used to remove excess saliva and toothpaste
- a specialist toothbrush accessory can be attached to the machine.

Movement and handling

The loss of muscle bulk and strength can make joints stiff and painful. Care is needed when lifting, handling and positioning to avoid causing any further pain or the dislocation of weak joints. You should receive training on how to move the person without causing distress.

A physiotherapist and/or occupational therapist should carry out a full assessment of the movement and handling needs of the person with MND and the capability of their carers. They should talk to you about:

- safe techniques for handling people with MND who have fallen
- how the limbs, head and neck should be supported during transfers
- equipment that may help, such as sliding sheets, hoists, profiling beds, mattress elevators, riser-recliner chairs and turning tables.

Positioning to help with breathing problems

If a person has respiratory problems, they may feel breathless when lying flat. This may feel uncomfortable, scary and, in some cases, may be dangerous.

It is vital to find positions that make it easier for the person with MND to breathe. The ideal position is usually upright or slightly reclined, with the arms, back, head and neck supported.

A semi-reclined position may be achieved by using a riser-recliner chair with arm supports, or a wheelchair with tilt-in-space. This position allows the diaphragm to move more freely and efficiently. It will help the person to maintain a good head position and will make it easier to swallow.

In bed, a semi-reclined position is likely to be more comfortable. A raised head, perhaps with more pillows, a pillow lifter or a profiling bed, may reduce night-time problems.

If breathing is laboured:

- The person should have a respiratory assessment, if they haven't already had one.
- A physiotherapist can teach or give advice on techniques to help with breathing, including posture and positioning, and clearing secretions.
- An occupational therapist can give advice on posture and positioning, as well as helping to identify equipment to help with positioning
- Some people with MND find it helpful to have an electric fan blow air into their face, as it provides some psychological relief when breathless.

Pressure care

- If a person with MND is using a mask for non-invasive ventilation, they may get pressure sores on the bridge of their nose. Their face shape may change as MND progresses and muscles waste, meaning the mask no longer fits well. A respiratory physiotherapist or the respiratory team can recommend alternative mask designs, or address concerns.
- Good skin and pressure care is vital to prevent sores. A person with MND may be aware of when they need to be turned or moved, but may need help to adjust their position.
- Consider appropriate equipment for skin sensitivity relief, such as a bed cradle to relieve the weight of bed clothes, lightweight bed clothing, a pressure-relieving mattress and cushions. Barrier creams may be applied to the skin to prevent pressure sores.
- Be aware that tissue breakdown is more likely if nutritional intake and hydration are poor.

Night time: disturbed sleep

People with MND may experience problems with sleep resulting from reduced mobility, muscle cramps, swallowing problems and anxiety.

People may be afraid to sleep if they are aware their breathing is impaired and fear they will not wake.

They may feel they haven't slept well, have headaches, feel 'hungover' and may fall asleep during the day. It may be difficult to rouse the person from sleep and they may seem confused on waking.

These may be the first signs of problems with the respiratory system. They should be reported to the person's healthcare team, who can refer the person for respiratory assessment.

One of the first steps may include use of a profiling bed, which allows the person to sleep with their head and chest raised up, making breathing easier.

Although a profiling bed is recommended, it's important to understand that a person living with MND may not wish to change their bed for many reasons: for example, if they share it with their partner or they find their bed comfortable. Any discussions about changing beds must be handled with sensitivity.

Eating and drinking

A dietitian should be involved in monitoring the weight and nutritional intake of the person with MND as the condition progresses. They can also give advice on the types of food to include and those to avoid while the person is still eating by mouth.

If the person with MND has problems with swallowing, the dietitian will work with a speech and language therapist to introduce a diet where the person can get the most nutrition from what they eat and drink.

At mealtimes, an upright position can help to reduce the risk of aspiration. It might help to use the 'chin-tuck' or 'chin-down' posture, which involves tucking the chin to the chest when swallowing.

This can prevent food going down into the airway. A speech and language therapist can teach the person with MND this technique.

An occupational therapist can give advice on equipment that may help at mealtimes.

These tips may be useful day to day:

- Serve several small meals rather than one large one: this can be less tiring for the person eating.

- Follow any advice given by the speech and language therapist about easy-to-swallow meals and food consistency. This may include using thickeners in fluids.
- Use garnishes and attractive colours to make food more appetising, and make sure the person eating can see and smell the food. This is especially important if food is mashed or puréed.
- Find out whether the person has preferences for particular comfort foods, such as puddings. Introduce small portions of these foods to create interest in eating and to promote wellbeing.
- Allow plenty of time for the meal.
- Keep food warm or reheat if necessary. A keep-warm plate may help.
- Let the person concentrate on what they're doing – allow the person to swallow before asking questions.
- Leave a gap between courses if eating is slow and tiring.
- The person's swallowing reflex may be stimulated by sipping a hot or cold drink before eating and between mouthfuls.
- A relaxed, quiet environment may help people to feel less anxious.
- The person with MND may feel unable to eat with other people because of swallowing problems. They may join others to socialise and eat a few spoonfuls, while eating most of their meal before or afterwards.

Further information for professionals

Information sheet P8 – *Dysphagia in MND*

Information to share with people affected by MND

Information sheet 7A – *Swallowing difficulties*

Information sheet 7B – *Tube feeding*

Eating and drinking with MND – information on how to adapt food and drink, as well as easy-swallow recipes.

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

Communicating with a person who has MND

If a person with MND has weak muscles in the lower face, jaw, tongue and throat (bulbar muscles), this can affect speech. A person's voice can also become weaker if respiratory problems mean they do not have enough breath to help produce a strong voice. Speech problems are known as dysarthria. It may take great effort for a person with MND to communicate, so it's important to make it as easy as possible for them.

A speech and language therapist can assess the person's needs, provide therapy techniques and recommend suitable communication aids. Speech and communication aids are often referred to as Augmentative and Alternative Communication (AAC). They can range from low-tech (gestures, notepads, alphabet boards, etc) to high-tech (computer-based, including tablets with text to speech software).



A member of the specialist respiratory team may teach breathing techniques, such as breath stacking, which can make it easier for people with weak respiratory muscles to cough more effectively and produce a stronger sounding voice.

Some care workers will be involved in helping with this type of therapy. The carer will need to have knowledge of the technique to provide support, so they should also receive training from the specialist respiratory team.

An occupational therapist can assess the person's needs for equipment such as environmental controls – switches that can be used to control lights, TVs, radios or computers. These can be operated by almost any part of the body the person can still move.

These tips may help communication:

Do:

- find out whether the person uses a simple code for yes and no: this can be a movement of any part of the body that can be carried out reliably, such as eye blinking or a finger movement
- find out how the person with MND prefers to communicate and any equipment they like to use
- make sure any necessary communication aid is available and the person with MND is in the best position to access it
- have a pen and paper handy so that the person, if they are able to, can write down any difficult words
- remember that unspoken communication is important: sit face to face, and watch the person's eyes, lips and gestures
- ensure the person with MND is comfortable and is the focus
- allow time and create a relaxed atmosphere
- encourage the person to slow down and over-emphasise words to help clarity
- check back with the person on what you think has been said and admit when you don't understand
- make it easier for the person to contact you. If they struggle to speak on the phone, they may prefer to use email or text message

- become an advocate for the person with MND and help them to communicate with others, if that is what they want you to do
- share your knowledge with other care workers who may be new to the person with MND. If you spend a lot of time working with someone, you will get to know how they prefer to communicate.

Try not to:

- alter the rate or sound of your speech, unless the person with MND has asked you to, or a speech and language therapist has recommended that you speak more slowly
- finish the sentences of the person with MND, unless they ask you to
- interrupt them: if the person uses assisted ventilation, they may have to speak in rhythm with the machine, so a gap when they are speaking won't always be a natural pause
- use family members or carers as a translator for the person with MND, unless it is clear that this is what the person with MND wants
- ask open questions: instead use closed questions which can be answered with a single word. This is also important when someone has cognitive change or frontotemporal dementia.

Further information for professionals

MND: Speech, communication and language support booklet

Information to share with people affected by MND

Information sheet 7C - *Speech and communication support*

Information sheet 7D - *Voice banking*

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

Planning ahead for end of life

People with MND should be encouraged to talk through options for their care and their preferences for end of life, before the need is urgent or before they find it too difficult or tiring to communicate.

The person may have this conversation with their GP or palliative care team. The rest of the health and social care team should be informed of their wishes. As a care worker, it is not your role to help the person with MND plan ahead for the end of life, but as you are in close contact with them, they may discuss it with you, so it can be helpful to know about the plans and documents discussed in this section.

Advance care plan

Having time to think things through and knowing that wishes have been recorded in an advance care plan gives many people peace of mind. As well as options for care, an advance care plan should cover all future needs, for example, who will care for a pet.

Advance statement

Usually included in or with an Advance Care Plan, this is a written statement of a person's preferences, wishes, beliefs and values for future management and care.

It can cover any aspect of health and social care, including where the person would like to be cared for. It is designed to guide anyone who may have to make treatment and management decisions if the person has lost the capacity to make or communicate their choices.

A person may also wish to record where they want to die. This will depend on the person, their family and their circumstances. Advance statements are not legally binding, but the person's preferences should be honoured, where possible, by professionals.

Advance Decision to Refuse Treatment (ADRT)

Sometimes referred to as an Advance Decision, this is a decision that can be made in advance to refuse specific treatments (including those that may sustain life) in certain circumstances in the future.

Before making an ADRT, the person should discuss the contents with an appropriate professional – usually the GP, specialist nurse or neurologist – to ensure they are clear about which treatments they wish to decline and their wishes are properly recorded.

The person with MND should have a full understanding of the possibility of discomfort and risk to their life. An ADRT cannot authorise a doctor to do anything illegal, such as euthanasia, but it can enable someone to refuse something that prolongs their life (eg artificial feeding or antibiotics). The person will still have the right to primary care and comfort.

The ADRT is not valid unless the person has lost the ability to make decisions or communicate. Every opportunity should be given to help the person to communicate, for example by blinking.

An ADRT is legally binding in England and Wales. It should be regularly reviewed in case the person changes their mind.



Do Not Attempt CPR (DNACPR)

Cardiopulmonary resuscitation (CPR) is the procedure used to try to restart the heart or breathing when it stops. A person can record a wish for Do Not Attempt CPR (DNACPR).

This is not legally binding but in most cases an appropriate healthcare professional will make a judgement depending on the circumstances. In England and Wales, someone can include a DNACPR in their ADRT, which is legally binding.

All professionals involved in the care of the person with MND, including the ambulance and out-of-hours service, should be aware of the DNACPR. It will be valid in the person's home, hospital and other care settings.

Your line manager should make you aware of the action you are expected to take if you are with the person with MND in the event that their breathing/pulse stops.

The person with MND should be encouraged to talk to their GP or an appropriate member of their specialist team to make sure their wishes are recorded. You should be aware of any decisions that have been made and any changes made to these.

Further information for professionals

A professional's guide to end of life care in MND booklet

Information to share with people affected by MND

End of life: a guide for people with MND

Information sheet 14A - *Advance Decision to Refuse Treatment (ADRT) and advance care planning*

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

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 is thought the person is approaching end of life, care plans should be reviewed so that appropriate care can be given. For most people with MND, death will be peaceful. People with MND very rarely die from choking.

Managing symptoms

If a person is dying, they will tolerate their symptoms less well. They may be taking medication to stop these symptoms, including pain, from becoming distressing. This medication may make them drowsy. As people are dying, they will also become drowsy as part of the dying process.

Eating and drinking

Most people stop eating and drinking in the final days of life. The end of life care team will advise on hydration by mouth or feeding tube.

Mouth care

In the final days of life, mouth breathing and minimal fluid intake can cause the mouth to become dry and the lips become more likely to crack. The mouth should be kept clean and moist: some people find ice lollies refreshing.

Terminal restlessness

This is the name given to agitation that is sometimes seen in people just before death, and is usually associated with a reduced level of consciousness. A person may appear unconscious, restless and unsettled. There may be disorientation, anxiety, fidgeting and looking scared or distressed. It can happen now and again or all the time.

In this situation, it can help to talk to the person in a gentle and relaxed way to try and reassure them. Ensure their environment is calm and they feel as safe as possible.

Communicating with the person with MND

This may become extremely difficult as the person with MND reaches end of life, but even if they are unresponsive, every attempt should be made to maintain communication. Eye movements and questions that only need a single word or yes/no answer may be used (eg 'Do you want to listen to the radio?') alongside picture/alphabet boards or other communication aids where appropriate.

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.

End of life - a guide for people with MND

This guide contains comprehensive information about end of life for people affected by MND, and can support you with any difficult conversations you may have. The guide covers subjects including:

- how MND progresses
- the benefits of planning ahead
- how to manage end of life discussions with health and social care professionals, family, children and friends
- what is likely to happen at end of life with MND
- advance care planning, advance decisions and the introduction and withdrawal of treatments for MND
- how to put personal affairs in order and what to do when someone dies
- the rules around organ and tissue donation with MND
- an overview of the law regarding suicide and assisted dying.

Call our MND Connect helpline on 0808 802 6262 for further support and to order a copy of the guide. Alternatively, visit **www.mndassociation.org/publications** to download the guide.

Caring for yourself

Caring for a person with MND can be hard work, both physically and emotionally. There may be occasions when it is hard to find the time to think about your own needs. It is important to look after yourself, to eat properly and to take breaks where possible.

An exhausted carer will not be able to provide the best possible support for a person with MND.

When you are caring for someone over a period of time, you will get to know them and you may find it distressing when they die. This is not unusual: many professionals feel this way after building a relationship with a person.

Seek support where you can. It may be helpful to share experiences and feelings with colleagues. Ideally you should have supervision sessions with your line manager to discuss this and other issues.

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



Key contacts

When you first start caring for someone with MND, find out who you need to contact if the person has particular needs. This list of issues is only an example of those covered by each professional.

Professional	Issue	Contact number
Consultant/MND specialist team/ MND care centre	General queries or concerns about MND; breathing problems; medication.	
Dietitian	Diet, nutrition or feeding tubes.	
District or community nurse	Medication; diet, nutrition or feeding tubes; certain equipment, eg profiling beds.	
GP	General issues or concerns about MND; medication; advance care planning and palliative care.	
Hospice	Complementary therapies; advance care planning and palliative care.	
Occupational therapist	Equipment; hobbies; adaptations for the home.	
Palliative care team	Medication; advance care planning and palliative care.	
Pharmacist	Medication; liquid feed.	
Physiotherapist	Exercise or passive exercise; posture; respiratory care.	
Respiratory team	Assisted ventilation; breathing problems; coughing; choking.	
Social services	Care package, safeguarding, equipment or adaptations.	
Speech and language therapist	Speech or communication issues; swallowing problems.	

Glossary of useful words

Advance Decision to Refuse Treatment (ADRT)

A decision that can be made in advance to refuse specific treatments in certain circumstances in future.

Aspiration

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

Breath stacking

This is an exercise that can be taught by a respiratory physiotherapist to improve the strength of a person's cough.

Cognitive change

Changes to thinking, reasoning and behaviour.

Dysarthria

Problems with speech.

Dysphagia

Problems with swallowing.

Emotional lability

A symptom of MND, also known as pseudobulbar affect, where a person may cry or laugh at inappropriate times.

Fasciculations

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 with force 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.

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 or mouthpiece 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.

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 medication available to treat MND. It does not reverse damage done by the disease, but may extend survival by three to six months.

Teglutik

This is a liquid form of Riluzole, which may be easier for some people with MND to swallow or take via feeding tube.

Tracheostomy

This is where a tube is inserted into the windpipe through the neck. It may be connected to a machine that takes over breathing.

How we can support you

MND Connect

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

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

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-advice

Information resources

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

www.mndassociation.org/publications

MND Association website

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

www.mndassociation.org/professionals

Education

Our education programme is designed to improve standards of care and quality of life for people living with and affected by MND.

www.mndassociation.org/education

MND Professionals' Community of Practice

A peer led group of health and social care professionals encouraging and supporting the development of good care for people living with, or affected by, MND.

www.mndassociation.org/cop

Support grants and equipment loan

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

www.mndassociation.org/getting-support

Research into MND

We fund and promote research that leads to new understanding and treatments, 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.

www.mndregister.ac.uk

Regional staff

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

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

MND care centres and networks

We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist MND care.

www.mndassociation.org/care-centres

Branches and groups

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

www.mndassociation.org/branchesandgroups

Association visitors (AVs)

AVs are trained volunteers who provide one-to-one local support to people affected by MND.

www.mndassociation.org/associationvisitors

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

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MND Association

Tel: 01604 250505

Email: enquiries@mndassociation.org

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