Caring for a person with motor neurone disease: a guide for care workers
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 happen to 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 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 a 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
Developed in partnership with the University of Northampton, 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 six 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
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Need to find out more?
You can contact our helpline MND Connect on 0808 802 6262 or mndconnect@mndassociation.org if you have any questions or want more information about anything in this booklet. See page 37 for more information about how the MND Association can support you in your role.

If you think the person you are caring for needs extra support, you may be able to speak directly to the appropriate member of the person’s health and social care team. Alternatively, you should report the issue to your manager or supervisor, who can seek more information from the right professional.
The care worker’s role

As a care worker, you play a key role in helping to maintain 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 might happen next and what support might be needed. If you notice any early signs of change and alert the right people, this may help to get support in place sooner.

If you are able to give detailed, objective feedback on the person’s condition and any changes, this can be very useful for other professionals who are providing care.

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:

- counselling/psychology
- dietitian
- district or community nurse
- GP and primary care team
- neurologist
- occupational therapist
- palliative care team
- pharmacist
- gastroenterologist
- physiotherapist
- respiratory specialists
- social services
- specialist nurse
- speech and language therapist
- staff or volunteers from the MND Association (see page 37) and other voluntary organisations
- wheelchair services.

Other professionals may be involved at different stages of the condition.
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 36 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 who should contact the person’s GP or specialist team
• speak to the person’s GP or MND team if you have direct contact.

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.

Good communication with the person’s unpaid carer(s) is vital if you are providing care in addition to the care they provide, 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.

When someone has MND, the health of their partner or main carer can sometimes be overlooked. I feel any professional carer should also consider the effect of MND on this person.” Steve, professional carer
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 25 for more about posture and positioning)

• automatically give the person oxygen, unless it is under guidance of an MND specialist (see page 12 for more about oxygen).

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 should also be available if needed, in:

• assisting with 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. There may be many different pieces of equipment you need to use when caring for a person with MND.

Training in specific areas of care should be provided by relevant members of the person’s health and social care team. Regional staff from the MND Association can also offer awareness training about MND and the Association’s services, as well as more detailed study days. Call MND Connect on 0808 802 6262 to find out more.
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 carers that 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** | **body weight measurements (taken every week)** |
| **a daily diary** | **accident policies and report sheets** |
| **a medication sheet** | **an up-to-date risk assessment** |
| **relevant contact numbers** | **complaints procedures and report forms** |
| **details of emergency procedures** | **death of a client policies and procedures.** |
| **services check sheets (eg fire alarm)** |

A daily diary should include:

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

Continuity of care

Ideally, a person with MND should be cared for by the same person or team of people. We appreciate that this is difficult in practice, but the number of carers should be kept to a minimum and the person with MND should be told about any changes.
I find small group meetings, where ideas are shared with other carers, very useful. Sometimes we struggle on our own with an issue, when another carer has already faced it and found a solution. Sometimes, professionals such as doctors may not have the answer to simple care-related problems.”

Ross, freelance care/support worker
What are the signs and symptoms of MND?

Not everyone will experience all of the following symptoms, or in any particular order. Some people may even have symptoms that are not mentioned here, as the disease can affect everyone differently. Some will also have 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 decrease in mass (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, coordination 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 25 for information on positioning.

**Twitching (fasciculations)**

Twitching and rippling sensations under the skin, called fasciculations, are often among the first symptoms 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.
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. This is because respiratory function is linked to the progression of MND. Noticing problems early means that action can be taken sooner.

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 13).

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 25 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. The machine detects when the person with MND tries to take a breath and delivers an extra flow of air to increase the amount of air they breathe in. There are two main options for ventilation support for people with MND:

• **Non-invasive ventilation (NIV)** – where a portable machine is used to provide extra air through a mask. A range of mask designs are available, from a nasal tube to a full head mask.

• **Full or invasive ventilation via a tracheostomy** – where a machine takes over breathing via a tube inserted into the windpipe through the neck. This will occasionally be requested by people with MND, but is not routinely available. The person may live for 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**

If plans for end of life haven’t already been discussed, they should be talked about when a person with MND starts to experience breathing problems and is thinking about assisted ventilation.

This is because 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 page 31 for more information about advance care planning.

**Oxygen**

When a person uses non-invasive ventilation, it may look like they are using oxygen, but they are not. This type of ventilation makes use of air that’s already in the room where it is used.

Oxygen is not generally used in MND. It may be used in a small number of cases where oxygen levels are low, but only when recommended by specialists involved in the care of the person with MND.

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**Information you can share**

We have a range of information sheets (8A to 8E) for people with MND on breathing problems and ventilation. Download from our website at [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or see page 37 for details of how to order copies.
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, so they may not get enough to eat or 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) 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 really important that the site where a feeding tube is inserted is kept clean, as this can help to avoid complications that may otherwise result in emergency admission to hospital.

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.

There is more information about eating and drinking on page 26.
Choking
Swallowing will get more difficult over time and there may be times when a person with swallowing problems will have episodes of coughing and choking. A weak cough, caused by weakened respiratory muscles, will make it more difficult to remove whatever is stuck, whether it’s food, drink or saliva. This can be distressing for the person with MND and those around them, but it is a common misconception that people with MND die from choking. Choking is very rarely a direct cause of death in MND.

If a person with MND chokes, 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 25 for more about posture).

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

Information you can share

The MND Just in Case Kit is a box to be kept within the home that contains medication that can be used to reduce symptoms of breathlessness, choking and associated panic. The kit must be ordered by the person’s GP, who should contact MND Connect on 0808 802 6262.

Other resources for people affected by MND include:

• MND Association Recipe Collection: easy to swallow meals
• Information sheet 7A – Swallowing difficulties
• Information sheet 7B – PEG and tube feeding – making the decision
• Information sheet 11B – Mouth care

Download from our website at www.mndassociation.org/publications or see page 37 for details of how to order copies.
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, perhaps 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. Mouth care is also important. The teeth, tongue and gum margins should be cleaned regularly and before oral medication is given.

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.

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 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.
Fatigue

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

If you’re working in a residential care setting, help the person with MND 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.

An occupational therapist can give advice on fatigue management and aids to make daily tasks easier. Some hospitals and palliative care teams offer fatigue management programmes.

Emotional lability (also known as 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 does not affect everyone with MND and is an involuntary response. 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.

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.

Supporting 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.
Changes in thinking, reasoning and behaviour

Some people with MND experience changes to thinking, reasoning and behaviour (cognitive change). These can range from mild memory problems to more severe changes. 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 will develop a type of dementia called frontotemporal dementia (FTD), which involves severe cognitive change.

Some people with FTD will experience changes in behaviour that are challenging for the people around them, including care workers. For example, they may show lack of empathy or emotional understanding, 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, making caring for them more difficult, and may in some cases lead to a care plan breakdown.

As a carer of a person with MND, you may pick up on some of the early signs of cognitive change, which may include problems with processing information, or difficulties with language or spelling. These changes 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 so the person knows what to expect
• 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 carrying them out
• keeping objects in the same place so they can be found easily.

Read our booklet for professionals on Cognitive change, frontotemporal dementia and MND. Download it from our website at [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or see page 37 for how to order copies.
What is not affected by MND?

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

The **heart muscle** and **sexual function** are unaffected. However, movement problems, medical equipment and self-esteem may make sexual expression and intimacy more difficult.

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

**Continence** – bowel and bladder functions are not usually affected by MND, but mobility problems can make it more difficult to access and use the toilet. Changes in eating, 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 as a result of persistent constipation. Changes to bladder and bowel function may not be due to MND. They should be investigated by the GP, who may refer the person to a continence nurse.

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

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I had worked in palliative care for many years before I started caring for Susie, so I knew about MND. But I went on a training course provided by the MND Association, to see if anything had changed.

Susie and I worked together to build her confidence to go out and about. Soon she felt as though she was living again. It is absolutely vital that carers treat the person they are caring for as they would wish to be treated themselves. It is also important to remember the person with MND is in control. Susie knows exactly what she wants to do and it is up to me to help her with that.” Amanda, professional carer
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. Some people cannot tolerate the drug.

Riluzole is available in a tablet or a liquid form. The liquid form may be easier for some people with MND to swallow.

Information you can share

- Information sheet 5 – Riluzole

Download from our website at www.mndassociation.org/publications or see page 37 for details of how to order copies.

Symptom management

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

Taking medication

Some people will be taking medication for specific symptoms, for example for 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, medication may be given through this, too.

MND specialist team

The MND specialist team, including the neurologist and specialist nurses, can advise on all aspects of the care of a person with MND, including treatment of symptoms and referral to other professionals as needed.
Physiotherapy
This can help a person with MND maximise their movement and mobility and help to 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, exercise programmes, ways to manage falls and can give advice to you on moving and handling the person with MND. A respiratory physiotherapist can help with management of respiratory symptoms.

Occupational therapy
This can help a person with MND to continue daily routines and activities of daily living with as much independence as possible, and includes advice on posture and equipment to help with specific needs.

Speech and language therapy
This involves assessment and advice on problems with speech and swallowing, and teaching techniques to reduce their impact. A speech and language therapist can also give advice on communication aids.

Dietetics
A dietitian can assess nutritional intake and weight, suggest ways to optimise the person’s nutritional intake, or can suggest other ways to change the person’s diet to maintain their weight (see page 26).

Palliative care
This type of care aims to achieve the best possible quality of life for people with advanced progressive illness and their families by managing pain and other symptoms, preventing and relieving suffering, and providing psychological, social and spiritual support.

Complementary therapies
They will not reverse the damage done by MND, but many people living with the disease find complementary therapies, such as aromatherapy, reflexology, massage, relaxation techniques or acupuncture, can help to relieve symptoms and reduce stress. It is important that the therapist has some knowledge of MND, the treatment isn’t expected to be a cure, it will not do harm, and it is affordable for the person with MND.
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. This may be a relative.

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 supervisor when needs are changing and a review is required.

Information you can share

- Understanding my needs: a tool that enables people with MND to record their wishes and preferences for care.

Download from our website at www.mndassociation.org/publications or see page 37 for details of how to order copies.
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 29 and 30).

• **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 prepared 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/spouse 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.** 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.**
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 in these and all areas of personal care is vital.
• Personal space should be respected.
• If people are able to carry out tasks for themselves and do not fatigue easily, this can improve morale and dignity.
• The support a person receives from their professional team can help them to 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.

“I cannot overstate the need for the carer to respect the dignity of the person with MND at all times.”
Steve, professional carer

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 to identify the movement and handling needs of the person with MND and 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 can recommend alternative mask designs, or address concerns about the mask’s seal.

• 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.
Clothing and temperature control

• Loose-fitting layers can help to trap heat, and it is easier to remove layers when hot.
• Different types of materials can help with temperature control – cotton and cotton-rich fabrics are usually best.
• Use warm socks for cold feet and warm up clothes before dressing.

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 they are not breathing fully 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.

Bed comfort

Although a profiling bed may be 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 and take a few spoonfuls, while eating most of their meal before or afterwards.
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. 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).

A person’s voice can also become weaker if respiratory problems mean they do not have enough breath to help them produce strong sounds. 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.
Do:

• 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. This can reduce frustration and misunderstanding

• remember that unspoken communication is important: sit face to face, and watch the person’s eyes, lips and gestures

• use hand gestures to assist with your own speech where suitable. Over time, this will become a very important tool, for example using the ‘thumbs up’ sign to mean ‘good’

• ensure the person with MND is the focus of communication

• allow time and create a relaxed atmosphere

• encourage the person with MND to slow down and overemphasise words to help clarity

• check back with the person on what you think has been said and admit when you don’t understand

• 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 without causing fatigue, such as eye blinking or a finger movement

• 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 messaging

• 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 carers who may be new to caring for 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. Also, avoid interrupting them. If the person you are caring for uses assisted ventilation, they may have to speak in rhythm with the machine. 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 complex questions that require long or difficult answers and can take up time and energy.
- use multiple choice questions. Questions that can be answered with yes, no or a single word are easier when speech is difficult. This is also important when someone has cognitive change or frontotemporal dementia: any question asked should only have a maximum of two choices of answer.

A client of mine who had MND had recorded in his person notes/preferences: ‘I want to be heard.’ This really affected me at the time and has since influenced how I communicate with people with MND.”

Steve, professional carer

Information you can share

Our resources for people affected by MND include:

- Notepad for people with speech difficulties
- Speech card for people with speech difficulties

See page 37 for details of how to order copies.
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. If not, the GP should be told of the person’s wishes, so they can talk to the rest of the health and social care team.

**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 health and social care 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 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 that all treatments being refused are named. 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 (e.g. 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. It should be regularly reviewed in case the person changes their mind. See www.adrt.nhs.uk for more information, or the MND Association’s End of life guide (see page 34).

**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.
End of life care for someone with MND

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.
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.

The MND Association’s *End of life guide*

This booklet has plenty of 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
- 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
- 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, you can visit to **[www.mndassociation.org/publications](http://www.mndassociation.org/publications)** to download the guide.
Caring for a person with MND can be hard work, both physically and emotionally.

It is important to look after yourself, to eat properly and 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 it may be 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. Ideally you should have supervision sessions with your line manager to discuss this and other issues.

Anyone looking after a person with MND should make sure they have as much knowledge as possible. Carers also should not struggle, but make use of the fantastic equipment and aids that are available.” Amanda, professional carer
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.

<table>
<thead>
<tr>
<th>Professional</th>
<th>Issue</th>
<th>Contact number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant/MND specialist team/ MND care centre</td>
<td>General queries or concerns about MND; breathing problems; medication.</td>
<td></td>
</tr>
<tr>
<td>Dietitian</td>
<td>Diet, nutrition or feeding tubes.</td>
<td></td>
</tr>
<tr>
<td>District or community nurse</td>
<td>Medication; diet, nutrition or feeding tubes; certain equipment, such as profiling beds.</td>
<td></td>
</tr>
<tr>
<td>GP</td>
<td>General issues or concerns about MND; medication; advance care planning and palliative care.</td>
<td></td>
</tr>
<tr>
<td>Hospice</td>
<td>Complementary therapies; advance care planning and palliative care.</td>
<td></td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>Equipment; hobbies; adaptations for the home.</td>
<td></td>
</tr>
<tr>
<td>Palliative care team</td>
<td>Medication; advance care planning and palliative care.</td>
<td></td>
</tr>
<tr>
<td>Pharmacist</td>
<td>Medication; liquid feed.</td>
<td></td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>Exercise or passive exercise; posture; respiratory care.</td>
<td></td>
</tr>
<tr>
<td>Respiratory team</td>
<td>Assisted ventilation; breathing problems; coughing; choking.</td>
<td></td>
</tr>
<tr>
<td>Social services</td>
<td>Equipment or adaptations for the home.</td>
<td></td>
</tr>
<tr>
<td>Speech and language therapist</td>
<td>Speech or communication issues; swallowing problems.</td>
<td></td>
</tr>
</tbody>
</table>
How the MND Association can support you

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

**MND Association website**
Access information for care workers on our website at [www.mndassociation.org/careworkers](http://www.mndassociation.org/careworkers)

**MND Connect**
Accredited by the Helplines Standard, MND Connect offers information and support, and signposting to other services and agencies.
Main contact number: **0808 802 6262**
Email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

**Information resources**
We produce high quality information resources for professionals who work with people with MND. We also have a wide range of resources for people living with and affected by MND.

You can order copies from MND Connect, or downloads of most of our publications are available from our website at [www.mndassociation.org/publications](http://www.mndassociation.org/publications)

**MND Association membership**
Join us now and help fight MND. Membership costs £12 for individuals. It is free for people with MND and for carers, spouses or partners of people living with MND. Call **01604 611855** or email [membership@mndassociation.org](mailto:membership@mndassociation.org)
MND support grants and equipment loan
Where statutory funding or provision has been explored but is not available, we may be able to provide a support grant or equipment loan. Referrals for this support need to be made by a relevant health or social care professional. For enquiries about MND support grants or equipment loan, call the MND Support Services team on 01604 611802, email support.services@mndassociation.org or visit www.mndassociation.org/getting-support

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

Research into MND
We fund and promote research that leads to new understanding and treatment and brings us closer to a cure. Contact the Research Development team on 01604 611880 or research@mndassociation.org Visit www.mndassociation.org/research for more information.

Local support
Regional care development advisers
Our network of regional care development advisers (RCDAs) have specialist knowledge of the care and management of MND. They work closely with local services and care providers to ensure effective support for people affected by MND, provide education for health and social care professionals in MND, and are champions at influencing care services.

MND care centres and networks
We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist clinical expertise from diagnosis onwards.

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

Association visitors (AVs)
Association visitors are volunteers with experience of MND who provide one-to-one local support to people affected by MND.
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**
Swallowing problems.

**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.

**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. In the UK, there are two main MI:E devices used: the NIPPY Clearway and the CoughAssist E70.

**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.

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

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

What is your profession or specialism?

__________________________________________

Did you find this resource useful?

☐ Yes    ☐ Somewhat    ☐ Not really    ☐ No

Please explain your answer

__________________________________________

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

☐ an increased understanding of their symptoms
☐ an increased understanding of their condition
☐ more independence
☐ an increased ability to raise awareness of their needs
☐ more confidence
☐ improved quality of life
☐ a greater ability to maintain dignity

Continued overleaf
Feedback form continued

Were there any particular topics that were useful to you?

________________________________________________________________________

________________________________________________________________________

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

________________________________________________________________________

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

________________________________________________________________________

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

☐ Yes (please include your email address below)  ☐ No

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

☐ Yes (please include your email address below)  ☐ No

Please return your completed form to:
Education and information team
MND Association
PO Box 246
Northampton NN1 2PR

Name:

Email:
Acknowledgements
Thank you to the following people for their valuable contributions to this booklet:

Katy Harrison, End of Life Care Facilitator, City Care Centre, Peterborough

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Nicky McGreavy, Specialist Neurology Nurse, Suffolk Community Healthcare

Steven Rawson, Professional Carer

Barbara Strevens, Occupational Therapist, MND Service for Leicester, Leicestershire and Rutland, LOROS Hospice

If you’d like to help us by reviewing future versions of this or other resources, please email us on infofeedback@mndassociation.org

Please also use this email address if you would like to receive the list of evidence sources used to create this document.
About us
The MND Association was founded in 1979 by a group of volunteers with experience of living with or caring for someone with MND. Since then, we have grown significantly, with an ever-increasing community of volunteers, supporters and staff, all sharing the same goal – to support people with MND and everyone who cares for them, both now and in the future.

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

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

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

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

About MND
• MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
• It attacks the nerves that control movement so muscles no longer work. MND does not usually affect the senses such as sight, sound and feeling.
• It can leave people locked in a failing body, unable to move, talk and eventually breathe.
• It affects people from all communities.
• Some people may experience changes in thinking and behaviour, with a proportion experiencing a rare form of dementia.
• MND kills a third of people within a year and more than half within two years of diagnosis.
• A person’s lifetime risk of developing MND is up to 1 in 300.
• Six people per day are diagnosed with MND in the UK.
• MND kills six people per day in the UK.
• It has no cure.