Occupational therapy for motor neurone disease
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?

You can 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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Royal College of Occupational Therapists

This guide has been endorsed by the Royal College of Occupational Therapists
Introduction

Motor neurone disease (MND) is a rapidly progressive and ultimately fatal disease that results in degeneration of the motor neurones in the brain and spinal cord.\textsuperscript{1} Although there is no cure for MND, occupational therapists have a crucial role to play in supporting people to adapt to changing symptoms of MND and have the best possible quality of life.

Care of people with MND requires up-to-date knowledge about the condition and the ability to manage its complexity, to anticipate change and provide timely interventions. This booklet provides an overview of MND and its effects, and the role occupational therapists can play.

Information for you
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
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

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What is MND?

Motor neurone disease (MND) is insidious in its onset and development. The initial stages, speed and pattern of progression can be variable. Not all symptoms necessarily happen to everyone, nor do they develop in the same order or progress at the same rate.\(^2\)

MND results in progressive muscle weakness and wasting, usually first affecting limbs, trunk or bulbar regions, without sensory disturbance. This can lead to decreasing mobility and postural changes. MND can affect adults of any age. However, incidence is highest in people aged 55-79, and onset below the age of 40 years is uncommon.\(^3\)

**Common initial symptoms**

MND can present as isolated and unexplained signs or symptoms, which may include:

- stumbling, falls or trips
- foot drop
- loss of dexterity
- weakened grip
- cramps
- fasciculations
- change in voice quality, such as quiet or slurred speech
- awareness of swallowing changes, such as having to ‘double swallow’
- muscle wasting.\(^3\)

**First symptoms may progress to:**

- loss of function of limbs
- weakness and wasting of muscles of the trunk and neck
- progressive weakness of bulbar muscles, leading to dysphagia and dysarthria, affecting speech, eating and drinking, and clearance of thin or thick tenacious saliva\(^3\) or mucus.\(^4\)

Respiratory muscles are likely to be involved later in the disease, leading to breathlessness and signs such as daytime sleepiness, fatigue, morning headaches or shortness of breath when lying down.\(^3,5\)
Up to half of all people with MND experience some degree of cognitive or behavioural change, ranging from mild effects to noticeable impairment, and up to 15% will develop frontotemporal dementia (FTD).³

As an occupational therapist, it is vital to consider that most people with MND will become increasingly dependent upon others and equipment as the disease progresses.⁶

**Additional symptoms**

- fatigue – this is common throughout the disease⁷
- difficulty managing secretions, including saliva
- emotional lability – inappropriate or excessive crying or laughter⁸
- anxiety and depression⁹
- pain and discomfort from muscle cramps or spasticity¹⁰
- insomnia⁵
- constipation.¹¹
**Prognostic factors**

A third of people with MND die within a year of diagnosis and more than half die within two years. It is well recognised that some individuals live considerably longer than the average survival times.

Cause of death is almost always respiratory failure as a result of muscle weakness and/or repeated chest infections, often due to aspiration.\(^1\)

The following factors, if present at diagnosis, are associated with shorter survival:

- speech and swallowing problems (bulbar presentation)
- weight loss
- poor respiratory function
- older age
- lower Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS or ALSFRS-R) score\(^{20}\)
- shorter time from first developing symptoms to time of diagnosis.\(^3\)

**Variants of MND**

MND is the term used in the UK and Australia to denote various diseases of the motor nerves, classified by whether they affect upper motor neurones (UMN), lower motor neurones (LMN) or both. There is considerable overlap between the different forms of MND.

Clinical presentation is sub-divided in two ways: by the presence of upper motor neurone (UMN) and/or lower motor neurone (LMN) signs, and the anatomical area first affected.\(^{12}\)

- Limb-onset MND affects around two-thirds of people with MND.
- Bulbar-onset MND affects around a third of people with MND.
- Respiratory-onset is rarer, affecting around 3%.\(^{12}\)

It is important to be aware of the presentation and prognosis of the disease in order to plan and anticipate a person’s needs.
Amyotrophic lateral sclerosis (ALS)\textsuperscript{11}

- most common form, accounts for over 80% of cases of MND
- characterised by a combination of muscle wasting with spasticity
- arm, leg or bulbar (speech and swallowing) onset
- bulbar region is usually affected, but may not be prominent in everyone with ALS.

Note: In some cases, people initially present with features of primary muscular atrophy (PMA) or primary lateral sclerosis described below, but go on to develop more typical ALS.\textsuperscript{12}

Progressive muscular atrophy (PMA)\textsuperscript{12, 13}

- accounts for 5-10% of people with MND
- limb onset, with muscle wasting and weakness, often with visible twitching or rippling under the skin, known as fasciculations
- ‘flail arm’ falls within this group, characterised by slowly progressive, symmetrical, and usually upper limb weakness
- survival is often longer than seen in ALS, typically more than four years. If someone presents with a single flail arm or leg, survival is often five to 10 years or more from onset.
 Primary lateral sclerosis (PLS)\textsuperscript{2,12,14}  
• accounts for approximately 3% of all people with MND
• characterised by spasticity/brisk reflexes
• balance is often impaired
• survival is notably longer - more than 10 years from symptom onset, with many people living a typical lifespan
• some people with PLS may experience bladder involvement, in the form of spasms and urinary urgency.

Progressive bulbar palsy\textsuperscript{2,11}  
• a term used to describe bulbar onset MND
• accounts for approximately 5% of cases of MND
• a small number of people with bulbar-onset MND have symptoms relatively confined to the bulbar region for several months (occasionally years), before it moves to involve the limbs
• muscles in the upper limbs, neck and shoulder girdle may become progressively weaker
• characterised by rapidly progressive speech and swallowing problems, often with emotional lability.

Kennedy’s disease\textsuperscript{37}  
Although it is not a type of MND, the MND Association also provides support for Kennedy’s disease, which causes progressive weakening, wasting of the muscles and hormonal changes. The principles in this guide may still be applicable, however it is worth noting that the disease progresses more slowly and most people with Kennedy’s disease live an average life span.

Information to share  
Information sheet 2B - *Kennedy’s disease*  
Information sheet 2C - *Primary lateral sclerosis*  
Information sheet 2D - *Progressive muscular atrophy*  

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Multidisciplinary teams for MND

The NICE Guideline on MND recommends that care should be delivered by a coordinated multidisciplinary team (MDT) with expertise in MND. This way of working allows prompt referrals to other relevant health and social care professionals as needed.\(^3\)

The MDT should be responsible for assessment, management and review of:

- weight, diet, nutritional and fluid intake, feeding and swallowing
- muscle problems, such as weakness, stiffness and cramps
- physical function, including mobility and activities of daily living
- saliva problems, such as drooling of saliva (sialorrhoea) or thick, tenacious saliva
- speech and communication
- cough effectiveness
- respiratory function, respiratory symptoms and ventilation (NIV)
- pain and other symptoms, such as constipation
- cognition and behaviour
- psychological support needs
- social care needs
- advance care planning and end of life care needs
- information and support needs of the person, their family and carers.\(^3\)

An occupational therapist should be part of the core MDT, but may also be a member of a team the specialist MDT accesses. This may include specialist palliative care and hospices, social services, orthotics, rehabilitation, wheelchair and assistive technology services.\(^3\)

Occupational therapists supporting people with MND should aim to:

- liaise with occupational therapists in different settings, particularly to avoid repeat assessments
- liaise with professionals from other disciplines to ensure integration of systems, for example, wheelchairs with AAC devices and environmental control systems
• coordinate visits with other professionals where possible
• signpost the person, their family and carers to relevant services.

Information for you
Multidisciplinary team working for MND

Information to share
Information sheet 1A - NICE guideline on MND
What you should expect from your care - a pocket-sized booklet to help people with MND have discussions about the treatment and care recommendations from the NICE guideline on MND.

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org
The principles of occupational therapy for MND

In order to help the person with MND to participate in occupations that are important to them and their family, the occupational therapist should consider assessing and advising on, among other things:

- optimisation of meaningful activities of daily living, and what is important to the person
- maintenance of social and leisure activities for as long as possible
- modification of the home environment to take account of declining function and mobility and occupational performance
- raising awareness of safety
- posture and positioning
- fatigue management and conservation of energy
- psychological strategies
- self management
- avoiding undesired hospital admission
- use of adaptive equipment, include potential future needs, allowing this to be planned and organised ahead
- facilitation of meaning, quality of life and well-being
- providing support around physical, emotional and spiritual issues
- promoting a positive approach to death.

Equipment may include aids to support personal care, posture and mobility. This may include specialist head and neck supports, static seating and wheelchairs, mobile arm supports, switches and other devices for accessing computers and using environmental control systems. See Providing support on page 20 for more information.

Occupational therapists can:

- maximise functional abilities as far as possible to minimise the impact of MND on activities of daily living
- help the person adjust to changing roles
- facilitate the realisation of meaningful goals
• offer person-centred assessment and intervention
• explore and trial strategies to enable choice and control
• facilitate exploration of future needs so interventions, adaptations and equipment can be implemented in a timely manner
• support people with MND and their families to express choice, have control and develop goals together, helping people to redesign their lives and life goals
• explore interventions, equipment and strategies to address physical and psychosocial problems to enhance participation in everyday activities
• support people with MND to achieve good quality of life in a holistic way throughout the course of the disease (from diagnosis to death)
• support family and carers, throughout the course of the condition, and in bereavement, where possible. It is important to identify what is important to them and how this may vary from what is important to the person with MND to ensure they are both supported.

By exploring and offering possible solutions, the person is offered:
• support to adapt to changing symptoms
• maintenance of occupational participation and quality of life
• choice and control.
Promoting choice and control

People with MND have described living with the condition as experiencing a ‘series of losses’, including the loss of future plans and hopes, abilities, independence and control over their life.

As occupations shape our identity, feelings of self-worth and connect us with people, occupational therapists can use occupations as a vehicle to help someone exercise choice and control in their lives.

Occupational therapists should not have to give or explain a diagnosis of MND, as this is the role of the specialist neurologist. However, the occupational therapist will be able to explore the impact of living with the disease with the person with MND.

They can explore losses experienced and facilitate future planning to minimise the impact of further deterioration.\(^{15}\)

The occupational therapist may have to address difficult questions as the disease progresses. The person with MND may ask questions such as “When will I have to use a wheelchair?” or “When will I stop being able to manage the stairs?” It is important to answer these questions openly and directly. This booklet may help you provide appropriate guidance.

Discussions about potential difficulties before they become an issue can help to reduce delays in accessing equipment and support.
Assessment and outcome measures

Occupational therapists use a range of frames of reference and theoretical models to guide and underpin their practice. Use of a model can indicate appropriate assessments and outcome measures to use.

The NICE Guideline on MND recommends repeated, ongoing assessment and review, and continuity of care, as the disease can progress quickly.

Timely, holistic assessments, covering physical, psychological, emotional, social, spiritual and financial needs, are essential for creating and reviewing comprehensive care plans for a person with MND.

Occupational therapy is client centred and it is important that a person and the person’s family and carers, identify their own goals and priorities. It is important to recognise that these may not be the same and the OT is key in supporting people to make informed choices about their ongoing management of MND.

Selecting an appropriate assessment tool

The focus for any occupational therapy assessment is to analyse the person’s strengths, skills and needs in carrying out occupations, and how the environment supports or inhibits this. Assessment should anticipate future needs as much as the presenting ones.

Adapting assessments, tools or outcome measures reduce their validity or reliability, and as such standardised assessment tools should not be adapted or changed.

Alongside occupational therapy assessments, practitioners should be aware of, and where possible, select tools that have been specifically designed for MND.

When selecting an assessment tool, consider:

• information already gathered from previous assessments
• reason for referral
• expectations of the person and their family
• the purpose of the assessment.
The assessment process
Assessment needs to be holistic and timely. Within the assessment process, occupational therapists should:

- consider all areas of needs, functions and domains
- establish a list of main concerns, anticipated future needs and prioritise goals
- be mindful of the type of MND and likely rate of progression
- anticipate future needs based on diagnosis and what is important to the person
- consider the key impairments and occupational difficulties, as well as identifying existing strengths
- consider the potential impact of cognitive or behavioural changes, both on the assessment and any interventions suggested
- consider the person’s insight into their current strengths and weaknesses and how this may affect their judgement and safety
- discuss functional ability and roles
- consider activity analysis and observations
- allow sufficient time for the individual to discuss difficulties, taking into account any communication or cognitive needs, and fatigue. Assessments may need to be completed over several contacts
- consider the person’s response to their diagnosis and their acceptance of interventions, recommendations and involvement of specific services
- be aware of local support services and charities available to the individual and carer, and make early referrals to them
- involve other professionals as needed throughout the disease course
- arrange regular reviews of the person’s ability and carers’ needs
- identify whether a welfare benefits or financial check is required, and refer to appropriate support.
Carer and family needs

The assessment should acknowledge and address the needs of the person with MND, their carers and family, including children. This can help to build a relationship with those who may be the person’s primary means of support. The occupational therapist should consider:

• immediate needs and anticipate future needs
• a plan for introducing support for the carer and person with MND
• intervention to ease burden of care as far as possible
• early identification of potential risks which could lead to breakdown of care and implement plan to help prevent this
• discussions about agencies to support the carer as necessary, for example counselling, psychology, GP or our MND Connect helpline (see page 2 for contact details)
• asking the carer if they want to be referred for a carer’s assessment.

Information for you
Supporting children and young people close to someone with MND

Information to share
Caring and MND: support for you - our main guide for carers
When someone close has MND - our activity workbook for 4-10 year olds
So what is MND anyway? - our guide for teens.
MND Buddies - our online activity hub for young children - visit www.mndbuddies.org
Storybook - Why are things changing?
Information sheet 10G - Support for families with children
Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org
Sharing information after assessment
Systems need to be in place to ensure all relevant health and social care professionals can access current information about the person’s needs, preferences and advance decisions.

Practitioners should be aware of the involvement of other occupational therapists and avoid replicating assessments unnecessarily, in line with any local information governance policies that apply.

Review
MND is a progressive condition, so ongoing, regular review should be built into any service provided.

The NICE Guideline on MND advocates regular, ongoing monitoring of the person’s mobility and daily living needs and abilities. Equipment, adaptations, daily living aids, assistive technology and wheelchairs must be regularly reviewed and updated to meet the changing needs of the person with MND, their family and carers.3

A person’s needs may change rapidly, and the NICE Guideline on MND recommends that untimely case closure should be avoided. It is important for continuity of care that the same health care professionals stay involved with a person’s care throughout the course of the disease. This helps build relationships between the person, their family and the therapist, and also promotes seamless care and interventions.

Use of outcome measures
Any intervention plan arising from the assessment should have clear outcomes. Outcome measures should be used to:

• promote wellbeing, by identifying and measuring what the person with MND considers important in their lives
• record progress towards meeting the person’s goals, including the actions of the occupational therapist(s)
• measure the effectiveness of intervention.
The use of standardised outcomes can be challenging. It can be difficult to provide meaningful outcome measurements when the disease may be progressing rapidly. People with MND are adjusting continually to changing symptoms and level of disability, so their experience of MND and what is important to them is individual.

Research has shown little correlation between perceived quality of life and severity of illness, so any outcome measures should aim to capture and measure what is important to the person and their family.

**Useful resources**

**ALSFRS-R**
The Revised Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS-R) is a tool for evaluation of functional status and change in people with MND. Research has shown that ALSFRS-R scores correlate significantly with quality of life scores in MND. Visit [https://pubmed.ncbi.nlm.nih.gov/10540002](https://pubmed.ncbi.nlm.nih.gov/10540002) for more details.

**The Allied Health Professions (AHP) Outcome Measures UK Working Group**, a cross-disciplinary group representing a number of professional bodies including Royal College of Occupational Therapists, has developed a checklist, *Key questions to ask when selecting outcome measures: a checklist for allied health professionals*. It is designed to assist allied health professionals and teams with selecting outcome measures. The checklist is intended to guide discussions and support decision-making. It contains some key questions to ask when considering which outcome measure is most suitable for your area of practice. The checklist is available to download from [www.rcslt.org/outcome-measures-checklist](http://www.rcslt.org/outcome-measures-checklist).

**NICE Quality Standard on MND (QS126)**
The NICE Quality Standard on MND draws attention to specific, measurable aspects of good care for MND, allowing health and social care professionals to assess whether they have the structure and processes in place to meet them. Visit [www.nice.org.uk/guidance qs126](http://www.nice.org.uk/guidance qs126).
Providing support

Occupational therapists should proactively anticipate what equipment and adaptations may help to enable the person with MND to participate in valued occupations.

Timing of interventions

MND is rapidly progressive. The NICE Guideline on MND recommends provision of equipment and adaptations that meet the person’s needs without delay, so that people can participate in activities of daily living and maintain their quality of life as much as possible.\(^3\)

In order to reduce any potential delays, the guideline advocates anticipating and planning for potential future needs, to allow enough time for support or equipment to be put in place.

Service delivery models should enable prescribing of equipment that may fall outside of standard eligibility criteria to ensure maximum benefit of any equipment provided.\(^3\)

Although anticipatory prescribing is ideal, this should be done in partnership with the person and their family to avoid causing any potential distress.

Psychological impact of interventions

Occupational therapists should talk through assessment findings and recommended interventions, but be mindful that people living with MND and their families may not agree with those recommendations.

People may be resistant to the idea of using equipment, as they are reluctant to acknowledge increasing disability and progression of the disease. Where someone has reducing independence in activities of daily living, they may exercise control over their situation by declining assistance, such as care or equipment.\(^15\)

It is important that the occupational therapist establishes a rapport with the person with MND, their family and carers. This will help to facilitate discussions involving functional loss and future planning to minimise crisis situations occurring.
Without appropriate and timely intervention, someone experiencing deterioration may find their independence and activities restricted, leading to feelings of despair and frustration. For further information, see also *Social and psychological support* on page 67.

**Information to share**

*Making the most of life with MND* - focuses on how people can continue doing the things they want to do.

*Emotional and psychological support* - includes how to seek support and the different therapies available.

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**What can the occupational therapist do?**

Occupational therapists should work with the person to fully explore the benefits and potential problems of using a piece of equipment, to ensure the person can make an informed decision about whether to accept it or not.

Explore with the person what it is about the activity that they can no longer do that they got pleasure from, so an alternative occupation can be found which meets the same needs.

Ensure all possibilities and ideas are explored, without being influenced by what is available through statutory services alone. Some people may be able to fund solutions that would not be possible through statutory services, and so it is important to explore these options to enable the person to make a fully informed choice.

Listen to the person’s reasons for refusing the equipment and acknowledge these, whilst making recommendations for intervention. Remember that the pace and manner of acceptance of the diagnosis and prognosis of MND will differ for every person.

It is best to have an open door policy so the person can contact you when they are ready to accept help, or need further assistance.
It is important to consider the impact of providing equipment on how a person feels about their home, and how they interact with their family within their home. Creative solutions may be required when considering particular types of equipment.

**For example:**

<table>
<thead>
<tr>
<th>Possible barrier</th>
<th>Potential solution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adaptations that change the look of the home, associating it with disability</td>
<td>Consider blending a ramp into the existing property rather than using an obvious metal structure. Encourage the person to consider their enhanced independence as a result of adaptations.</td>
</tr>
</tbody>
</table>
| Single profiling beds affect intimacy and maintenance of emotional and physical connection between couples.  
20 | Is a direct payment available for a double bed where one side has profiling features? Alternatively, consider a single profiling bed alongside a standard single bed. It is worth noting that double profiling beds can potentially prohibit care if two carers are required, as only one side of the bed is easily accessible. |
| Resistance to living on a single level of the home                              | Interim hired stairlift while the person is able to safely use one and continue to plan for the future. Discuss positives such as being able to go outside, if downstairs. |

**Information to share**

Information sheet 11C - *Equipment and wheelchairs*

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Mobility

MND is characterised by progressive muscular weakness and most people with the disease will eventually be affected by reduced mobility. However the speed and pattern of progression is variable. Those with bulbar-onset MND may retain independent mobility for longer, although prognosis is often poorer, with more rapid progression.

Within the occupational therapy assessment, a need for further input from a physiotherapist, orthotics or a wheelchair service may be identified. Common reasons for further input include footdrop, falls or enhancing gait.

Exercise

Active or passive exercise, as recommended by a physiotherapist experienced in neurological conditions, can help a person with MND maximise their range of movement and mobility and help to maintain good balance and posture.

Equipment

When first experiencing problems with mobility, people with MND may use walking aids such as sticks, frames and rollators to support walking. Grab rails can help with mobility within the home or where a stick or frame cannot be used. However, progressive weakness in upper limbs and trunk will limit how long these are useful.

Wheelchairs

As MND progresses, most people will need to use a wheelchair. Initially this may be to aid energy conservation, but over time, dependency on a wheelchair for mobility tends to increase.

It is important that a person with MND has a holistic wheelchair and seating assessment as early as possible.

This should account for the progressive nature of MND and determine what will best suit the person’s changing needs. For example, someone may be able to manage standard wheelchair control initially, but as MND progresses, they may not be able to use this.
It is important to consider all the possible symptoms of MND. For example, if someone experiences cognitive change, this may affect their ability to operate a powered wheelchair.

A timely referral to wheelchair services is critical. This will ensure that the service can work with the person with MND and other agencies to ensure wheelchair access is being considered at the person’s home and that they can come to terms with the type of wheelchair they will need.

The NICE Guideline on MND recommends that, if needed, people with MND should be referred to wheelchair services without delay, followed by assessment and provision of a manual or powered wheelchair that meets the person’s ongoing needs.\(^3\)

The MND Wheelchair Pathway focuses on the provision of wheelchairs in a timely way and to a specification to meet the users ongoing needs. The challenging changing nature of MND means that equipment needs to be provided in at an appropriate time. The wheelchair also needs to be able to adapt to the changing needs of the user and it is essential that the user and carers are able to use the equipment properly. As with all equipment provided, ongoing review of its use and suitability is essential.

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**Information for you**

*Wheelchair Pathway for MND*

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**Transport**

Larger manual and electric powered indoor/outdoor wheelchairs (EPIOC) are difficult or impossible to transport in an unadapted vehicle.

Boot hoists may be appropriate for some vehicles but will require folding or removal of the chair backrest. This option requires the person living with MND to transfer into the car seat, and so its effectiveness may be time limited.
A wheelchair accessible vehicle (WAV) enables the wheelchair to be driven into the vehicle and allows the user to travel while seated in the wheelchair. A WAV may be available through the Motability scheme if the person is eligible. There are also wheelchair accessible hire cars and taxis. See *Driving* on page 53.

**Information for you**
Information sheet P2 – *Wheelchairs for people with MND*

**Information to share**
Information sheet 11C - *Equipment and wheelchairs*
Information sheet 12A - *Driving*
Information sheet 12B – *Choosing the right vehicle*
Information sheet 12C – *Travel and transport*

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**Specialist MND wheelchair services**
The MND Association funds specialist therapists who may be able to provide support to local wheelchair services through training, joint assessments, advice and support to find the right wheelchair solutions for people with MND.

If the person with MND experiences problems accessing a specialist assessment or obtaining an appropriate wheelchair, please contact MND Connect. See page 2 for contact details.
Posture and positioning

As MND progresses, mobility and comfort can become more difficult to manage. Changes in muscle activity, including possible cramps and spasticity, will affect alignment and the response of the body to movement, sitting and lying. If a body segment is falling in a certain direction due to weakness, gravity will exacerbate the effect, also pulling the body segment in this direction.

Some people with MND may initially experience weakness in their shoulders, arms and hands. This is often referred to as ‘flail arm’. Due to muscle weakness and the weight of the arms in the arm and shoulder joints, there is a risk of partial dislocation (subluxation) of the shoulder joint. It is essential that people are advised on positioning and assisting movement.

Consider:

- the carer supporting the arms when moving
- the person having their arms supported, either by armrests or with pillows/cushions while seated
- referral to orthotics for shoulder or arm support
- complementary therapies, such as massage and acupuncture.

Weakness in the neck and upper back muscles can cause head drop. Weakness in the trunk can cause a person to slump or slide forward in a chair.

Seated posture

As MND progresses, the person will spend more time sitting and will be less able to adjust their own position or stay upright against the effects of gravity.

Inadequate support can lead to poor posture, affecting function and distribution of weight, which may lead to pressure sores. This can be further affected by neck and trunk weakness, and potential curvature of the spine (kyphosis).

The preferred position for someone with neck weakness is tilted back, with their arms, back, head and neck supported.
The aim is to support posture to maximise function, while minimising risk of deformity and pressure injury. This may be achieved with seating with greater postural support, including a backrest shaped to the spine.[23]

Options may include:

- a posturally supportive armchair
- a riser/recliner chair with a waterfall type back to support the neck and lumbar region of the spine
- more supportive seating if indicated following assessment
- tilt-in-space wheelchairs, offering more gravity assisted postural correction (see pages 23-24)[23]
- separate back rest and seat adjustments for posture and comfort
- wide arm rests with pressure relieving qualities
- wheelchair head supports.

**Pressure sores**

Risk factors for pressure sores in MND:

- reduced ability to move and therefore relieve pressure in seating
- poor posture in sitting resulting in loading over a small area, which results in higher pressure over the supporting area
- sliding forward on the seat (which can result from trunk weakness where tilt in space is not used) resulting in shear forces over the buttocks
- inadequate seating (including shower / bathroom chairs) which do not accommodate or support postural limitations
- loss of soft tissue mass resulting in vulnerable bony prominences
- inadequate nutrition and weight loss due to swallowing problems.[23]

Consider:

- people with MND retain sensation, so will know when they need to move, or need help to be moved
- those with communication difficulties may not be able to express that they want to be repositioned
• appropriate cushioning for seating and wheelchairs to provide pressure relief
• seating (including shower and bathroom chairs) that accommodates and supports postural limitations
• use of barrier creams.

Head and neck support

Head drop can result from weakness in the neck, shoulder girdle and long back extensor muscles, leading to difficulties with correct positioning for speaking, breathing and eating.

A tilt-in-space feature on a wheelchair or riser recliner armchair, and lateral tilt on a profiling bed, can help to counter the effects of gravity and help keep the trunk and head in a more upright position. Seating backrests should accommodate the shape of the spine to enable the head to be supported.

It is important to have adequate arm support, as the weight of the arms can pull the upper body forward and exacerbate curvature of the spine. Supporting the arms can also help open the chest cavity to aid respiration.
There is not one type of support that will be suitable for everyone with MND, and different ones may need to be trialled before finding the right one. Sometimes, a combination of collars will be required for different situations.

Many people will choose not to wear their collar all the time. Because MND is progressive, needs will change over time, making ongoing reassessment essential. A simple, soft collar may be tried as a first step in the early stages of neck weakness, and may be used as an interim measure until a collar providing more support is required.

A range of supports are available for wheelchairs and these should be considered alongside the postural support gained from the wheelchair.

People living with MND retain sensation, so can experience discomfort associated with immobility. It is therefore crucial that a collar fits correctly and does not create pressure points.

Forehead bands give freedom around the chin, mouth and throat, making it easier to eat, drink and speak, but may place too much pressure over the forehead.

Many people with MND experience swallowing problems as a result of bulbar weakness. A collar with an anterior area cut away may make swallowing easier.

Practical solutions, such as a roll of foam under the chin with a Velcro fastening, can offer some relief in certain circumstances. Use these solutions with caution and only after conducting a full risk assessment. Seek advice from a second occupational therapist to ensure suitability.

Information for you
Information sheet P1 - Head supports

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

Contracture can result from muscle weakness and the inability to move joints through a full range of movement. In addition, upper motor neurone lesions can result in spasticity, decreasing range of movement and pain.

To help maintain a level of function and independence in joints, and in muscles unaffected by MND, length and range of movement must be maintained to limit the adverse effects of stiffness.\(^{25}\)

Where appropriate, splinting may be used to provide a prolonged stretch, and facilitate function through improved range of movement in joints. The NICE Guideline on MND advises referral for orthotic services to help with muscle problems.\(^3\)
Bed mobility

Issues may include:

- inability to lift legs into or out of bed
- difficulty sitting up from lying down
- difficulty turning in bed
- discomfort with increased loading through the shoulder and hip joints when people are lying on their sides, often worsened by a reduction in soft tissue
- pressure sores resulting from limited movement and inability to adjust positioning.

NHS provision is normally only available for the person living with MND so this will likely mean a single profiling bed.

It may be possible to access funding through direct payments or personal health care budgets which can enable a couple to purchase a double bed with independent variable tilt, which may be more acceptable to them. Another option would be to place a single profiling bed beside a regular bed of the same height.

Transfers

Depending on level of need, options may include:

- rails and bars to aid bed mobility
- low friction slide sheets (advise on nightwear to avoid excessive slide)
- a static or powered pillow lift
- raising a bed to allow clearance for a mobile hoist under the bed. This will also help with sitting to standing transfers
- a profiling bed, which can help with moving from lying to sitting, sitting to standing, or standing to sitting (with variable height).

See Transfers on page 34 for more information on safe moving and handling, including hoisting.
Pressure care
Consider:

• pressure relieving mattresses or mattress toppers
• avoiding memory foam mattresses, as the person sinks in and may find it more difficult to move
• a bed cradle to relieve the weight of bedclothes
• lightweight bed clothing
• an electric blanket in winter, with lighter bedclothes.

Supported positions to consider

Side Lying:
Rather than laying directly on one side, encourage a quarter turn on to the back, pulling the shoulder forward. You can support this position with a rolled pillow positioned behind the back (tucked under slightly to prevent it rolling out).

Place a pillow in between the thighs, knees and lower leg to reduce pressure and pull on joints.

Supine Lying (lying on back):
Place a pillow under head and shoulder.

Help flex the hips by placing a firm support under the knees to prevent sliding when the bed head is elevated.²³

Bed safety
Discuss the advantages and risks of bed rails and cot sides, if these are being considered. These are widely used to reduce the risk of falls, but may bring other risks, such as the person becoming trapped between the bars, or rolling over the top of the bar. The wide range of bed rails, beds, mattresses and other equipment in use, together with the person’s individual needs means a thorough risk assessment is essential.

Further information is available from Medicines and Healthcare Products Regulatory Agency at: www.gov.uk/guidance/bed-rails-management-and-safe-use
**Breathlessness**

Breathlessness on lying flat (orthopnoea) is often one of the first signs of respiratory insufficiency in MND. The person may wake with headaches or not feeling rested, and may feel tired during the day. Refer any change in symptoms to the person’s MND specialist or respiratory team.

Lying flat can worsen respiratory symptoms. A semi-reclined position is likely to be more comfortable for a person with MND, particularly those experiencing respiratory problems.

Consider raising the head with more pillows, a pillow lifter or a powered, profiling bed. Select one that provides variable tilt, reverse tilt positioning and auto-regressing head rests (eg four section profiling beds).

The bed should lift from the hip rather than the abdomen, which may further compromise respiratory function.

If non-invasive ventilation (NIV) is used, the person will most likely have to sleep on their back, with the head of the bed raised. Support under the shoulders, arms and legs is important.
Transfers

The NICE Guideline on MND recommends that the person with MND and their main carer and family should be given advice on safe manual handling. Transfer boards or belts, slide sheets and turntables may be considered while a person with MND is still able to weightbear. Transfer ability usually continues to deteriorate, as limb strength and function decline. Hoisting may be necessary as MND progresses.

Hoisting

By the time hoisting needs to be considered, the person with MND will have already experienced much functional loss. Accepting the prospect of hoisting can be difficult for some people. It is essential to provide the person with reassurance and time to consider the need for a hoist, in order to facilitate acceptance and allay fears.

For those with respiratory involvement in particular, posture and positioning is crucial, avoiding compression of the chest and torso. Full training for the person, their family and carers is critical, and may help to calm fears and improve confidence in hoisting.

A ceiling track hoist may be more suitable than a portable or fixed hoist as MND progresses, saving space and reducing manual handling. Hoist slings must be fitted to the individual, with the correct sizing specified in a hoisting plan.

A specific hoist may be required for bathing and toileting, as there is no clearance beneath a bath or toilet to fit a hoist. If a person has a stairlift, a hoist may be needed on each floor for transfers so the person can continue using it.

Getting up and down the stairs

Early discussion with the person with MND, their family and carers is essential to ensure a plan is in place for managing each stage of disease progression. It is important to discuss longer term plans for accessing facilities within the home earlier than the person may wish to think about it. Adaptations could take a long time and have costly implications if not planned in advance.
Consider how someone will be able to manage in the short, medium and long term. For example, a stair lift may enable someone to access upstairs for a period, depending on the rate of progression of MND. However, if there is no scope to use the stair lift in the long term, it would not be sensible to adapt a first floor bathroom. Consider how they will mobilise on each floor of the house.

Access upstairs may be provided by:

• handrails on both sides of the stairs – for as long as leg mobility and hand and grip strength are maintained
• a stair lift – although this may be a time limited option. As MND progresses, the person may find it difficult to transfer on and off the seat and maintain a safe posture when seated
• a through-floor lift will give wheelchair access on each floor, without having to transfer in or out of it. Assessment for suitability is needed, as not all homes can accommodate this option.

Information to share
Information sheet 11C - Equipment and wheelchairs

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

Bulbar weakness contributes to various respiratory complications, including increased risk of aspiration, weak cough and abnormal respiratory patterns.

Respiratory insufficiency usually arises late in the course of the disease, due to involvement of the diaphragm and accessory muscles. It is the usual cause of death in people with MND.

For some patients, breathlessness, reduced vocal power, poor sleep quality or daytime fatigue may be the initial presenting symptoms.

Rarely, patients are admitted via accident and emergency departments in respiratory distress without any other symptoms.

Monitoring for signs and symptoms

The specialist MND or respiratory team are responsible for the ongoing assessment and monitoring of respiratory symptoms. This allows for timely interventions that can improve or maintain quality of life. This may include non-invasive ventilation (NIV), which has been shown to improve survival and quality of life.

Any new or changed respiratory symptoms should trigger referral to the specialist team.

The occupational therapist can advise on:

- posture and positioning, including solutions to counter breathlessness on lying flat, or to ensure a slightly reclined position when seated
- fatigue management
- using fans and increasing air flow to reduce psychological feelings of breathlessness
- techniques and strategies to manage anxiety or breathlessness.

The MND just in case kit

The MND just in case kit is designed to hold medication for the relief of anxiety and breathlessness. Its presence in the home provides tangible evidence for people with MND and carers that fears have been addressed and practical help is at hand.
Once the need for a kit has been discussed and agreed with the person with MND and their carer, their GP orders a kit from MND Connect (see page 2) for a named person with MND. The kit is supplied free of charge. The GP prescribes medication to be supplied with the kit.

**Information for you**
- Information sheet P5 - *Managing respiratory symptoms in MND*

**Information to share**
- Information sheet 8A – *Support for breathing problems*
- Information sheet 8B – *Ventilation for MND*

Download from [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or contact MND Connect to order hard copies. Call 0808 802 6262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)
Cognitive change and frontotemporal dementia (FTD)

Through occupational assessments and observations, occupational therapists may notice changes in cognitive ability and recommend further assessment.

Occupational therapists should be aware of the potential for changes, query as necessary and make sure cognition is assessed. They can help to describe and explain the nature of the impairments and the implications of these on functional ability to the person and their family.

There is now increased awareness of cognitive and behavioural changes in MND, and people affected by the disease may fall into one of four groups:

- around 50% are unaffected by cognitive change
- around 35% experience mild cognitive change, with specific deficits in executive functions, language, behaviour and/or social cognition
- up to 15% develop frontotemporal dementia (FTD), either at the same time or after diagnosis of MND
- up to 15% of patients with FTD go on to develop motor impairments where MND is diagnosed after dementia.

Keep in mind that up to half of people with MND will experience some degree of cognitive change. Changes may be subtle or more noticeable and may cause problems with:

- learning new tasks, including the use of equipment (such as powered wheelchairs or environmental controls)
- lack of awareness or insight into their problems or their impact
- poor concentration
- inappropriate social behaviour
- impulsivity, which can include repetitive or persistent actions and a tendency to consume sweet foods
- literacy and language
- making decisions, reasoning and problem solving
• planning for the future
• managing affairs and finances
• inflexibility in thought or how activities are undertaken. Others may perceive this as stubbornness.

Not all of the above may be evident and they can vary in degree. Changes can be subtle and may be masked by movement and speech problems. Some may be part of the normal ageing process.

**Information for you**
*Cognitive change, frontotemporal dementia and MND*

**Information to share**
*Changes to thinking and behaviour with MND*

Download from [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or contact MND Connect to order hard copies. Call 0808 802 6262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)
Screening for cognitive change
Occupational therapists may take a role in screening for signs of cognitive and behavioural change using the Edinburgh Cognitive and Behavioural ALS Screen (ECAS). Other screening tools are available, but ECAS has been specifically designed for use with people with MND. It can be used by any trained health or social care professional. The training and the ECAS tool are available at: http://hdl.handle.net/1842/6592

Where indicated, refer to a clinical psychologist for a full assessment and advice on management. Alternatively, liaise with the person’s consultant.

Impact on occupational therapy interventions
Being alert to the possibility of cognitive and/or behavioural change at any stage of MND can be valuable, as these changes may impact on service use and decisions. Occupational therapists can advise on strategies and techniques to adapt to change, and how family and carers can support a person to remain engaged in daily living.

If someone is affected by cognitive impairment, management strategies should focus on forward planning and organising appropriate support for the person with MND, their families and carers.

If cognitive change has been identified, all members of the multidisciplinary team should be informed, allowing them to react and implement any changes needed in care planning.

Considerations:

• discussions around interventions and advance care planning should be started sooner rather than later, with additional support to aid and check understanding
• a speech and language therapist may avoid introducing complex communication options
• professionals may choose to give information that is easier to understand, or in a different format
• levels of support provided around the home may increase
• checks may be required to enable safety in the home – eg removing or locking away items that could be used inappropriately
• clinical neuropsychology services, where available, may be involved in care
• working with care providers to ensure carers are familiar with potential issues
• keep care teams small so that the person is confident in them and gets to know them and vice versa.

Ongoing reassessment of needs is essential. Cognitive or behavioural change may not affect daily life at first, but issues may emerge when the person faces new challenges and has to make significant decisions about their care.

**Emotional lability (pseudobulbar affect)**

Some people with MND experience laughter and/or crying at inappropriate times, which is difficult to control and may not reflect how the person is feeling. For example, someone may laugh at inappropriate times, such as at a funeral or when they experience pain.

This is an involuntary motor response, and is not related to, or a sign of, cognitive change.

Recognition that this is a symptom by the person with MND and the people around them can provide reassurance.

Not reacting to the emotional response can help to reduce the impact. For example, if someone is crying but not emotionally upset, it may be helpful to ignore it.

There is medication available that may help to treat this symptom. Refer to the specialist team.

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**Information to share**

*Emotional and psychological support*

Download from [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or contact MND Connect to order hard copies. Call 0808 802 6262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)
Communication

Weakness of bulbar and respiratory muscles leads to many people with MND experiencing slurred, quiet or complete loss of speech. Communication problems can also have a psychological impact, including isolation, frustration, increased fear and anxiety, low self esteem and loss of self determination.

Information for you

View our webpages at:
www.mndassociation.org/forprofessionals/dysarthria
Information sheet P10 - Voice banking

Information to share

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

Occupational therapists should work closely with the speech and language therapist assessing the person’s communication needs.

It is important to establish what strategies or equipment someone is currently using to aid communication, before exploring with the person their wants, needs, motivations and expectations of communication aids.

An occupational therapist may support communication with:

- seating, positioning, wrist, hand, finger, head and neck supports
- switches and pointers
- mobile arm supports
- tables to access communication aids
- equipment to support computer use for communications such as email and social media
- environmental controls.
Communicating with someone with MND

The following suggestions may already be familiar to occupational therapists who frequently work with people with MND and communication difficulties.

• Allow extra time to assess needs as it may take great effort for a person with MND to communicate.
• Find out how the person with MND prefers to communicate, and what equipment they like to use.
• Establish whether it is acceptable for you to complete their sentences.
• Find out whether the person uses a simple code for “yes” and “no”. This can be a movement of any part of the body, such as blinking.
• Using closed or direct questions can assist the conversation.
• Remember that unspoken communication is important.
• Ensure the person with MND is the focus of communication.
• Check back with the person on what you think has been said and admit when you do not understand.
• People may persevere with speaking and you may be unable to understand them. Sensitively encourage them to use another method to communicate to minimise their frustration and facilitate conversation.

Try not to:

• alter the rate or volume of your speech, unless the person with MND has asked you to
• finish the sentences of the person with MND, unless they ask you to, and avoid interrupting them
• use a family member or carer 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 take up time and energy
• ask open questions. Simple questions that can be answered with yes, no, or a single word are easier when speech is difficult.
**Digital communication**

As technology progresses, more people with MND are using apps such as Zoom, Microsoft Teams and FaceTime. Virtual appointments, check-ups and support groups are becoming increasingly common, and may be more convenient for the person with MND.

In addition to the communication suggestions on the previous page, the following may be helpful:

- Give your full attention, maintain eye contact, listen closely, as if you are in the room with them.
- Ensure you can see the person’s lips and can clearly hear them.
- Give the person plenty of time to respond.
- Accept any method of communication that they choose – some people will type in the chat box if they feel it is better, others write on paper and show it to the screen.
- If another person is on the call is helping the person to be understood, check first if the person with MND is ok with that, and then confirm that what was said by the other person is correct.
- It is good practice to find out ahead of time what AAC a person is using, and how it may be easier to use in a video call.
- Some AAC software allows the words / speech to be added into the video call from within the app – for example Grid 3 can connect to Skype or Microsoft Teams, and Predictable can connect to Facetime sessions.
- It is often possible to ‘cast’ a phone or a tablet screen to a video call. Check with the speech and language therapist or other team members if they have done this.
- Have a back-up, just in case the AAC device is not available – the person may also use a low-technology AAC system, or a carer may be able to help.
- Always consider what will happen if your connection breaks or the quality is not good enough.
- Some device speakers may not be loud enough. A bluetooth speaker can help.
**Augmentative and alternative communication**

Early referral to a speech and language therapist can ensure assessment of range of movement in lips, tongue and palate, and advice on strategies for communication and provision of augmentative and alternative communication (AAC).

The NICE Guideline on MND recommends the involvement of occupational therapists to ensure AAC equipment is integrated with other assistive technologies, such as environmental control systems and personal computers or tablets.³

**Voice banking**

Voice banking is a process that allows a person to record a set list of phrases with their own voice, while they still have the ability to do so. This recording is then converted to create a personal synthetic voice.

When the person is no longer able to use their own voice, they can use the synthetic voice on communication devices to generate an infinite number of words and sentences.

The voice created will be synthetic and not be a perfect replica of the person’s natural speech, but it will bear some resemblance. The speech and language therapist can assist the person to arrange this.

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**Information for you**

Information sheet P10 - Voice banking

**Information to share**

Information sheet 7D - Voice banking

Download from [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or contact MND Connect to order hard copies. Call 0808 802 6262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)
Fatigue management

Many people with MND experience fatigue, contributing to poor quality of life. It can affect people in different ways, but is usually experienced as an overwhelming tiredness that occurs gradually or suddenly, often not in proportion to activities being undertaken.

Signs of fatigue may include:

• prolonged exhaustion after physical activity or very little activity
• feeling tired on waking (note that this may be a sign of respiratory impairment)
• limbs that are heavy and difficult to move
• feeling too tired to carry out activities
• difficulty concentrating.

Cause of fatigue in MND

Fatigue appears to be experienced as an inability to sustain motor function and as generalised tiredness. It tends to worsen throughout the day and is only partially relieved by rest.\textsuperscript{26}

Increased muscle weakness, wasting and problems with mobility will lead to muscles tiring more quickly. This, combined with other metabolic changes, can lead to fatigue. People with MND may also experience fatigue due to other aspects of the condition:

• loss of physical function
• breathing problems or breathlessness. Carbon dioxide retention (hypercapnia) can result from weakened respiratory muscles and may contribute to feelings of fatigue
• sleep problems – because of breathing problems, difficulty with bed positioning and the psychological impact of MND.
• side effects of some medications, including riluzole, the only drug available for the treatment of MND in the UK
• low mood or depression
• low calorie intake and weight loss, resulting from swallowing problems, decreased appetite or other problems affecting nutritional intake.
Impact of fatigue

Fatigue, and the anticipation of fatigue, may affect a person’s motivation to continue with some of the activities of daily living. It can also be aggravated by stress, which may be triggered by the conflict between wanting to continue activities and finding it more difficult to do so.

If fatigue is not recognised, a person often experiences peaks and troughs in their ability to function. For example, when someone feels well they carry out lots of activity that results in feelings of extreme tiredness and fatigue, leaving the person needing to rest and be inactive for a few days in order to recover. Once recovered they feel well enough to engage in activity again.

Assessing fatigue

The Neurological Fatigue Index for MND (NFI-MND)\textsuperscript{26} is an eight-item fatigue summary scale, with separate scales for measuring fatigue experienced as:

- reversible muscular weakness
- feelings of low energy
- whole body tiredness.

The Index may be applicable when assessing a person’s balance of occupations. For further details, see: \url{http://medhealth.leeds.ac.uk/info/732/psychometric_laboratory/1493/scales}

Management of fatigue

Every person with MND has a different experience of the condition, so it is often not possible to predict the activities that will make them feel fatigued.

It is important to ensure MND symptoms and treatments are well managed. With all interventions, consider the balance between promoting independence, with subsequent effects on self esteem and dignity, against management of fatigue.
Occupational therapists may give advice on:

**Keeping a fatigue diary** – encourage the person to keep a log of how they feel after each activity. This may help to judge which activities leave them feeling fatigued and help them to plan their days.

**Energy conservation** – help the person to prioritise activities that mean the most to them and their quality of life, so they can preserve energy for those particular tasks or events.

**Accepting help** – encourage people to accept help for tasks that are less important for them to complete independently, enabling them to have the energy to do the activities that are most important to them.

**Prioritisation list** – when completing a list of tasks carried out during the day, it is helpful to encourage the person to rate the tasks in order of enjoyment and importance to them. This can aid the person to decide on tasks to delegate, do differently or do less frequently.

**Encourage flexibility** – in routines, but also in how long tasks take to complete.

**Regular rest breaks** – the person may want to consider incorporating regular rest breaks between activities and short naps, especially before going out, or planning rest days before important events.

**Travel** – getting around may require a lot of effort and be stressful and tiring for the person. Planning ahead will ensure more time is allocated to travelling, preventing the need to rush and allowing for breaks.

**Living environment** – assess and discuss the person’s living space in order to help them save their energy, considering grab rails, placement of chairs etc.

**Body temperature/clothing** – excessive heat can lead to tiredness, while coldness can cause muscles to feel stiff and tight. Layers of loose, lightweight clothing can provide insulation, but also be easily removed. See *Clothing* on pages 60-61.

**Modifying activities** – discuss changes to activities such as sitting down to complete chores, and taking time to complete tasks rather than trying to complete everything quickly.
Equipment – let the person with MND know about any equipment or other solutions that may help with conservation of energy, for getting around, eating and drinking, using the toilet and bathing and showering, for example wearing a towelling robe to dry the body.

Sleep – advise on sleep patterns and techniques to ensure a better night’s sleep, and ensure symptoms are managed eg respiratory problems, muscle cramps and spasticity. A profiling bed may make breathing and positioning easier at night. See Bed mobility on page 31.

Some practical tips you can share with the person include:

- keeping organised, avoiding wasted energy searching for items
- sitting rather than standing where possible
- using an electric toothbrush or razor instead of a manual one
- wearing clothing that is easier to put on and take off
- resting before and after taking a bath or shower
- making larger meals and freezing extra portions for another day
- soaking dishes before washing and leaving them to dry on a draining board
- storing regularly used items in easy reach
- placing chairs around the house for rest
- pushing, sliding or rolling items, rather than lifting
- hiring professional help, such as cleaners or gardeners
- having groceries delivered.
Referral to other professionals will be required for management of:

**Nutrition and hydration** – losing weight can affect energy levels. A speech and language therapist may assess swallowing and discuss changes to diet consistency, while a dietitian can assess and advise on weight management, nutrition and hydration, including alternative feeding methods such as gastrostomy.

**Muscle cramps and spasticity** – muscular pain may disrupt sleep patterns. Exercise cannot reverse damage to muscles weakened by MND, but can help strengthen muscles not yet affected. Too much exercise can lead to additional fatigue. A physiotherapist can advise on exercise, and a prescribing professional may prescribe medication.

**Respiratory insufficiency** – the specialist respiratory team can assess symptoms and discuss options for management. A sleep study may determine whether disrupted sleep is a result of breathing problems.

**Medication review** – discussion will be needed on whether the benefits of medication to treat a symptom outweigh the side effect of fatigue. If the person is taking riluzole and experiencing extreme fatigue, withdrawal of the medication may be considered.

**Employment**

If a person is still working, fatigue may affect their ability to perform duties at work.

Employers have a responsibility to look at how MND affects how a person does their job and to allow flexible working or put measures in place to help them to carry on working for as long as the person feels it is possible. For further information see *Work* on page 54.

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**Information to share**

Information sheet 11D - *Managing fatigue*

Download from [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org
Driving

All people with MND are legally required to inform the DVLA or DVA immediately after diagnosis. Failure to do so is a criminal offence and the person could be fined up to £1000, or prosecuted if they are involved in an accident as a result of being disabled.

In most cases, they will permit the person to continue driving until weakness and/or cognitive change compromise safety. However, their driving ability may need to be assessed first. This can be a contentious issue, and needs to be handled with sensitivity.

Consider adaptations to a person’s existing vehicle that can facilitate continued driving or being a passenger, such as:

- driving controls, such as steering wheel aids, alternative hand and foot controls, infrared or wireless controls, easy release handbrakes
- access to the vehicle: swivel seats, transfer boards, hand holds, hoists and leg lifters
- wheelchair or scooter storage
- boot hoists or wheelchair accessible vehicles for drivers or passengers.

These options are at a cost to the individual and may only meet their needs for a short period. For example, a boot hoist still requires the person to transfer into the car. For those with slower progressing forms of MND, these options may be worth considering.

A wheelchair accessible vehicle (WAV) is the preferred solution for those not able to transfer easily in and out of a standard vehicle. New or second hand cars can be converted to WAVs, or these may be available as ready made options. Some companies have adapted cars or WAVs to lease.

Advise the person to consider a test drive and a driving assessment at a mobility centre. Visit www.drivingmobility.org.uk to find your local centre.

The person may be eligible for the Motability scheme. Bear in mind that a person applying for the first time will not be eligible if they are over 65 years old. Visit www.motability.co.uk for further information.
Information to share

Information sheet 12A - Driving
Information sheet 12B - Choosing the right vehicle

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

Taxis

Many taxi firms offer accessible vehicles that can accommodate a standard manual wheelchair. Finding a taxi able to carry a large electric wheelchair can be difficult. Taxi drivers will not accept passengers unless there is enough space between the top of the person’s head and the taxi ceiling.

Public transport

Using public transport can be challenging for someone with MND, but careful planning can make this easier. Advise the person to:

• plan their journey early
• consider all parts of the journey, including at departure and transfers
• discuss their needs with any travel agents, tour operators, transport organisations and accommodation they will be using
• make sure any equipment they are taking is in good working order
• allow extra time in case of any delays
• book any help needed in advance
• research the destination, and take contact details for local facilities such as pharmacies, wheelchair repair shops etc.

Information to share

Information sheet 12C - Travel and transport

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

A person who is working when diagnosed with MND may want to continue for as long as possible; others may want to plan their departure or leave straight away.

Leaving work may raise financial and emotional concerns. Work can provide a sense of purpose and social contact and leaving this behind may be difficult, especially as it is not necessarily out of choice.

If the role is stressful or physically difficult, leaving may be a relief. In the case of some physical jobs, it may not be possible to carry on working for safety reasons.

**If someone wants to stay in work:**

Certain tasks may be more difficult or take longer to complete. Fatigue may also be a factor. Talk to the person with MND about:

- adaptations to the work environment
- the Access to Work scheme - visit [www.gov.uk/access-to-work](http://www.gov.uk/access-to-work) for more information
- adaptations to tasks and exploring other ways of working
- equipment including assistive technology to support computer use
- changes in working hours or working from home.

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**Information to share**

Information sheet 10E - *Work and MND*

Download from [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or contact MND Connect to order hard copies. Call 0808 802 6262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)
Eating and drinking

Swallowing difficulties (known as dysphagia), saliva control, decreasing mobility and use of ventilation will affect the ability to prepare food, and to eat and drink. There are also social implications for those who feel self-conscious eating with others or in a social setting.

A dietitian should monitor the person’s weight and nutritional intake, working with a speech and language therapist to introduce a diet that maximises nutritional intake.

The specialist team should also discuss the potential for feeding via gastrostomy as soon as possible, as early placement is recommended.  

Early access to a dietitian may not be available in all areas, so the occupational therapist may need to consider weight and request urgent referral as needed.

The NICE Guideline recommends assessment and management of factors related to swallowing, eating and drinking that come under the responsibility of the occupational therapist. These include:

- positioning, seating and posture
- strategies for eating and drinking in social situations
- use of eating and drinking aids and adapted utensils
- advice and help with food preparation.

Posture

Consider:

- the position for eating – what type of chair, where table is in relation to the chair, and the distance between plate and mouth (how far they have to lift food to reach mouth)
- an upright posture and tucking the chin down to the chest when swallowing can prevent food aspiration
- head and neck supports, and how they can support or hinder eating and drinking (see page 28-29).
Equipment
Consider, where appropriate to the individual:

• non-slip mats
• keep-warm plates
• arm supports
• electronic feeders
• modified cups, mugs, plates and bowls
• straws with non-return valves
• modified cutlery to help with grip and control
• height adjustable table
• head and neck support to ensure an appropriate position for effective swallowing (see pages 28-29)
• drinking aids
• a portable suction unit to help clear the mouth of debris.

Information for you
Information sheet P8 – Dysphagia in MND
Information sheet P3 – Managing saliva problems in MND
Information sheet P9 – Oral suction

Information to share
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
Self care

Equipment and adaptations can maximise the independence of a person with MND, but as the disease progresses, they are likely to need support to manage their personal care.

The needs and preferences of the person with MND should be discussed, with information and support provided as needed.

Wherever possible, personal care should be carried out by familiar care workers, known to the person, their family and carers, ensuring continuity of care.³

Information to share

Caring for a person with MND: a guide for care workers
Information sheet 11C - Equipment and wheelchairs

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

As well as modifications to activities, occupational therapists may also consider equipment, such as:

• shower seats, and particularly tilt-in-space shower seats with head extensions for those with trunk weakness or respiratory insufficiency
• 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.

Even if not needed at first, it is important to consider the person’s long-term needs, allowing time for support, equipment or adaptations to be put in place.
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. Needs will progress over time, but suggest lightweight fabrics and looser fitting items that improve comfort and reduce frustration when dressing and undressing.

Advise on:

• 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
• items for protection and warmth when outdoors (eg quilted bags, capes, covers, hand muffs, to use with wheelchairs/scooters).

Consider:

• large neck openings and loose sleeves
• styles that allow for easy access to go to the toilet – refer to local continence service if needed
• 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.

Avoid:
• 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 – these 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, consider a foot-up device. If a person uses foot supports, footwear may need to be wider or larger than usual.

Information to share
Information sheet 11A - Clothing
Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org
**Toileting**

While MND rarely affects bowel and bladder function, immobility may affect the ability to get to the toilet in time, and loss of muscle activity can affect the strength required to defecate. People with MND may also be at risk of constipation due to other factors such as changes in eating, dehydration, anxiety or medication. It can be common for the person to sit on the toilet for a long time, so a suitable toilet seat is essential.

Maintenance of dignity and self-esteem are paramount. Consider aids to support independence:

- **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.

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

- **Catheterisation** - may be considered for some people with MND, in consultation with the specialist team. This is usually due to transfer difficulties. Occupational therapists may have to address transfer issues more effectively to help prevent the need for a catheter and avoid associated risks, such as infections.
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.\textsuperscript{28}

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.

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.\textsuperscript{29}

- 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
- a toothpaste that does not contain sodium laurel sulphate
- preventive treatment with fluoride gels (with cotton swabs) or mouthwash rinses.

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.

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 during brushing
- finger protectors may be used by carers assisting with oral hygiene.

Information for you
Information sheet P12 - MND information for dental teams

Information to share
Information sheet 11B - Mouth care

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

The NICE Guideline on MND recommends that the person with MND should have prompt access to assessment for home adaptation. Occupational therapists should proactively anticipate what equipment might be required to enable the person with MND to continue with valued occupations.

Any potential adaptations to the home environment should be considered well in advance to ensure time to implement recommendations and funding.

Environmental controls

Environmental controls can enable a person with MND to control electrical devices when they can no longer access them via the usual means (remote controls, door locks, telephone etc).

Environmental controls can offer independence with a range of activities including:

• operating a TV, radio and other electronics, eg computer
• making phone calls
• control fans or heaters
• answering the door
• adjust an electronic profiling bed
• call for assistance
• opening and closing curtains.

Many systems can be operated by wireless technology using a laptop, tablet or smartphone. Adapted switches are available to suit the person’s needs, and can be controlled using different parts of the body, such as the head, eyes, mouth or foot.

A referral to environmental controls services or adult social care services should be considered. Some technology and interfaces are readily available on the market.
Information to share
Information sheet 11E - *Environmental Controls*

Download from [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or contact MND Connect to order hard copies. Call 0808 802 6262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

Access
An occupational therapist should assess access to and around the home, bearing in mind immediate and potential future needs. Among other things, consider:

- larger door handles
- multipurpose knob turners and key turners
- hands-free telephones
- stair lifts or through-floor lifts
- computer access equipment
- environmental controls, including switches
- extended plug sockets and plug pulls
- liaison with other services that impact on accessibility, such as wheelchair services
- garden access.

Safety at home
For home safety, consider:

- a cordless or mobile phone positioned close by or carried by person, or a smart wrist watch that includes a phone function
- an alarm worn as a pendant or on the wrist that automatically alerts emergency services or particular contacts if help is needed
- environmental controls with alarm function, as well as options to operate the TV, lights, door entry etc.
Social and psychological support

Social, recreational and leisure activities
As outlined in the NICE Guideline on MND, the person’s needs and preferences should be discussed, with information and support to help them access work, social activities and hobbies, including access to social media and physical access to activities outside their home.\(^3\)

Consider voluntary organisations and charities that can help facilitate access to leisure activities.

A compensatory and adaptive approach should be taken to the modification of activities, to support participation and maintain quality of life.

Information to share
Making the most of life with MND
Emotional and psychological support

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 impact of MND

MND is characterised by a series of losses and change, with the accompanying issues of grief and bereavement.

People with MND and those close to them often experience considerable psychological and emotional distress.9

Emotional reactions may include:

- denial of diagnosis and what it means
- anger as a result of frustration and loss of control
- feelings of hopelessness, in recognition that many of life’s expectations will never be realised
- fear of ‘choking to death’ or ‘fighting for breath’
- loss of independence and dignity
- increasing dependency and becoming a burden
- inability to cope and loss of control
- fear of the unknown, death and the process of dying.

The impact will be influenced by other factors, including the person’s age, personality and life stage.

Spiritual beliefs, current life stresses, cultural background and the help and support they receive will affect the person’s ability to cope. Much can be done to alleviate distress, help people to adjust and make the most of their coping skills.

Allow the person to express thoughts, feelings and concerns to help identify information and support needs. Remember that communication problems or cognitive change may affect the ability of someone with MND to share their thoughts and feelings.

- Give information to help the person and their family make sense of what is happening, to maintain control and make plans, without overwhelming them.
- Check information needs regularly and give opportunity for people to return for more detail.
- Potential carers may want information early, to help them prepare for their future role.
• Signpost to further sources of emotional and psychological support, including the MND Association online forum, Association visitors, local branches and groups, and the MND Connect helpline.
• Referral to appropriate health care professionals eg psychologist
• Ensure any sleep problems are assessed appropriately, with management options explored.
• Educate the person on coping strategies to manage anxiety.

**Anxiety and depression**

It may not be easy to diagnose depression, or differentiate it from the symptoms of MND. However, formal screening of anxiety and depression should be considered for people with MND and carers.

There are a number of screening tools that any health and social care professional could consider using with the person, such as Patient Health Questionnaire 2 (PHQ-2), the Hospital Anxiety and Depression Scale (HADS).

**Psychological impact of interventions and adaptations**

Changes to the home may be particularly challenging for some people with MND to accept. If MND progresses rapidly, someone may quickly need changes to their home, which may be seen as a reminder of their progressive disability.

Consider the impact of equipment in a holistic way, including how it will affect the family and roles within the family. Certain equipment may affect closeness, intimacy and sexuality. For example, moving into single beds where the person with MND has a profiling bed may be difficult for a couple to accept.

**Roles and relationships**

**Parents and grandparents with MND**

All professionals should take a family-centred approach to the care of people with MND, considering the needs of the person and those close to them holistically. The needs of any children in the family should be considered, particularly if there is the potential for them to provide care at some point in the future. Referral for an early help assessment, or a young carer’s needs assessment, should be a priority.
Information for you
Supporting children and young people close to someone with MND

Information to share
Caring and MND: support for you - our main guide for carers
When someone close has MND - our activity workbook for 4-10 year olds
So what is MND anyway? - our guide for teens
MND Buddies - our online activity hub for young children - visit www.mndbuddies.org
Storybook - Why are things changing?
Information sheet 10G - Support for families with children
Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

Partners who become carers
When one partner is diagnosed with MND, the balance of the relationship may change. If the person with MND has been the main breadwinner, the potential effect on finances can lead to additional strain. It may be particularly challenging if the relationship had difficulties before diagnosis.

Some partners will not see themselves as a carer, but as a partner first, who will do what is required to support the other person. Others may be unwilling to provide care. Either way, a carer’s assessment may help them to access appropriate support. If one person becomes the primary carer, this may strengthen the relationship, or cause stress as roles shift and change.

Information to share
Caring and MND - Support for you
Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org
**Sex and intimacy**

MND does not directly affect sexual function, but emotional reactions to MND and disability can affect intimate relationships and the physical ability to have sex. The sense of touch is not lost, but limited mobility may affect sexual activity.

Emotional reactions to MND, anxiety, fear, depression and fatigue, along with some medications, can all reduce arousal and interest in sex. Awareness of changes to their body may affect the person’s self esteem. If one partner becomes the main carer, it may be difficult for them to shift from providing intimate personal care to being intimate with their partner.

Depending on the relationship the person with MND has with their partner, the sexual side of their relationship may become more or less important. Encourage open communication – with each other, but also allow them to discuss their concerns with you. This can help to dissipate misunderstanding, self doubt, fear and uncertainty.

- If communication is difficult, developing a variation of sign language, a special code, notes or communication aids can help.
- Body mapping or sensate focus can be helpful for some couples.
- Different ways of being intimate, sexual positions, activities, sexual aids and altering the environment may help.
- If the couple sleep in separate beds, are there other ways they can be physically close during the day, such as a sofa or inflatable mattress?
- If hands or arms are affected, the partner may take the hands and use them to stroke their own body, so that both partners can share the warmth and intimacy of this touch.
- If fatigue is an issue, a different time of day may be more suitable.
- If someone has a feeding tube, taping it to the skin or wearing tighter clothing can help hold the tube still.
- Where there are breathing problems the couple might try an upright or semi-upright position and a position where the partner supports their own weight. A sofa or chair may be more supportive than a bed, or slings and other equipment may help to achieve a more comfortable position.
• If someone uses a ventilator, it is not harmful to have sex: they may wear the mask, feel able to manage without it, or can have it nearby if needed.

• It may be beneficial for the person to accept some external support with personal care tasks, if their partner is also their main carer and support is available. This can help maintain a sense of intimacy between the couple.

• The person with MND may not feel comfortable to raise these issues with a professional, due to embarrassment or lack of understanding that professionals can offer support regarding sexual needs. It can be helpful to introduce these discussions gently, for example “Some people I have worked with find it difficult to be physically close to their partner. Is this something you would like to discuss?”

Information to share
Information sheet 13A - Sex and relationships for people with MND
Information sheet 13B - Sex and relationships for partners of 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

Bereavement
Those close to the person with MND should have the opportunity to access bereavement support before and after the person dies. Occupational therapists should consider and carry out equipment collection in the most efficient but sensitive way.

It is important to be aware of bereavement support in your local area, and refer people when needed. Some local hospices can provide support to bereaved families. The GP may also be able to support the person to access appropriate sources of support.
Information for you
A professionals’ guide to end of life care in MND

Information to share
Our bereavement webpages at:
www.mndassociation.org/bereavement

Our online forum includes a discussion board about bereavement:
https://forum.mndassociation.org

Finding your way with bereavement – This booklet includes information about grief and emotions, accessing support and the practical things that need to be done when someone dies.

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

Funding for equipment and adaptations
Consideration of potential funding routes ahead of time is a crucial part of anticipating need. Statutory service provision should be considered in the first instance when recommending equipment and adaptations.

All options for equipment and adaptations should be explored, ensuring the person is aware of what the limitations of statutory funding are. It is important to be clear with the person with MND, their family and carers about what statutory services can and cannot provide, and any potential delays.

Be creative and supportive in exploring different options for provision and finding solutions to identified problems. Lack of statutory funding should not prevent assessment for potential problem-solving equipment. This approach enables the person to make an informed choice about the type of equipment that would provide the assistance required or resolve specific problems even if this requires private or external funding.

Disabled Facilities Grants (DFG)
A DFG can be applied for to fund any major adaptations that help the person with MND continue to live in their own home. Eligibility for a DFG varies depending on where the person with MND lives.

This may include provision of:

• a stair lift
• widening doors and installing ramps
• a wash and dry toilet
• a through-floor lift
• a hoist system
• minor adaptations including items such as adapting heating or lighting controls to make them easier to use
• major structural adaptations such as an extension, downstairs bathroom or wet room conversion or ramps.
Most types of installed equipment can be included in a DFG, but the work can take months to be approved and completed. With MND, this could mean the equipment is no longer suitable by the time it is installed. It is important to consider whether a DFG is, therefore, the only possible funding route.

Funding for adaptations via a DFG can take some time to be put in place, so it is essential that this be considered as early as possible.

It is means tested, so some people will not be eligible. Consider eligibility at the earliest opportunity to help people plan and seek alternative funding as required. A grant cannot be awarded retrospectively for works already completed.

DFGs are available in England, Wales and Northern Ireland, but there may be regional differences. There may also be some differences to how DFGs are managed by different councils within England, Wales and Northern Ireland. The local council or Northern Ireland Housing Executive can offer local information.

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**Information to share**

Information sheet 10C - *Disabled Facilities Grants*

Download from [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or contact MND Connect to order hard copies. Call 0808 802 6262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

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**Self funding**

Some people will be self funding, either because funding is not available or because provision is not timely. Even if the person with MND is not eligible for funding, information and support for arranging adaptations should still be offered.³

It is essential to emphasise the importance of assessment before any equipment is ordered, to avoid costly and inappropriate purchases.

In some cases it may be cheaper for someone to pay for an entire adaptation rather than getting a DFG and paying a contribution, due to local authority supplier contracts.
MND Association support grants and equipment loan
Where statutory funding or provision has been explored and is not available, or inappropriate delays are anticipated, the MND Association may be able to provide a support grant or equipment loan.

Referrals for support grants or equipment loan need to be made by a relevant health or social care professional.

Visit www.mndassociation.org/getting-support or call our MND Connect helpline. See page 2 for contact details.

Remap
This national charity has volunteer inventors who make bespoke items for people with disabilities where off the shelf equipment is not suitable. Equipment and gadgets are designed, made and provided free of charge. Referrals usually come directly from individuals, occupational therapists or other health professionals. Visit www.remap.org.uk
Charitable funding
Funding may be available from other local or national charities. Larger employers may have welfare funds or financial support available for current or former employees.

Support in ongoing equipment maintenance
The person with MND, their carer and family should be trained in how to use and maintain the equipment and should receive ongoing support with its use.

They should also be advised on what action to take in the event of equipment breakdown, how often and by whom servicing and maintenance is carried out, and who has financial responsibility for this.

If a person is awarded a DFG for large equipment such as a stair lift or hoist, they become the owner. They will then be responsible for maintenance, repairs or removal once it is no longer needed.

Financial support
A person with MND may need information and help to access financial support, including money management and how to access benefits and entitlements.³ The MND Association Benefits Advice Service provides free advice by phone and e-mail in England, Wales and Northern Ireland. It also provides advice via web chat in England and Wales.

Our qualified advisers will help people with MND and their carers to identify the benefits they may be able to claim and work out the best way of claiming them. Our advisers can also deal with complex benefits issues and appeals against decisions.

Depending on where the person lives and their circumstances, they may be able to arrange a home visit to help with the completion of forms.

Visit [www.mndassociation.org/benefitsadvice](http://www.mndassociation.org/benefitsadvice) for further information about our Benefits Advice Service.
Providing evidence for benefit applications

You may be asked to provide medical evidence for an application for benefits. The welfare benefits system is complex, but you can help to reduce stress for people with MND by providing good quality evidence to support a claim.

This can:

• speed up the process of the claim, helping to ensure it is dealt with quickly and with a greater chance of success
• reduce the potential stress of claiming benefits
• help avoid further medical assessment (which may be conducted by people who have little experience or knowledge of MND) and speeds up the process of the claim.

Healthcare professionals can help by providing detailed evidence that focuses on how MND affects the individual, and not simply a general description of what MND symptoms include.

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**Information for you**

Information sheet P5 - *Providing medical evidence for benefit applications*

**Information to share**

Information sheet 10A - *Benefits and entitlements*
Information sheet 10G - *Support for families with children*

Download from [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or contact MND Connect to order hard copies. Call 0808 802 6262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

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**NHS Continuing Healthcare (CHC)**

If the person with MND has complex, intense or unpredictable needs, they may be eligible for NHS Continuing Healthcare (CHC). In this case, their care package and any equipment needed would be provided free of charge by the NHS.
To be eligible, the person needs to be assessed by a team of healthcare professionals to determine whether their primary need is health-related.

Occupational therapists can complete an initial checklist which determines whether someone should have a full assessment.


NHS Continuing Healthcare works in a similar way in England and Wales. In Northern Ireland there is no guidance or framework for NHS funded healthcare, but Health and Social Care Trusts are encouraged to refer to the guidance used in the rest of the UK.

**Information for you**
Information sheet P7 - *CHC for MND*

**Information to share**
Information sheet 10D - *NHS Continuing Healthcare*

Download from [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or contact MND Connect to order hard copies. Call 0808 802 6262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)
Palliative care

People with MND have complex care and support needs, particularly in the final stages of life. Because MND can be rapidly progressive, and there is the possibility of a person experiencing communication problems or cognitive change, it is important that people with the condition are offered referral to specialist palliative care services as early as possible.

There is a delicate balance between ensuring decisions are made about a person’s future care in a timely manner, and being respectful of what the person is psychologically and emotionally ready to discuss. Bear in mind that these conversations will be more difficult if the person has communication problems or cognitive impairment.

Early links with palliative care and specialist services can provide a useful source of support. However, introducing palliative care may present difficulties, due to stigma around what it is and what it provides. It is important to ensure conversations are handled with sensitivity.
It may help to introduce the service via day care, complementary therapies or respite. Services operate differently geographically - in some areas, people with MND are supported by palliative care teams from the point of diagnosis. In other areas, neurology teams will offer support to the person until the disease has progressed to a certain point, at which time they will be referred to palliative care services.

**Further information for you**

*A professional’s guide to end of life care in MND*

**Information to share with people affected by MND**

Information sheet 3D - *Hospice and palliative care*

*End of life: a guide for people with MND*

Download from [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

**Spiritual support**

It is important to recognise the spiritual needs or beliefs of people affected by MND, and give them the opportunity to discuss these if they wish to. Spiritual care is not always religious and may be provided by a chaplain or dedicated spiritual care provider or community leader, counsellor, psychologist or therapist.

**Advance care planning**

People with MND need to be able to exercise choice and control about their care. They should be encouraged to talk through options for their future care needs and their preferences for end of life. Conversations may be more difficult if the person’s speech becomes affected, or if they experience cognitive impairment.

When decisions about future care needs and end of life are made, they should be clearly documented, ideally in a personalised advance care plan, and communicated to relevant health and social care professionals. Having time to think things through and knowing that their wishes have been recorded may give peace of mind to the person with MND and their family.
It is no single profession’s responsibility to have these conversations. Occupational therapists may be involved if they are best placed to do so, or if the person with MND raises the subject. Consider the following when planning future care and end of life care and support:

**Advance statement**
This is a written statement of the person’s preferences, wishes, beliefs and values for future management, medical choices and care, including preferred place of care and death. They may be included in an advance care plan or they can stand alone. Advance care plans and statements are not legally binding, but support health teams to understand the person’s choices and preferences.

**Advance Decision to Refuse Treatment (ADRT)**
This is a written instruction to refuse or withdraw specific treatments, including life-sustaining treatment, under precise circumstances in the future. In England and Wales, this is a legally binding document, as long as it has been completed correctly. In Northern Ireland it is not legally binding, but can be used to guide health and social care professionals.

**Information to share**
Information sheet 14A - *Advance decision to refuse treatment (ADRT)*
Download from [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

**Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)**
Someone with MND may choose to have a DNACPR. This will be respected in most instances, but is not legally binding. In England and Wales, refusal of CPR may be included on an ADRT, in which instance it becomes legally binding, with clear instructions about when this should be applied.
Reviewing decisions
Any advance decisions made should be regularly reviewed. If changes are made, new copies of each document should be signed, dated and distributed to those holding the existing paperwork.

Making a will
The person may wish to make a will to leave instructions about what will happen to their finances, property and possessions after they die. Signpost them to www.gov.uk/make-will or their local Citizen’s Advice.

When the person dies
Families affected by MND sometimes report a feeling of abandonment when the person they love dies. Frequent visits and support from professionals ends abruptly, and they may feel isolated. Where possible, occupational therapists can support families at this stage by:

• signposting to bereavement support and counselling
• providing the family with bereavement visits
• coordinating the collection of equipment sensitively, with appropriate timing according to the family’s wishes.
Looking after yourself

Occupational therapists play a vital role in improving the quality of life for people with MND, but the certain outcome can be distressing for all involved in the care of a person with the disease.

MND can provide a significant emotional challenge to professionals, in terms of its often short prognosis, the rapid progression towards disability and impending death, the limitations of available treatments and interventions, and any pressure you may feel to remain positive and convey hope.\textsuperscript{31}

Occupational therapists work intensively with people experiencing challenging physical, mental, emotional and social problems and may experience stress and emotional exhaustion as a result. It is important to address these difficulties to maintain a good standard of practice, avoid burning out and keep yourself well.

When a person you have been supporting dies, you may experience grief and sadness, or difficulty letting go of the friendship and rapport you had developed.

You may become preoccupied with thoughts of what you could have done differently. The death may also bring back distressing experiences of your personal losses and cause you to focus on your own mortality. These feelings can leave you feeling emotionally drained.\textsuperscript{33}

Some professionals may experience what is known as compassion fatigue, where ongoing stress can lead to a pronounced change in the professional’s ability to feel empathy for the people they are supporting.\textsuperscript{35}

**Suggestions for self care\textsuperscript{36}**

**Recognition of stress**

It is important to regularly monitor yourself for signs and symptoms of stress, such as feeling overwhelmed, frustrated, exhausted and loss of energy and enthusiasm. Being aware can help you to address stress earlier and avoid it escalating.
Debriefing
Talking about the emotional challenges of your role can help you to cope more effectively. Seek support where you can. This could be in the form of regular supervision with your line manager, during team meetings, or more informally with a trusted colleague. Support from the wider team who were involved in the person’s care can also be helpful. You can also call our MND Connect helpline on 0808 802 6262.

Self care
It is important to take time for yourself to relieve work related stress. This could be in the form of leisure activities for pleasure and distraction from the pressures of work. Taking care of your physical needs, such as eating and sleeping well, and getting some exercise can foster your sense of wellbeing.

Managing your workload
A useful strategy is to look at your working day and ensure it is balanced. Take regular breaks away from your work. Balance intense or stressful tasks with simpler, more enjoyable tasks in between.

Manage your expectations
With a progressive condition like MND, the person’s functional ability will continue to decline despite your best efforts. It may be helpful to base your sense of personal accomplishment on the development of your own expertise, rather than the progress of the person with MND.

Closure
When a relationship with someone ends due to death, bringing a sense of closure to the relationship can help you to move on. This may be by attending a funeral where appropriate, or meeting with the family one final time. Alternatively, it could be a private act that you do on your own, such as lighting a candle and taking a few moments to have a final thought about the person who has died.
Useful resources

Royal College of Occupational Therapists’ Adaptations Without Delay
A guide to planning and delivering home adaptations differently. Available at www.rcot.co.uk/adaptations-without-delay

Gold standards framework
Offer training, tools and resources to support generalist frontline staff to provide a gold standard of care for people nearing the end of life. Visit www.goldstandardsframework.org.uk

NICE Guideline on MND
www.nice.org.uk/NG42

Occupational Therapy and Neurological Conditions (Preston & Edmans, 2016)
This book has been produced by members of the UK Royal College of Occupational Therapists Specialist Section Neurological Practice.

References

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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

Information resources
We produce high quality information resources 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

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 treatment and brings us closer to a cure.
www.mndassociation.org/research

MND Register
The MND Register aims to collect detailed information about every person with MND to detect changes in rates over time and identify best practice to improve patient care and outcomes.
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@mn dassociation.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

This guide has been endorsed by the MND Professional's Community of practice.