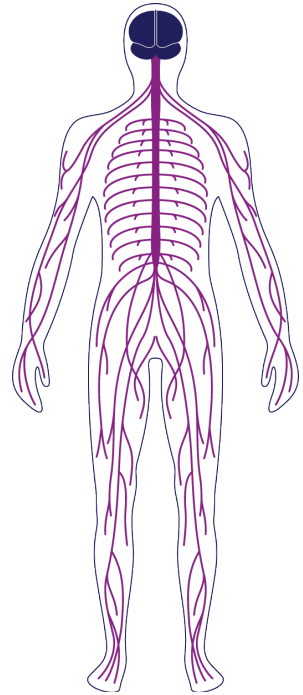




Occupational therapy for motor neurone disease

About MND

- MND is a rapidly progressing terminal disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work.
- It can leave people 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.
- A third of people with MND die 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 takes six people's lives 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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Introduction

Motor neurone disease (MND) is a fatal, rapidly progressing neurological condition affecting up to 5,000 adults in the UK at any time. The disease causes messages from nerves (motor neurones) in the brain and spinal cord that control movement to gradually stop reaching the muscles, leading them to weaken, stiffen and waste.

The result is that people become locked in a failing body, unable to move, talk, swallow and eventually breathe. Some may experience changes in thinking and behaviour, with a proportion experiencing frontotemporal dementia. MND does not usually affect senses such as sight, hearing and sensation. It also does not directly affect sexual function or bowel and bladder functions.

MND can affect adults of any age. However, it is most common in people aged 55-79, and onset below the age of 40 is uncommon. Onset under the age of 30 is extremely rare.

Occupational therapists play a vital role in supporting individuals with MND to adapt to changing symptoms and enhance their quality of life. This booklet provides guidance to occupational therapists on understanding MND and their role in promoting independence and quality of life. It offers suggestions for supporting individuals, but it is not exhaustive, and therapists are encouraged to use their expertise to explore various options for addressing specific needs.



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*

See page 69 for details of how to order our publications.

Overview of MND

MND was historically classified based on whether it predominantly affected upper motor neurons (UMN) or lower motor neurons (LMN), or both. UMN involvement results in muscle weakness, spasticity, increased muscle tone, loss of fine motor skills, and difficulties with speech and swallowing. LMN involvement leads to muscle weakness, muscle wasting, reduced muscle tone (making the muscles 'floppy'), twitching under the skin (known as fasciculations), poor reflexes, and impaired coordination.

While UMN or LMN involvement may affect disease progression rate to some extent, there are not distinct types of MND, but rather a spectrum with varying rates of progression. Occupational therapists should be aware of the following terms which may help to understand the potential speed of MND progression to better support people with MND.

Amyotrophic lateral sclerosis (ALS) key features:^{1,2}

ALS and MND essentially mean the same thing. MND is the overarching term, largely only used in the UK and Australia, with ALS more generally used in the USA and other countries.

ALS has a wide range of onset ages, typically in the mid-60s. It affects both upper and lower motor neurons, leading to muscle wasting, hyperreflexia, and sometimes spasticity. ALS can start in the arms, legs, or bulbar region (lips, tongue, throat, swallowing muscles).

The region of symptom onset usually experiences the most functional loss over time. The bulbar region is eventually affected in most cases, but not always prominently. Some individuals initially have symptoms confined to the bulbar region, known as progressive bulbar palsy.

Survival varies, with 75% of people with ALS surviving less than five years from onset. Bulbar-onset or dementia-related cases often have a shorter survival. It is important for occupational therapists to be aware of this prognosis, and its implications for timely equipment provision and adaptations.

Previously, lower motor neuron-dominant cases with muscle wasting were called progressive muscular atrophy (PMA), but they are now considered similar to ALS. A rare variant called 'Flail arm syndrome' primarily affects men and has a slower progression, lasting up to 10 years or longer.

Primary lateral sclerosis (PLS) key features:^{3,4}

PLS is a rare variant of motor neurone disease (MND) that primarily affects the upper motor neurons. It accounts for less than 3% of all MND cases.

PLS usually has an earlier onset, typically in the 40s or 50s. It exclusively affects the upper motor neurons, leading to marked spasticity. The initial symptoms of PLS are often seen in the legs, and occasionally in the bulbar region. Impaired balance and bladder hypersensitivity are common.

Unlike other forms of MND, PLS progresses very slowly. Survival is more than 10 years from symptom onset, with many people with PLS living a typical lifespan. It is important to view MND/ALS as a single disease with variable symptoms, sites of onset, and rates of progression. Some individuals initially diagnosed with PLS may later develop more typical ALS with faster progression.⁶

In addition to ALS and PLS described above, some professionals may still refer to the historical 'types' of MND, and some people may have been given them as a diagnosis. We have included a description of these below, however we recommend viewing MND/ALS as a single disease with variable symptoms, sites of onset and rates of progression.



Progressive bulbar palsy (PBP)^{1,5}

- A small group 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.
- Characterised by rapidly progressive speech and swallowing problems, often also with emotional lability. Muscles in the upper limbs, neck and shoulder girdle may become progressively weaker.
- Both UMN and LMN may be involved.

Progressive muscular atrophy (PMA)^{1,5}

- Accounts for 5-10% of people with MND.
- Characterised by LMN degeneration, with muscle wasting and weakness.
- Limb onset, often with visible fasciculations.
- Includes ‘Flail arm syndrome’, and is characterised by slowly progressive, symmetrical, and usually proximal upper limb weakness.
- Sometimes misdiagnosed as multifocal motor neuropathy.

Kennedy’s disease³⁷

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*

See page 69 for details of how to order our publications.

The occupational therapist's role

To help the person with MND to participate in functional activities 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, work, social participation and leisure opportunities for as long as possible, focusing on what is important to the person
- modification of the home environment to maximise function and mobility
- facilitating safe participation in functional activities as function declines
- posture and positioning
- fatigue management and conservation of energy
- psychological, cognitive and behavioural strategies
- facilitating timely provision of adaptive equipment for current and anticipated needs
- providing support around physical, emotional and spiritual issues, including open discussions about planning ahead, death and dying
- help the person adjust to changing roles
- supporting the person and their family members to express choice and control, and support them to develop their life goals together
- support for family and carers, throughout the course of the condition, and in bereavement.

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.⁷

The goal of assessment is to analyse a person's strengths, skills, and needs in performing daily activities, considering how the environment influences them. Assessments should anticipate both current and future needs.

Modifying assessments, tools, or outcome measures can compromise their validity and reliability, so standardised assessment tools should not be altered. In addition to occupational therapy assessments, practitioners should be mindful of and, whenever possible, use tools specifically designed for MND.

The assessment process

Assessment needs to be holistic and timely. Within the assessment process, occupational therapists should:

- provide support to enable the individual to understand and adjust to the potential implications of their diagnosis, providing the person is ready to discuss this
- consider all areas of need, functions and domains, being mindful of the person's likely rate of progression
- establish a list of main concerns, anticipated future needs and prioritise goals based on what is important to the person
- consider the need for equipment and housing adaptations as soon as possible to ensure timely provision in relation to rate of disease progression
- consider the potential impact of cognitive or behavioural change, and how this may impact on assessment and support planning, including how the person engages with interventions
- discuss the impact MND could have on the person's roles and relationships

- allow sufficient time for discussions, considering communication difficulties, cognitive needs, and fatigue
- 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, including local MND specialist services eg care centres or networks, specialist nurses etc
- arrange regular, ongoing reviews of the person's ability and their carers' needs
- identify whether a welfare benefits or financial check is required, and refer to appropriate support
- address the needs of carers and family, including offering a referral for carer's assessments or signposting to other support.

Review

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. A person's needs may change rapidly, and the NICE Guideline on MND recommends that untimely case closure should be avoided.⁷

Ideally the same health care professionals should stay involved with a person's care throughout the course of the disease. This helps build relationships between the person, their family and the professionals, and promotes seamless care and interventions. It will also help reduce duplication and save time, as people with MND often have a large number of professionals involved in their care.

Use of outcome measures

Any intervention plan should have clear outcomes. Outcome measures should be used to record progress towards meeting the person's goals, including the actions of the occupational therapist, and the effectiveness of interventions. The use of standardised outcomes can be challenging, as MND may progress 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. 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)¹⁰ is a tool for evaluation of functional status and change in people with MND.

<https://pubmed.ncbi.nlm.nih.gov/10540002>

Key questions to ask when selecting outcome measures: a checklist for allied health professionals is a checklist developed by the Allied Health Professions (AHP) Outcome Measures UK Working Group. It is designed to assist allied health professionals and teams with selecting outcome measures. It contains key questions to ask when considering which outcome measure is most suitable for your area of practice.

www.rcslt.org/outcome-measures-checklist

NICE Quality Standard on MND (QS126) 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.

www.nice.org.uk/guidance/qs126

Timing of interventions

MND can be 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.

To reduce delays, the occupational therapist should anticipate and plan 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.⁷

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

Psychological impact of interventions

It is important that the occupational therapist establishes a rapport with the person with MND, their family and carers to help facilitate sensitive discussions involving functional loss and future planning to minimise crisis situations occurring.

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.

Occupational therapists should work with the person to fully explore:

- the benefits and potential challenges when using a piece of equipment or adaptations
- what it is about the activity that they can no longer do that they got pleasure from, so that they can consider adapting the activity or find an alternative which may help meet some of those needs
- all possibilities and ideas, without being influenced by what is available through statutory services alone
- the person's reasons for refusing the equipment and acknowledge these, whilst making recommendations for intervention
- the person's mental capacity to understand any potential risks of not using a particular piece of equipment or advice, so they can make an informed decision
- maintaining an open door policy so the person can contact you if they change their mind, their needs change or they need advice.

It is also 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:

Possible barrier	Potential solution
Adaptations that change the look of the home, associating it with disability	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.
Single profiling beds affect emotional and physical connection between couples	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. Note 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.

See page 52-58 for more about the psychological impact of MND.

When the person dies

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

- signposting to bereavement support services
- providing the family with bereavement visits
- coordinating the collection of equipment sensitively, with appropriate timing according to the family’s wishes.

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.

See page 69 for details of how to order our publications.



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.⁷

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.⁷



People who enjoy exercise as a hobby may wish to continue this using adaptive equipment such as weight gripping aids, adapted bikes and accessible gyms (where available).

Occupational therapists should explore what is available locally, ideally with some input from the person's physiotherapist. The charity REMAP may be able to help make bespoke items for people where off the shelf equipment is not suitable. Visit www.remap.org.uk for details.

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 may affect the person's ability to use these as time progresses.

Wheelchairs¹¹

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.

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.⁷

The assessment should consider the progression of MND and determine what will best suit the person's changing needs. For example, someone may be able to use standard wheelchair controls initially, but as MND progresses, they may lose that ability. As with all equipment, ongoing review of its use and suitability is essential.

A timely referral to wheelchair services also helps ensure that the service can work with the person with MND and other agencies to ensure access is being considered at the person's home. It also allows time for the person to start to come to terms with the type of wheelchair they will need.

Larger manual and electric powered indoor/outdoor wheelchairs (EPIOC) are difficult or impossible to transport in an unadapted vehicle. This is due to space limitations, issues with securing the wheelchair and implications for moving and handling the equipment in/out of the vehicle safely. See travel and transport on page 59.

Some people may wish to purchase a folding powered wheelchair to ensure it can be transported. These may be useful for a while, but may not offer enough postural support as their condition progresses.

Information for you

Information sheet P2 – *Wheelchairs for people with MND*

Wheelchair Pathway for MND

Information to share

Information sheet 11C - *Equipment and wheelchairs*

See page 69 for details of how to order our publications.



Posture and positioning¹¹

As MND progresses, mobility and comfort can become more difficult to manage. Changes in muscle activity, including possible cramps and spasticity⁷, 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.

Due to muscle weakness and the weight of the arms, 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.

Weakness in the neck, shoulder girdle and upper back muscles can cause head drop. Weakness in the trunk can cause a person to lean sideways, 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 most effective position for someone with neck weakness is tilted back, with their arms, back, head and neck supported. The aim is to support a symmetrical 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. If the person cannot tolerate this position, experimentation may be needed.

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 specialist seating that fits the person's proportions, with options for increased postural support eg thoracic supports, adapted headrests etc
- tilt-in-space wheelchairs, offering more gravity assisted postural correction
- separate back rest and seat adjustments for posture and comfort
- wide arm rests with pressure relieving qualities
- wheelchair head supports
- a head support orthosis – see *Orthotics* on page 22.



Pressure injuries

Risk factors for pressure injuries in MND include:

- reduced ability to move to relieve pressure in sitting and lying
- poor posture in sitting resulting in loading over a small area, such as one side of the pelvis or a specific area of the back and spine, which increases the pressure on the that area
- sliding down and forward on the seat resulting in shear forces over the buttocks and back
- seating which does not adequately accommodate or support postural limitations
- loss of soft tissue mass resulting in vulnerable bony prominences eg ischial tuberosities, spinal processes of spine and shoulder blades (scapular) etc
- poor head positioning and saliva management issues resulting in moisture lesions and or pressure injury on chin, chest, ears etc
- inadequate equipment provision to support bed mobility for independent relief of pressure during bed use
- inadequate hydration and nutrition and resulting weight loss due to swallowing problems.

People with MND retain sensation, so will know when they need to move, or need help to be moved. However, those with communication difficulties may not be able to express that they want to be repositioned.

Postural support for seating and wheelchairs can reduce the risk of pressure injuries. Barrier creams can also be considered. The need for pressure relieving cushions and mattresses (including air-flow) should be regularly assessed, with timely provision.

Additionally, referral to local district nursing and tissue viability services should be considered if the person requires ongoing pressure care management.

Orthotics

There are several orthotic devices that can be useful in managing symptoms and providing support to people with MND. The specific orthotics prescribed may vary depending on individual needs and the stage of the disease. The NICE Guideline on MND advises referral for orthotic services to help with muscle problems.⁷

Some orthotics commonly used in MND include:

Ankle-foot orthoses (AFO): AFOs are devices that provide support and stability to the foot and ankle. They can help prevent and manage foot drop (a common symptom in MND), improve walking ability, and reduce the risk of falls.

Hand and wrist orthoses: Depending on the progression of weakness and loss of dexterity in the hands and wrists, various orthotic devices may be used. These can include functional wrist, hand or finger splints to support the individual to participate in daily activities, or resting splints to help maintain muscle length and reduce risk of contractures.

Knee orthoses: Knee braces or orthoses may be recommended if there is weakness or instability in the knee joint. These braces can provide additional support, improve stability, and assist with walking.

Neck collars: In some cases, individuals with MND may experience weakness in the neck muscles, leading to difficulties in holding the head upright. Neck collars or cervical collars can provide support to the neck and help maintain proper alignment.

Information for you

Information sheet P1 - *Head supports*

See page 69 for details of how to order our publications.

Bed mobility

Issues may include:

- inability to lift legs into or out of bed
- difficulty sitting up from lying down
- difficulty turning in bed
- difficulty moving up or down the 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 injuries resulting from limited movement and inability to adjust positioning.

Depending on level of need, options may include:

- leg lifters
- rails and bars to aid independent bed mobility
- low friction slide sheets (advise on nightwear to avoid excess slide)
- satin nightwear to make sliding easier
- a static or powered pillow lift or mattress elevator
- a profiling bed, which can help with moving from lying to sitting, sitting to standing, or standing to sitting (with variable height)
- patient turning systems
- consideration of pressure relieving mattresses or mattress toppers - avoid memory foam, 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
- provision of two-way or four-way bed slide sheet systems
- mobile/gantry/ceiling track hoist for supported bed mobility, considering whether the bed needs to be raised to allow mobile hoist access.

Health and social care equipment provision is normally only available for the person living with MND, so the provision of a single (as opposed to a double) profiling bed may be the only option offered. This can have implications for the person living with MND and their partner with regard to intimacy and also care giving.

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 features as outlined above, which may be more acceptable to them. Another option could be to place a single profiling bed beside a regular single bed of the same height.

Supported positions to consider

Lying on the side:

Rather than laying directly on one side, encourage a quarter turn on to the back, pulling the shoulder forward. With the head supported on a pillow, 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.

Lying on the back:

Place a pillow under head and shoulders. Help flex the hips by placing a firm support under the knees to prevent sliding when the bed head is elevated, or utilise the knee break if using a powered profiling bed. 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, mattress elevator or by raising the head section of a powered, profiling bed. When choosing a profiling bed, select one that provides variable tilt, reverse tilt positioning and auto-regressing profiling sections. The head of the bed should lift from the hip rather than the abdomen, which may further compromise respiratory function.

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. If bed falls are considered to be a high risk, consider a low or floor bed as an alternative to bed rails.

Further information is available from Medicines and Healthcare Products Regulatory Agency at:

www.gov.uk/guidance/bed-rails-management-and-safe-use



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.⁷ Transfer boards or belts, slide sheets, turntables, stand-aids and standing hoists may be considered while a person is able to weight-bear/partially weight-bear. Transfer ability usually continues to deteriorate, as limb strength and function decline. Hoisting may be necessary as MND progresses.

Hoisting

Although the person with MND may be reluctant to consider using a hoist, it is important for occupational therapists to consider all options early in anticipation of need. These conversations can be challenging for everyone involved, and may require time and reassurance.

If discussions are left too late, there is a risk the person won't have timely access to the equipment when they need it. It is best for the person with MND, their carers and professional care workers to be familiar with equipment and gradually increase use as needed.

Proper posture and positioning, especially for those with respiratory involvement, are crucial to avoid chest and torso compression. Comprehensive training for the person and their carers is essential to alleviate fears and increase confidence.

As MND progresses, a ceiling track hoist is often more suitable than a portable or fixed hoist, saving space and reducing manual handling. Hoist slings should be personalised to the individual, with correct sizing specified in a moving and handling plan.

Information to share

Information sheet 11C - *Equipment and wheelchairs*

See page 69 for details of how to order our publications.

In certain cases, a specific hoist may be necessary for bathing and toileting since there is no clearance beneath a bath or toilet for a regular hoist to fit. If the person has a stairlift, hoists may be required on each floor to facilitate transfers and enable continued use of the stairlift as their symptoms progress.

Getting up and down the stairs

It is essential to address long-term plans for accessing upstairs facilities early on – this may be sooner than the person with MND may anticipate. Failure to plan ahead can lead to lengthy delays and costly consequences in making necessary adaptations.

It is important to consider the individual's ability to function in the short, medium, and long term. For example, installing a stairlift is likely only to meet short to medium term needs due to progressive loss of sitting balance and transfer ability. Equally, creating a first-floor wet-room without a through-floor lift will again only meet short to medium term needs as stair use becomes difficult.

Although use of stair lifts can be time limited, they should not be discounted, as there are different progression rates of MND and they may be very useful in some cases. Consider rental of stair lifts where their use is likely to be short term.

Options for accessing upper floors may include:

- handrails on both sides of the stairs, as long as leg mobility and hand and grip strength are maintained
- a stair lift, understanding that this may only be a temporary solution. As MND advances, transferring on and off the seat and maintaining a safe posture while seated can become challenging
- a through-floor lift, which would provide wheelchair access on each floor without the need for transferring. However, not all homes can accommodate this option, and an assessment is necessary to determine its feasibility
- in many cases, ground-floor living with appropriate wet-room adaptations can be the preferred long-term option.

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.

The Royal College of Occupational Therapists (RCOT) have produced *Adaptations without delay*, a guide on planning and delivering home adaptations. Visit www.rcot.co.uk/adaptations-without-delay to download a copy.

Environmental controls

Environmental controls can enable a person with MND to control electronic devices they can no longer access via the usual means.

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. Some can be used with home assistants such as Alexa. 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*

See page 69 for details of how to order our publications.

Access

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

- internal and external ramps
- grab rails alongside internal or external steps
- automatic door openers
- larger door handles
- multipurpose knob turners and key turners
- video doorbells or similar intercom systems
- stair lifts or through-floor lifts
- 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 wristwatch that includes a phone function
- a personal alarm worn as a pendant or on the wrist that automatically alerts an emergency call centre or particular contacts if help is needed
- environmental controls with alarm function.

Communication

Many people with MND experience slurred, quiet or complete loss of speech. 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 a person's ability to communicate with:

- seating, positioning, wrist, hand, finger, head and neck supports
- switches and pointers
- mobile arm supports
- tables to support access to communication aids
- equipment to support computer use for communications such as email and social media
- environmental controls (see page 28).

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.

- It may take great effort and time and time for a person with MND to communicate, so longer appointments or visits may be needed.
- Find out how the person with MND prefers to communicate, and what equipment they like to use.
- 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 with speech problems may persevere with speaking, making them difficult to understand. Sensitively encourage them to use another method to communicate to minimise their frustration and facilitate conversation.
- Consider sending questions regarding more complex matters to the person with MND in advance of your meeting to enable them to have time to think through and prepare their answers.

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 the person with MND wants you to
- 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 have become significantly more mainstream following the covid pandemic, 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 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 enable assessment of range of movement in lips, tongue and palate. The speech and language therapist can also provide 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.⁷

Information for you

Communication, speech and language support

Information sheet P10 - Voice banking

Information to share

Information sheet 7C - *Speech and communication support*

Information sheet 7D - *Voice banking*

See page 69 for details of how to order our publications.



Eating and drinking

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.⁷

Posture

Consider:

- the position for eating – what type of chair is used, where the table is in relation to the chair, and the distance between the plate and the person's mouth (how far they have to lift food)
- enabling an upright posture and the ability to tuck the chin down to the chest when swallowing to help prevent food aspiration
- head and neck supports, and how they can support or hinder eating and drinking (see page 22).



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, if recommended by an SLT
- modified cutlery to help with grip and control
- height adjustable table, considering a curved table if additional forearm support is needed
- head and neck support to ensure an appropriate position for effective swallowing (see pages 19-20)
- drinking aids
- a portable suction unit to help clear the mouth of debris
- if the person eats a pureed diet, consider food moulds so each individual puree is recognisable to the person (eg carrot shaped mould for carrot puree).

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.

See page 69 for details of how to order our publications.

Impact of cognitive change

Cognitive change and frontotemporal dementia can also have an impact on eating and drinking. Some people may cram food, become rigid about only eating certain foods, or experience changes to food preferences, often preferring sweet foods. A speech and language therapist and dietitian can advise the person, their carers and family on strategies to manage food safely.

Conversely, some people may avoid eating. Explore strategies such as primary coloured plates, offering finger foods, or naming each food when it is offered. Ensure a calm, uncluttered environment so the person can focus on the meal. Liaise with the person's dietitian and speech and language therapist to establish a mealtime strategy. See pages 47-50 for further details on cognitive change.



Personal 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. ¹⁴

Information to share

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

Personal care guide

Information sheet 11C - Equipment and wheelchairs

Information sheet P12 - MND information for dental teams

See page 69 for details of how to order our publications.

Bathing and showering

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

- fixed or mobile shower seats to be positioned in existing shower units, or tilt-in-space shower chairs with head extensions for those with trunk weakness or respiratory problems
- grab rails and non-slip mats
- bath boards, swivel bathers or a mechanical bath lift
- a powered or manual hoist to transfer in and out of the bath
- accessible, level access shower cubicles or ideally a wet room.

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 with dressing and grooming:

- long handled hairbrushes and hands free hair dryers
- dressing sticks
- electric razors
- dry shampoo or shampoo caps
- modifications to oral hygiene – see pages 41-42
- clothing considerations and adaptations – see next heading.

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 it may be helpful to 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
- adapting clothing fastenings eg sew buttons on outside of shirt to give the appearance of buttons, but use Velcro to fasten the shirt
- dressing aids, such as zip pulls, button hooks, zip pullers, dressing sticks, shoe or sock devices, leg lifters and shoe horns
- items for protection and warmth when outdoors (eg quilted bags, capes, covers, hand muffs etc to use with wheelchairs or 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 – these may cause sliding, affecting posture and positioning, so assessment is needed
- 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. Consider adaptive footwear with zipped or Velcro openings for ease of access and fastening.

Toileting

Although bowel and bladder function is rarely affected by MND, immobility can hinder timely access to the toilet, and loss of muscle activity may impact the strength required for defecation. People with MND are also at risk of constipation due to various factors like changes in eating, dehydration, anxiety, or medication. Prolonged time spent on the toilet is common, highlighting the importance of a suitable toilet seat.

Preserving dignity and self-esteem is crucial. Consider the following aids to promote independence:

- specialised equipment, such as a bottom wiper with a long looped handle and a paper grip
- adapted clothing for easy toileting access
- specialist underwear and disposable pads if there are concerns about timely access to the toilet
- wash and dry toilets or bio bidets, which maintain hygiene, independence, and dignity for individuals with reduced mobility
- wheelchair toileting, where removable wedges in wheelchair cushions enable toileting using a female urinating device or urinal bottle
- equipment to facilitate transfers, including raised toilet seats, height adjustable shower/commode chairs, toilet frames, grab rails, and hoists, ensuring the toilet can be used for as long as possible.
- urinary sheaths or urinal bottles for use at home or while traveling
- catheterisation may be considered in consultation with the specialist team for individuals with MND experiencing transfer difficulties. Addressing transfer issues effectively will help prevent the need for catheterization and associated risks like infections.
- bowel irrigation systems - refer to nursing colleagues.

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.

If the person cannot tolerate a toothbrush in their mouth:

- 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).
- A small washcloth with toothpaste on it can be used to clean the teeth and mouth.
- 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 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 for carers assisting with oral hygiene.



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.

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)¹³ 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:

www.ncbi.nlm.nih.gov/pmc/articles/PMC3282643

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 and after 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 sufficient 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, reducing stair use during the day 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 38-39.

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. Consider delegating part of the activity so that the person with MND can complete the most enjoyable part.

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 for 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 pages 23-28.

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
- using non-iron or crease-resistant clothing
- 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.

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 61.

Information to share

Personal care guide - includes information on managing fatigue.

See page 69 for details of how to order our publications.

Cognitive change and frontotemporal dementia

There is now increased awareness of cognitive and behavioural changes in MND, and people affected by the disease may fall into one of three 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.⁸

Keep in mind that up to half of people with MND will experience some degree of cognitive change.

Information for you

Cognitive change, frontotemporal dementia and MND

Information to share

Changes to thinking and behaviour with MND

See page 69 for details of how to order our publications.



Changes may be subtle or more noticeable and may cause the person to experience difficulties 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
- 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.

Occupational therapists may identify cognitive changes through assessments and observations, prompting them to recommend further evaluation. You should remain vigilant about potential changes, inquire as needed, and ensure cognitive assessments are conducted. Occupational therapists can also assist in describing and explaining the nature of impairments and their impact on functional abilities to the individual and their family.

ECAS

Occupational therapists may use the Edinburgh Cognitive and Behavioural ALS Screen (ECAS) as a screening tool to detect signs of cognitive and behavioural changes. While other screening tools exist, ECAS is specifically designed for individuals with MND and helps determine the need for a comprehensive assessment by a psychologist. The ECAS tool, and training can be found at:

<http://hdl.handle.net/1842/6592>

MiND-B

The Motor Neurone Disease Behavioural Instrument (MiND-B), is an assessment that detects neuropsychiatric symptoms and rates the severity of behavioural changes in people with MND. It is completed by a family member or friend (known as an informant), and covers apathy, disinhibition and stereotypical behaviour.

The MiND-B asks the informant about changes in behaviour they have noticed over the past month, in comparison to the time before the person had MND, and can be used as a starting point for an interview with the family member to discuss management strategies for the behaviours detected.

Find the research study at <https://bit.ly/MiND-B>. If you require access to the most updated MiND-B form and scoring guide, or more information, please contact Professor Eneida Mioshi at e.mioshi@uea.ac.uk.

The team behind MiND-B are currently developing an online toolkit to help professionals and carers to effectively support someone with MND and behavioural changes. For the latest updates, visit <https://mindtoolkit.org>



Impact on occupational therapy interventions

Being aware of the potential for cognitive and behavioural changes in any stage of MND is crucial, as these can influence service utilisation and decision-making. Occupational therapists can provide guidance on adaptive strategies and techniques, as well as advise family members and caregivers on supporting the person's engagement in daily activities.

When cognitive impairment is present, it is important to focus on proactive planning and arranging appropriate support for the individual with MND, their families, and caregivers.

If cognitive changes are identified, it is essential to inform all members of the multidisciplinary team, enabling them to respond and incorporate any necessary changes in care planning.

Considerations include:

- initiating discussions about interventions and advance care planning earlier, providing additional support to aid understanding and ensure comprehension
- simplifying the information provided or presenting it in alternative formats
- ensuring safety by removing or securing items that could be used inappropriately
- ensuring that care workers are knowledgeable about potential issues and how to respond
- maintaining a small care team to foster familiarity and confidence¹⁴
- following the initial assessment, carry out regular review or reassessment, as cognitive or behavioural changes may develop over time, or become apparent as new interventions or situations are introduced.

Respiratory function

Many people with MND experience breathing difficulties, particularly as the disease progresses. This can lead to breathlessness, headaches, reduced appetite, quiet speech, poor sleep quality and fatigue. If the person experiences new or changed respiratory symptoms, they should be referred to the specialist team.

The occupational therapist can advise on:

- posture and positioning, including solutions for breathlessness when lying flat, or ensuring 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.

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*

See page 69 for details of how to order our publications.



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.⁷

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 maintain participation and quality of life.

Information to share

Making the most of life with MND

Emotional and psychological support

See page 69 for details of how to order our publications.

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
- worrying about increasing dependency and becoming a burden
- feeling unable to cope and that they are losing 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.

- Sensitively share 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 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 counselling services, 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).

Emotional lability

Emotional lability affects some people with MND. It is characterised by the person laughing or crying at inappropriate times or in an exaggerated way. The person with MND can be encouraged to manage this by letting those who support them know that they may display this symptom and how they want to be supported when it happens. The specialist team may be able to offer medications to help with this symptom of MND.

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 how they are able to express their sexuality. For example, moving into single beds where the person with MND has a profiling bed may be difficult for a couple to accept. Try to promote a level of choice and control for the individual by offering options where possible.

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

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

See page 69 for details of how to order our publications.



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 - our main guide for carers

See page 69 for details of how to order our publications.



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 and respiratory function 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.
- 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.

- 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.
- 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?”
- Offer the person a copy of the MND Association’s *Sex and relationships* booklet – see order details on page 69.
- Visit www.mndassociation.org/webinars to view a recording of our webinar on sex and relationships for professionals.



Travel and transport

Information to share

Getting around with MND guide

See page 69 for details of how to order our publications.

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 as needed.

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.

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, during transfers and on arrival
- 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
- consider toileting needs and access to Changing Places or disabled toileting facilities
- research the destination, and take contact details for local facilities such as pharmacies, wheelchair repair shops etc.

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.

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 for more information
- adaptations to tasks and exploring other ways of working
- equipment and aids, including assistive technology to support computer use
- changes in working hours or working from home.

If the person chooses to stop working, this may raise emotional concerns. Work can provide a sense of purpose and social contact. Leaving this behind may be difficult, especially as it is not necessarily out of choice. It may also raise financial concerns.

The person may need information and support to access benefits and financial support. Visit www.mndassociation.org/benefitsadvice for further information about our Benefits Advice Service.

Information to share

Information sheet 10E - *Work and MND*

Information sheet 10A - *Benefits and entitlements*

Information sheet 10G - *Support for families with children*

See page 69 for details of how to order our publications.

Funding and financial support

Funding for equipment and adaptations

Consideration of funding options in advance is crucial for anticipating needs. Start by considering statutory service provision when recommending equipment and adaptations.

Explore all possible options for equipment and adaptations, ensuring the person understands the limitations of statutory funding. It's important to be transparent with the person with MND, their family, and carers about what statutory services can and cannot provide, as well as any potential delays.

Be creative and supportive in exploring different provision options and finding solutions to identified problems. Lack of statutory funding should not hinder the assessment for potential problem-solving equipment. This approach allows the person to make an informed choice regarding the type of equipment that would provide the necessary assistance or resolve specific problems, even if it 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.

Information to share

Information sheet 10C - *Disabled Facilities Grants and home accessibility*

See page 69 for details of how to order our publications.

Home Improvement Agencies

Home Improvement Agencies (HIAs), also known as Care & Repair, provide advice and support to older, disabled and vulnerable people who own and live in their own property. They help people to repair, improve, maintain or adapt their home to meet their changing needs.

Some HIAs offer discretionary grants that are not means tested. Contact your local Home Improvement Agency to find out what support they may be able to offer.

Self-funding

Some people will be self-funding, either because they are not yet eligible for a DFG, funding is not available or because provision is not timely. If the person with MND is not eligible for funding, information and support for arranging adaptations should still be offered.⁷

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 70 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. They 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/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.⁷ 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 for people 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 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 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.

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*

See page 69 for details of how to order our publications.

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.

The checklist and guidance documents are available from **www.gov.uk**

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*

See page 69 for details of how to order our publications.



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How to order publications

Our publications are free of charge to people living with or affected by MND, or Kennedy's disease. Health and social care professionals can also order items for themselves or on behalf of someone with or affected by MND or Kennedy's disease.

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

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@mndassociation.org

Phone: 0808 802 6262

MND care centres and networks

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

www.mndassociation.org/care-centres

Branches and groups

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

www.mndassociation.org/branchesandgroups

Association visitors (AVs)

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

www.mndassociation.org/associationvisitors



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

We value your feedback

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

Visit our webpages for health and social care professionals:
www.mndassociation.org/professionals

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