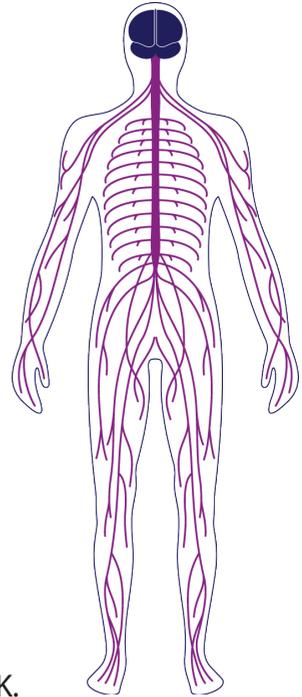




**Motor neurone disease:
a guide for social care services**

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 terminal, 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 a rare form of dementia. MND does not usually affect senses such as sight, hearing and sensation.

MND kills a third of people within a year and more than half within two years of diagnosis. It affects all communities, with a person's lifetime risk of developing MND around 1 in 300. Today six people will be diagnosed and six will die from MND. There is no cure.

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.

There is no single test to diagnose MND. Diagnosis is based on features in the clinical history and examination, usually accompanied by a range of tests to exclude the presence of other conditions.

The majority of people have a sporadic form of MND which is not inherited but is believed to be caused by a combination of genetics, lifestyle and environmental factors. Inherited MND (sometimes known as familial MND) accounts for approximately 5-10% of all cases.

This booklet has been developed for social workers, care managers and other social care professionals involved in statutory needs assessments and arranging care and support. It aims to support professionals to better understand MND, and the role they play in maximising independence and quality of life for people diagnosed with this fatal disease.

Information for you

We have a wide range of other resources for health and social care professionals, including items which may be particularly helpful to social care teams:

Occupational therapy for MND

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

Information sheet P7 – *NHS Continuing Healthcare*

Online module for care workers

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

www.mndassociation.org/careworkermodule

Information to share

We have a wide range of information for people with MND, their carers and family. Publications specific to social care include:

Information sheet 10A - *Benefits and entitlements*

Information sheet 10B – *What is social care?*

Information sheet 10C - *Disabled Facilities Grants*

Information sheet 10D - *NHS continuing healthcare*

Information sheet 10E - *Work and motor neurone disease*

Information sheet 10F – *Personal health budgets*

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

MND Checklist – designed to help someone with MND think about their wellbeing and the support they may need.

What you should expect from your care – based on the NICE Guideline on MND, this pocket-sized guide can help the person to open discussions with professionals and providers, and understand what support they should be receiving.

See page 53 for details of how to order our publications.

Mobility

Progressive muscle wasting in MND causes weakness and affects balance and posture. General muscle tightness and spasticity can affect mobility and co-ordination. Weakness can affect the limbs, neck and torso, and may lead to difficulties such as:

- pain
- increased risk of falls
- problems with balance and posture
- fatigue
- inability to adjust position
- difficulty with transfers
- challenges with all aspects of daily living.

Changes to mobility in MND can be very rapid, so regular review and reassessment of the person's needs is essential.

Equipment, aids and adaptations

Equipment, aids and home adaptations are very important to ensure the person with MND remains independent for as long as possible throughout the disease course, making the ongoing involvement of an occupational therapist essential.

As MND progresses, most people will need to use walking aids and then a wheelchair. You may be able to access an occupational therapist (OT) within your local authority or the GP team to support with this, or you may arrange the referral via the person's specialist team.

As symptoms of MND can progress rapidly, any provision needs to be delivered as soon as possible to be useful. Delays may lead to items no longer being suitable to the person's needs once they arrive.

Please see page 34 for detailed information about aids, equipment and adaptations.

Physiotherapy

Although muscles weakened by MND cannot be repaired, physiotherapy can help keep weakened muscles as strong as possible.

Strengthening healthy muscles not yet affected helps compensate for muscles that are no longer working properly. Regular exercise can help maintain muscle elasticity, improve range of movement for joints and prevent spasticity of muscles, improving comfort, reducing pain and stiffness.

Physiotherapy generally sits outside of the local authority's remit and can be accessed via the person's specialist team. If the person has not yet been diagnosed, or does not have a specialist team, the person's GP can make the appropriate referrals.

Some areas in the UK offer a self-referral service. However, this isn't available everywhere. Staff at the person's GP surgery or the local NHS Clinical Commissioning Group (CCG) or hospital trust should be able to advise whether this is available in your area.

Waiting lists for physiotherapy via the NHS can be lengthy, and some people choose to pay for private treatment. Most private physiotherapists accept direct self-referrals.

It is important that the physiotherapist has experience of progressive neurological conditions like MND.



Further information for professionals

Occupational therapy for MND

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

Information sheet P2 – *Wheelchairs for people with MND*

Information sheet P11 – *Pain in MND*

Information to share with people affected by MND

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

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

Information sheet 6A – *Physiotherapy*

Information sheet 6C – *Managing pain*

Information sheet 11C – *Equipment and wheelchairs*

Information sheet 11E – *Environmental controls*

See page 53 for details of how to order our publications.



Speech and communication

Over 80% of people with MND are affected by slurred, quiet speech, with many experiencing a complete loss of speech. This is caused by spasticity, largely resulting in weakness of the tongue, lips, facial muscles, pharynx and larynx. Breathing problems can lead to reduced volume and a breathy voice quality.

People may communicate in a range of ways, including using augmentative and alternative communication (AAC). This could include low tech equipment, such as eye-pointing frames and alphabet charts or high tech, portable electronic communication aids using computers or tablet devices.

It takes time and skill to ascertain the person's wishes, so it is best to allow them to prepare in advance and allow plenty of time for discussions. It can be useful to send the person a questionnaire or self-assessment form in advance to aid communication.

A person with MND's condition can deteriorate to the point where they cannot move or communicate verbally due to complete paralysis of nearly all voluntary muscles in the body except for eye movements. The person will still be aware. Communication may be possible through eye movements or blinking. It is important to establish communication techniques with the person to ensure any support is person-centred, and their wishes are known and accounted for.

When communication is severely limited, it is also important to consider and minimise risks, for example how to summon help and avoid isolation. For some people, eyelid movement is affected, and, in these cases, further exploration will be needed to find solutions, for example switch access may be an option if they can move a part of their body, even if only slightly. Breath-controlled switches are also available.

Early discussions about the person's future wishes and end of life care can help them make important plans and decisions before speech deteriorates. These conversations can be challenging for health and social care professionals and the person with MND. See page 39 for further information about end of life discussions.

Support for speech and communication support is available via a speech and language therapist, who may refer the person on to local AAC services following their assessment.

Further information for professionals

Communication, speech and language support

Information to share with people affected by MND

Information sheet 7C – *Speech and communication support*

See page 53 for details of how to order our publications.

Suggestions for communication

- Find out whether the person uses a simple code for yes or no, such as moving a part of the body like blinking or a finger movement.
- Find out how the person prefers to communicate and what equipment they use.
- Remember that non-verbal communication is important: sit face to face, and watch the person's eyes, facial expression, lips and gestures.
- Ensure the person with MND is the focus of the conversation.
- If the person's speech is unclear, encourage the person to slow down and over-articulate words to help clarity. Check back with the person what you think has been said and admit when you don't understand.
- Do not finish the person's sentences unless they ask you to.
- Use closed questions which can be answered with a single word.
- Be aware that communicating with AAC takes longer than speech. Allow extra time for the person to communicate.
- Providing notes or an agenda before meetings can help the person prepare ahead of time. People may feel awkward asking for extra support, so offer this.
- If technology is unreliable or fails during a meeting, be flexible and rearrange your meeting if needed.

Swallowing

Eating and drinking

As the face, mouth and throat muscles weaken, swallowing can be affected, making it difficult for the person to eat and drink. This can lead to weight loss and malnutrition if not managed. A speech and language therapist can assess the person's ability to swallow and advise on consistencies of food and drink. A dietitian can advise on diet, supplements and hydration.

The person with MND may experience coughing and choking episodes. Weakened breathing muscles make it more difficult for the person to cough and dislodge any food particles or secretions. This can be very distressing for the person and those around them.

Feeding can be managed through a gastrostomy, where a tube is inserted directly into the stomach through a hole in the abdomen. With a gastrostomy, the person can still eat and drink by mouth if they feel safe to do so and have been advised by a speech and language therapist.



Saliva and mucus problems

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

Some people with MND have a dry mouth, perhaps due to medication, dehydration or breathing through their mouth. The person should be supported to stay well hydrated - a dietitian can advise the person on how best to achieve this. Mouth care is also very important – see page 32 for further information.

The person with MND may use an oral suction unit, which removes secretions from the mouth, or a mechanical insufflation-exsufflation machine (often known as a CoughAssist). When a person is unable to cough well enough to remove secretions, this machine can help.

The person with MND, their carers and care workers will need appropriate training to use these machines. Machines are usually provided by the specialist respiratory team, or the multidisciplinary MND specialist team.

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 with people affected by MND

Information sheet 7A – *Swallowing difficulties*

Information sheet 7B – *Tube feeding*

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

See page 53 for details of how to order our publications.

Fatigue

Many people with MND experience fatigue, which has a negative impact on quality of life. It is usually experienced as an overwhelming tiredness that is not proportionate to the activities being undertaken. It tends to worsen throughout the day and is only partially relieved by rest.

Fatigue, and the anticipation of fatigue, may affect a person's motivation to continue with some activities of daily living. They may need support with some tasks to conserve energy for the activities that are most important to them.

An occupational therapist, either via the local authority or the MND specialist team can support the person with equipment and strategies to help manage their fatigue.

Suggestions for managing fatigue

Some practical tips you can share with the person include:

- keeping organised, avoiding wasted energy searching for items
- sitting rather than standing where possible, eg when washing dishes, ironing or preparing food
- using an electric toothbrush or razor instead of a manual one
- wearing clothing that is easy to put on and take off
- resting before and after a shower, wearing a towelling robe to dry off
- making larger meals and freezing extra portions for another day
- soaking dishes before washing them, and leaving to dry on a draining board
- placing chairs around the home to rest
- pushing, sliding or rolling items rather than lifting them
- having groceries delivered
- hiring help for household chores such as gardening and cleaners
- deciding on their priority activities each day based on what is most important to them.

Our *Personal care* guide includes information on managing fatigue. See page 53 for details of how to order our publications.

Breathing problems

Problems with breathing usually develop during the illness because the muscles involved in the voluntary control of breathing become impaired. The person may not be able to take in enough oxygen or expel enough carbon dioxide to meet the needs of their cells. This is known as respiratory insufficiency and is the usual cause of death in MND.

The person should be referred to the specialist respiratory team for regular monitoring and support for breathing problems. Depending on the needs and preferences of the person with MND, management of respiratory problems may include:

- breathing exercises
- physiotherapy
- advice on careful positioning
- guidance on effective coughing
- medication
- specialist equipment for assisted ventilation. See next heading.

Ventilation

Although ventilation may prolong survival, it will not stop the breathing muscles becoming weaker or slow the wider progression of the disease.

There are two options for ventilation in MND:

- non-invasive ventilation (NIV) - where a portable machine provides extra air through a mask
- ventilation by tracheostomy - where a machine supports breathing via a tube inserted into the windpipe through the neck.

Eating and drinking can become more difficult due to ventilation, as the flow of air may increase the risk of food or drink going into the airways (known as aspiration), and the person may need to consider having a gastrostomy for tube feeding. See page 11 for further information about swallowing and gastrostomy.

Depending on the impact of MND, and the type of ventilation used, the person may need 24 hours support to put on, take off or reposition their mask and operate the machine. If they have a tracheostomy, they will require support with suctioning to remove mucus and secretions from the throat and airway.

Tracheostomies decrease the ability to speak, and the person may need support to communicate in other ways.

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 53 for details of how to order our publications.



Cognitive change and dementia

There is now increased awareness of cognitive and behavioural changes in MND. About 50% of people with MND are affected, increasing to 80% in the final stages of the disease.

There is a wide spectrum of changes in cognition and/or behaviour in MND. Some people experience very mild changes which are barely noticeable, whereas for others the changes can be more pronounced. Around 15% of people with MND will develop frontotemporal dementia (FTD) which can have a major impact and will require additional support. See heading below.

Being alert to the possibility of cognitive change and/or behavioural change at any stage of MND can be valuable, as this may have an impact on service use and decision making.

Mild cognitive change in MND involves subtle and specific deficits, mainly affecting:

Executive function - includes the ability to set and achieve goals, to review and monitor performance and to adapt according to change and feedback.

Language - includes reduced verbal expression and initiation of conversation, problems with spelling, word-finding and understanding words and sentences.

Behaviour - includes disinhibition, acting impulsively without thinking, apathy, loss of sympathy and empathy for others. Some people experience hyper-orality and dietary change – overeating/cramming, altered food preference (often for sweet foods), excessive drinking or smoking.

Note: people who are cognitively normal can nonetheless have profound behavioural abnormalities. This is typically found in the early stages of FTD.

Cognitive change is strongly associated with an increased burden on carers. Many carers are unprepared for this symptom of MND, as they have not been made aware it can occur. The needs of family members and carers should be assessed, and support strategies put in place.

Cognitive or behavioural change may not affect daily life at first, but will progress over time. Issues may also emerge when the person faces new challenges, making ongoing reassessment essential. The MND specialist team, along with neuropsychology services can offer support for cognitive change and dementia.

Frontotemporal dementia (FTD)

Around 15% of people with MND develop a type of dementia called frontotemporal dementia (FTD), which involves severe behavioural and cognitive change. People with FTD display similar difficulties as those with milder cognitive change described above, however the changes will be more severe, and may include marked personality changes including aggression.

The person may be at an increased risk and require close supervision. For example, they may use household products and appliances incorrectly. Some people with FTD experience changes to their appetite, and may begin cramming food, which could be dangerous if the person has swallowing difficulties. Other examples of potentially dangerous situations include the person pulling out their tube if fitted for tube feeding, which may require medical attention.

Some people display inappropriate and disinhibited behaviour. This may put others at risk, as well as the person with MND.

People with MND who also have FTD may lack mental capacity to make certain decisions, and care should be taken to ensure informed decision-making, in line with the Mental Capacity Act 2005.

If the person is in hospital or a care home, the Deprivation of Liberty Safeguards (DoLS) can help ensure the person's freedom is not inappropriately restricted, and that arrangements are in their best interest.

The DoLS process should be followed if the person:

- is under continuous supervision and control in a care home or hospital, and
- is not free to leave, and
- lacks capacity to consent to these arrangements.

Professionals must be aware of the risks to carers and family where behavioural changes include aggression. A combination of lack of empathy and self-seeking behaviour may lead to family and carers, or the person themselves being in danger, especially if the person has good mobility. Situations such as these will be challenging for everyone involved, and day-to-day management must be considered.

Families may wish to explore residential or nursing care options in this situation.

Where a person with MND and FTD is being cared for at home by family members, there is an increased risk of the informal care and support breaking down. There may also be a risk of relationships with care workers breaking down, so contingency planning is essential.

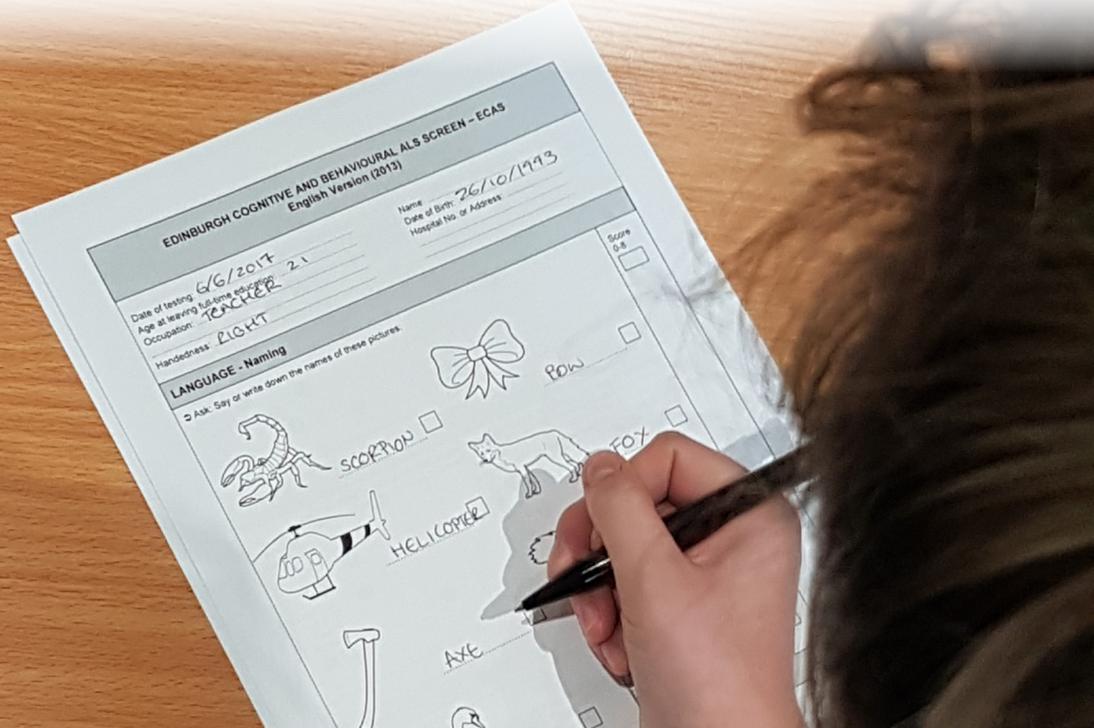
Information for you

Cognitive change, frontotemporal dementia and MND

Information to share

Changes to thinking and behaviour with MND

See page 53 for details of how to order our publications.



Psychological impact

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 emotional distress.

Emotional reactions may include:

- denial of diagnosis and what it means
- anger as a result of frustration or lack of control
- feelings of hopelessness
- fear of 'choking to death' or 'fighting for breath'
- loss of independence and dignity
- increasing dependence and becoming a burden
- fear of the unknown, death and the process of dying.

It is important to acknowledge the impact of a diagnosis of MND, and not to dismiss this by glossing over it or changing the subject if it feels uncomfortable.

Reassure the person that you are there to listen to their concerns and support them. Much can be done to alleviate distress, help people to adjust and make the most of their coping skills. Allow the person to express their thoughts, feelings and concerns – this can help you identify what information or support they need.

Remember that communication problems or cognitive change may affect the ability of someone with MND to share their thoughts and feelings.

The person's GP can prescribe medication to help alleviate anxiety or panic attacks (eg feelings of fighting for breath). The GP can also refer the person for psychological support eg counselling services. Local hospices can offer additional services, including emotional support, counselling and complementary therapies.

Information to share

Making the most of life with MND

Emotional and psychological support

See page 53 for details of how to order our publications.

Emotional lability

Some people with MND experience emotional lability (also known as pseudobulbar affect), which can result in uncontrollable laughter or crying. There may be inappropriate responses at embarrassing times, for example laughing during a funeral or when in pain. This can be disturbing to both the person and those around them.

It is important to reassure the person and their family this is a factor of MND, as some people find it easier to manage the impact when they understand the cause. The person's MND care team may be able to provide medication and strategies to help with this symptom.



Providing advice and information

Many people will be unfamiliar with how health and social care systems and provision work. MND can be overwhelming, adding to confusion and potential misunderstandings. High quality information and advice is essential to support the person to remain in control and make well-informed decisions about their care and support.

The Care Act 2014, and the Social Services and Well-being (Wales) Act 2014 introduced new responsibilities for local authorities around the provision of information and advice.

It is important to ensure that information and advice is available on:

- how the social care system works in the area
- the types of care services and providers available locally
- how to request an assessment of care needs
- how to access services (including housing services and benefits)
- how to raise concerns over the safety or wellbeing of someone with care needs
- how to get independent financial advice
- support available for carers.

People have a right to receive information in a format that is suitable to their individual needs. Some local authorities signpost people to their websites for this information, which may not be appropriate for someone with MND, as they may not be able to use a computer.

Offering the information in a range of formats, or in person, may be more appropriate depending on the progression of MND – see also next heading. It is also important to ensure that information is available in a range of languages, or that a translator service is available if needed.

Accessibility

The Accessible Information Standard (AIS) was introduced by the Government in 2016 to make sure that people with a disability or sensory loss are given information in a way they can understand. It is a legal requirement for the NHS and adult social care services to comply with the standard.

If the person with MND has cognitive change or frontotemporal dementia, easy read information may be suitable. If the person is unable to use their hands, audio or digital formats may be more appropriate. It is important to ask people if they have any information or communication needs and what support is required.

Further information about the Accessible Information Standard is available at www.england.nhs.uk/accessibleinfo

Signposting to the MND Association

In addition to the local information and signposting you usually provide people with, informing them of the support available from the MND Association can be very helpful.

To access any of the services or support listed in this section, please contact our MND Connect helpline. See page 54 for contact details.

MND Connect helpline

Our helpline provides support and information for people living with MND, their carers and families, our volunteers, and health and social care professionals. The team can direct to practical support, including our own services and appropriate external organisations. If someone simply needs to talk, they can listen.

Association visitors (AVs)

The AVs are trained, experienced volunteers who are able to provide emotional/informal support to people with MND, their carers and close family and friends. This is dependent upon the location and availability of the AVs.

Local branches and support groups

We have a network of more than 85 branches and groups, run by volunteers, throughout England, Wales and Northern Ireland. They provide the opportunity to meet others affected by MND. They offer guidance and support, including group meetings specifically for carers. People can share emotional and practical support, and exchange information.

Care information and publications

We provide over 70 items of care information and publications for people with MND, carers and families. These cover a wide range of topics from ventilation and end of life to planning holidays and driving. We provide introductory information in additional languages to English, and a limited translation service for further care publications. Visit www.mndassociation.org/careinfo

MND support grants

The Association is able to offer some financial support to help with:

- funding equipment and services that people with MND have been assessed as needing
- funding for children and young people aged 18 or under living with someone with MND
- non-paid carers supporting someone living with MND (available up to 12 months post-bereavement)
- improving quality of life for someone living with MND.

These are not in place of any statutory funding that should be available, however we can assist with obtaining statutory funding or funding from other charitable organisations.

Visit www.mndassociation.org/supportgrants for more information.

Online forum

Our online forum is a safe place to share experiences, ideas and a wealth of information, with other people affected by MND. The person can visit <https://forum.mndassociation.org> to view posts or register.

MND Association Benefits Advice Service

Our trained advisers can help identify benefits a person may be able to claim if living with MND or a carer. The service is available by telephone or email for people living in England, Wales or Northern Ireland, and there is also a web chat facility for those living in England or Wales.

Visit www.mndassociation.org/benefitsadvice for further information.

Providing urgent support

MND can progress very quickly, and some people may be reluctant to access services until they are in urgent need of support. Some local authorities have urgent response teams that can provide emergency support in a crisis, though this is often limited in its scope and how long they can support people for.

In England and Wales, urgent support may be accessed as outlined below. In Northern Ireland, eligibility for support is decided locally by each Health and Social Care Trust.

Care Act 2014 Section 19 (3): Power to Meet Needs Appearing Urgent

The Care Act makes it clear that a local authority can meet needs for care and support which appear to be urgent regardless of whether:

- the adult is ordinarily resident in its area
- there has been a needs assessment
- there has been a financial assessment.

The local authority may meet an adult's needs under subsection (3) where, for example, the adult is terminally ill within the meaning given in section 82(4) of the Welfare Reform Act 2012.

The definition of terminal illness states *"a person is "terminally ill" at any time if at that time the person suffers from a progressive disease and the person's death in consequence of that disease can reasonably be expected within 6 months."*

Although the Act states a six month timescale, the SR1 form allows people to be fast-tracked for benefits if their death is expected **within the next year**. This means quicker and easier access to fast track Personal Independence Payments, Attendance Allowance and other benefits.

Social Services and Well-being (Wales) Act 2014

Section 35-36: Duty to Meet Care and Support Needs of an Adult

The Act states that a local authority must meet an adult's needs for care and support if "the local authority considers it necessary to meet the needs in order to protect the adult from abuse or neglect, or a risk of abuse or neglect".

The person must be within the local authority's area, or ordinarily resident in that area. A local authority has the power to meet needs under this section whether or not it has completed a needs assessment or a financial assessment.

NHS Continuing Healthcare – Fast Track Pathway

The Fast Track Pathway should be used for people with rapidly deteriorating conditions such as MND, who may be approaching end of life and need an urgent decision to be made regarding eligibility.

It allows people to access NHS Continuing Healthcare quickly, with minimum delay, and with no requirement to complete the NHS Continuing Healthcare Checklist or the Decision Support Tool that are usually necessary. The Fast Track Pathway Tool is in itself enough to establish whether the person is eligible.

There are still misconceptions among professionals that only those with a certain number of weeks prognosis are eligible. The National Framework states that *"strict time limits that base eligibility on some specified expected length of life remaining should not be imposed: it is the responsibility of the appropriate clinician to make a decision based on the needs of the person"*.

The Fast Track Pathway Tool must be completed by an appropriate clinician, defined by the National Framework as a person who is:

- responsible for the diagnosis, treatment or care of the individual
- and**
- a registered nurse or a registered medical practitioner.

If you believe the person with MND needs to be fast-tracked, you should contact the clinician responsible for the person's diagnosis, care or treatment, and ask them to consider completing the Fast Track Pathway Tool.

Fast-tracked recommendations for CHC should be accepted and actioned by the CCG immediately. If there are any challenges to the use of the tool, the person's care package should be delivered, and they should not experience any delays while concerns are addressed.

Once someone is found eligible for CHC using the fast track tool, their funding should not be removed without a full review of their eligibility by a multidisciplinary team using the Decision Support Tool.

If the person has health-related needs but does not yet meet the criteria for the fast track timescale, a CHC checklist and subsequent Decision Support Tool should be completed.

Information for you

Information sheet P7 - *CHC for MND*

Information to share

Information sheet 10D - *NHS Continuing Healthcare*

See page 53 for details of how to order our publications.



Care and support needs assessment

There is often an emphasis in local authorities, on exploring other resources which may meet the need and minimise risks to the person, prior to arranging any formal care. This can be detrimental to someone with MND, due to the rapid progression many experience.

It is important to get care in place as quickly as possible. Additional resources can be explored at a later time, and the care package adapted if needed.

Whole-family approach

MND affects everyone in the family. Roles within the household shift, and any member of the family may require support. It can be very helpful to adopt a whole-family approach, where a needs assessment looks at the impact of a condition or situation for the whole household. This may result in additional family support for younger members or dependents.

The whole family approach can help ensure suitable services are arranged. This may reduce the pressure of care and enable the family to better face the challenges of MND as a team.

For information about supporting families and carers, see page 43.



Multidisciplinary working

Due to the complexity of MND, it is likely that a large number of health and social care professionals will be involved in the person's care and support at any one time.

A multidisciplinary approach can help ensure different services are well co-ordinated so the person can receive the best possible care. This allows professionals from multiple disciplines to work together to explore problems outside of normal boundaries, and reach solutions based on a new understanding of complex situations.

Professionals in the person's multidisciplinary team are a vital source of information when carrying out an assessment, so ask the person with MND for details of their care team.

Many people with MND will have a named MND co-ordinator who works with the MDT, who can also assist with providing additional information about the person's needs now and in the future.

Mental capacity

As discussed on page 16, some people with MND may experience cognitive change or frontotemporal dementia. This may impact on the ability to make certain decisions. This should be assessed for each decision in line with the Mental Capacity Act 2005. Wherever possible, the person should be supported to make their own decisions.

Some people may experience extreme fatigue and respiratory problems that impact on their mental capacity at certain times, but this may fluctuate. Infections may also reduce someone's mental capacity temporarily. It is best to reassess this regularly to maximise autonomy and choice.

Communication difficulties can make it challenging to establish someone's mental capacity and their wishes, so liaising with other professionals, family and carers can help to find the best way to communicate and establish mental capacity.

If you are in doubt about the person's mental capacity to make decisions, liaising with the person's MND care team can be helpful. They may have already completed an assessment and can advise on strategies to support decision making.

Practical considerations for home visits

- Give additional time for home visits to account for the extra time communication may take and any breaks the person may need.
- Find out what time of day is best to visit – the person may have more energy in the mornings.
- Consider sending a questionnaire in advance for the person to prepare for the meeting in their own time. This can be helpful as communication may be very tiring for the person.
- Explore whether a member of the person's MDT can do a joint visit with you. This can promote an open, collaborative working relationship and they may be able to fill in gaps.
- Family and carers will have expert knowledge of the person and how MND affects them currently.
- The person may have symptoms they find embarrassing, such as drooling or laughing/crying uncontrollably (emotional lability). Being prepared for this can be helpful in reassuring the person.
- As MND progresses quickly, the person may be in denial, having not fully accepted their diagnosis, or be in great emotional distress.
- Every effort should be made to understand the person's needs, wishes and preferences.
- When someone has advanced MND it may be easy to assume they have little quality of life, but the person themselves may perceive it differently, so ask for their thoughts and perceptions.
- Check if the person has completed an Understanding my needs booklet, or a similar record of their needs you can refer to.
- The initial home visit can be a good opportunity to share information about the MND Association if the person is not yet aware of the support we can offer. See pages 22-24.

Support planning and provision

Continuity of care

MND symptoms can get worse suddenly, and it is important to ensure that everyone involved in the person's care and support understands the disease. Consistency of care staff, and other professionals is important to ensure this. Cases should be kept open with a named worker to ensure prompt responses if the person's condition or situation change suddenly. Familiarity can also be beneficial to ease communication with the person with MND.

Continuity can be difficult if funding changes from the local authority to NHS Continuing Healthcare due to the loss of rapport and relationships if certain carers or other professionals are no longer able to support. Handovers to new staff should be done with sensitivity and careful planning to ensure the person with MND is informed and supported through the changes. It is important to ensure the new worker understands MND and how to support the person.

Care workers

Care workers involved in the person's care may require training, depending on how the person is affected by MND. For example, staff may need to be trained in:

- oral suction using a portable suction unit
- operating a ventilator, or machine to help the person cough
- adjusting and changing ventilation masks
- suctioning tracheostomies
- hoisting and manual handling
- feeding via gastrostomy
- administering medication.

Training may be available from the person's specialist MND team or via the care worker's agency. Local specialist care agencies may have staff with the appropriate skills and relevant training.

Movement and handling

The loss of muscle bulk and strength can make joints stiff and painful. Care is needed when lifting, handling and positioning to avoid causing pain or dislocation of weak joints. Care workers should be trained how to move the person as comfortably and safely as possible. A physiotherapist and/or occupational therapist can advise on safe techniques and equipment that may help.

Personal care

For people with MND, washing, dressing and toileting can take a long time, and they may need support with all aspects of personal care.

A wide range of strategies and equipment is available to support people to be as independent as possible, and also to make personal care easier for care workers and carers. These should be explored with an occupational therapist.

Oral care

Although MND does not directly affect the teeth or gums, the progressive nature of the disease can lead to poor oral health and make mouth care challenging. Weakness of the arms and hands can make it more difficult to carry out mouth care tasks.

Weakness in the tongue, mouth and throat can lead to swallowing difficulties, problems with mouth opening and aspiration. It is important to highlight to carers the importance of daily oral hygiene for people with MND. Training and guidance may be available from the person's dentist or MND Team.

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 53 for details of how to order our publications.

Direct payments and personal health budgets

If the person with MND meets the national eligibility criteria, the option of direct payments (or a personal health budget if NHS Continuing Healthcare funded) should be explored. This is a sum of money given to the person following an assessment of their needs, enabling them to organise and pay for their support, rather than the local authority or the NHS if health funded.

The increased flexibility will allow the person to arrange their care to meet their changing needs. Support options for managing the direct payment or personal health budget, both now and as their condition progresses, should be discussed.

It is important to include a contingency plan in case the person's informal or paid care breaks down for any reason. They should be advised what to do should this situation occur. Depending on how quickly the disease is progressing, reviews of direct payments may need to be carried out more frequently than usual.

For some people with MND, becoming an employer using direct payments or personal health budgets may be challenging to manage. The burden of recruitment, payroll and tax can be eased through use of a broker who can help with employment issues.

If the person prefers, the local authority or NHS Continuing Healthcare team can arrange the services directly on their behalf instead of providing a direct payment.

Carers have a right to a carer's assessments in their own right, which can result in a direct payment or support to meet their needs, for example training or short breaks.

Information to share with people with MND

Information sheet 10B – *What is social care?*

Information sheet 10F – *Personal health budgets*

See page 53 for details of how to order our publications.

Aids, equipment and adaptations

As MND progresses, mobility and comfort become more difficult to manage. Aids, equipment and home adaptations are essential to support the person with MND to remain at home for as long as possible.

An OT should be involved to help maximise the person's independence and comfort using aids and equipment. Larger adaptations such as building a wet room, installing ramps and widening doors may require an application for a Disabled Facilities Grant (DFG).

Disabled Facilities Grants (DFGs)

Local authorities can take many months to appoint an occupational therapist, complete the assessments and make a decision about eligibility for a DFG. Some occupational therapists may be unfamiliar with MND as it is quite a rare disease. They can get additional information from the person's health care team, or the MND Connect helpline. Email mndconnect@mndassociation.org or call 0808 802 6262.

In the case of a rapidly progressing disease like MND, it is important that applications are fast-tracked wherever possible as the person may not have time to wait. It is also essential to plan ahead, as the person's needs will continue to increase, and equipment may no longer be suitable by the time it is installed. Careful planning and liaison with the person's health care team can help avoid the need to apply for another DFG when the person's needs increase.

Foundations are an organisation contracted by the Ministry of Housing Communities and Local Government to support local authorities to improve the delivery of DFGs. Their website offers a range of useful information, practical resources and services such as training and regional advisers. Visit www.foundations.uk.com for further information.

Self-funded adaptations

If the person wishes to fund their own adaptations, we highly recommend they consult with an occupational therapist to ensure that they are suitable for their needs.

The person may wish to seek support from a home improvement agency, also known as Care and Repair in England and Wales, or Radius Housing in Northern Ireland. These agencies can provide information and advice about funding the work, contracting a reliable builder and supervising the building work. Some offer other practical help such as a handyman service which carry out minor adaptations such as installing grabrails.

Wheelchairs for MND

As the condition progresses, most people with MND will need to use a wheelchair. Provision from statutory services can take several weeks. Because MND is a rapidly progressing condition, a timely referral to wheelchair services is critical.

Someone with MND should be referred to wheelchair services as soon as they start to experience mobility problems and are willing to accept the need for a wheelchair.



Environmental controls

Environmental controls can assist someone with MND to operate a wide range of appliances and equipment using a remote control or switch. Environmental controls can be programmed to operate doors, alarms, curtains, lights, fans and almost any other electrical appliance.

The person can select their options using a wide range of switches and buttons that can be operated using direct touch (for example with a hand, foot or other part of the body that has movement), eye movement, head movement or breath.

Some have a scan and switch system, where options appear on the screen and the person uses a switch when the correct option appears.

A person with MND can be assessed for suitable environmental controls by the local OT. If the person is eligible, they will be referred to a specialist environmental control service. In some areas, referrals can be made by any health and social care professional.

Further information for you

Information sheet P2 – *Wheelchairs for people with MND*

Occupational therapy for MND

Information to share with people affected by MND

Information sheet 10C - *Disabled Facilities Grants*

Information sheet 11C - *Equipment and wheelchairs*

Information sheet 11E - *Environmental controls*

See page 53 for details of how to order our publications.

Travel and transport

Travel and transport will be an important consideration. People with MND who drive are legally required to disclose their diagnosis to the DVLA, or DVA in Northern Ireland. They must also inform their car insurance company. Failure to do so is an offence and may make their insurance policy invalid.

A wheelchair accessible vehicle or other adaptations can support the person to continue driving for as long as possible. Depending on their symptoms they may be able to continue driving for a while, but ultimately, they will need to explore other options such as public or community transport, taxis or being driven by someone else. Ongoing transport needs should be considered as MND progresses.

The person may be entitled to Personal Independence Payments, which includes a component to assist with mobility costs. Further information, and contact details for the Department of Work and Pensions is available at www.gov.uk/pip

The Motability Scheme enables anyone in receipt of a higher rate mobility allowance (such as the enhanced rate of the mobility component of Personal Independence Payments) to use their mobility allowance to lease a car, scooter, powered wheelchair or wheelchair accessible vehicle. Visit www.motability.co.uk for further information.

Information to share

Getting around with MND guide

See page 53 for details of how to order our publications.



Work

The person with MND may wish to continue working for as long as possible, and adjustments to their work environment may be needed. Employers have a legal responsibility to make certain changes (known as 'reasonable adjustments') to ensure the person is not disadvantaged when doing their job. These could include changing working hours/location or providing equipment. The person also has the right to ask their employer to consider flexible working hours.

The Access to Work scheme may be able to assist with funding for equipment, adaptations, support workers or help getting to and from work. For further information, visit www.gov.uk/access-to-work

The Advisory, Conciliation and Arbitration Service (ACAS) are also able to provide specialist advice and guidance regarding employment issues. Further information can be found at www.acas.org.uk

The person may decide to leave work, which can impact on their social networks and finances. They may wish to consult with a pensions or financial advisor, or seek legal advice. See page 24 for details of the MND Association Benefits Advice Line who can discuss the options available.

Information to share with people affected by MND

Information sheet 10E - *Work and MND*

See page 53 for details of how to order our publications.

Reviews

MND can progress very quickly, so it is essential that the person has frequent reviews to re-evaluate their agreed key outcomes and support package. This should be done sensitively, as it is likely the person's abilities will have declined.

It is important the person knows how to inform you if their needs or circumstances change between reviews, and that contingencies are in place to enable them to access additional support while the review or reassessment is taking place.

Palliative and end of life care

The Association of Palliative Care Social Workers

The Association of Palliative Care Social Workers work to raise the profile of palliative care social work and inspire excellence by sharing best practice. They have a wide range of useful resources, including *The Role of Social Workers in Palliative, End of Life and Bereavement Care* (2016). Their resources are available at www.apcsw.org.uk/download-resources

End of Life Care for All (e-ELCA)

This e-learning programme aims to support professionals to confidently deliver high quality care to people who are in their last days of life. It includes modules on communication skills, advance care planning, social care, spirituality and bereavement. Visit www.e-lfh.org.uk/end-of-life-care for further information.

Discussing end of life

People with MND may have many concerns about the progression of the disease, the process of dying and death itself. They may or may not express these fears openly. The person should be encouraged to discuss their preferences and options for end of life care. Conversations may become more difficult if the person's speech deteriorates or they experience cognitive change.

Time and good communication skills are needed for the person to feel comfortable enough to express their worries. It is important that concerns are taken seriously and acknowledged compassionately. Solutions, where possible, should be made available.

It is important the language used, while remaining sensitive, is clear and easy to understand. This means not being afraid to use words such as 'death' and 'dying' instead of euphemisms. This may feel difficult at first, but if the person with MND and those close to them are ready for it, this clarity is vital.

The person's specialist palliative care team or MND care team may be able to support you with difficult or important conversations. Local hospice social workers may be able to provide advice, guidance and reassurance.

Advance care planning

A person with MND can influence how their care will be managed in the later stages of the condition using advance care planning. The person with MND should, with their health care team, discuss medical decisions about topics such as artificial feeding and ventilation, resuscitation, their preferred place of care/death and who they want to be involved in their care.

Within the law they are able to record advance decisions to refuse or withdraw treatment in the event they become unable to communicate these decisions for themselves. This is known as an Advance Decision to Refuse Treatment (ADRT) and is legally binding if it is valid and completed correctly.

Suicide and assisted suicide

Living with MND can create fear about what will happen as the disease progresses. You may be asked about suicide and assisted suicide.

People with MND may consider suicide for fear of becoming a burden or due to other concerns about independence. Discussion is crucial in order to explore and understand these issues. Let the person know that thoughts of suicide are common among people with MND.

Being able to explore the reasons for these thoughts and knowing they are not alone can help. If suggestions or solutions to their concerns can be provided, thoughts of suicide often subside.

The information below explains what is and isn't allowed within the law (at time of publication). It is not intended to replace legal advice or act as guidance to take any specific action, but simply to provide the facts.

It is **legal** for someone to:

- take their own life
- refuse life-sustaining treatments they feel are no longer helpful or have become a burden. This is not assisted dying.

It is **not legal** for someone to:

- encourage another person towards suicide (including advising them how to do this)
- assist them with their suicide.

Health and social care professionals found to be assisting someone's suicide could face prosecution and up to 14 years' imprisonment.

Liaise with the person's specialist palliative care team or MND care team for advice and support in managing conversation about suicide and assisted suicide, as they will have experience of this.

The Royal College of Nursing has produced *When someone asks for your assistance to die: RCN guidance on responding to a request to hasten death* to support health and social care professionals in practice who may be asked to become involved in assisting suicide.

It is available from the RCN website:

www.rcn.org.uk/clinical-topics/end-of-life-care/professional-resources

Involving palliative care services

Palliative care is the active holistic care of people with advanced, progressive illness. It involves:

- management of pain and other symptoms
- psychological support
- social support
- spiritual support.

The aim of palliative care is to achieve the best quality of life for people with MND, their families and those close or important to them. It is important to distinguish between palliative and end of life care.

Many people believe that palliative care is just offered near the end of life, but the terminal and unpredictable prognosis of MND means it is vital that people with the disease are offered access as early as possible, so that symptoms and support can be managed effectively. Many aspects of this type of care are applicable earlier in the course of the illness in conjunction with other treatments.

While early links with specialist palliative care services can provide a useful source of advice and support, introducing this concept may present some difficulties. This is often because people are unaware of what palliative care is and what it can provide. It is important to explain the role of the palliative care team and the potential benefits they can offer to the person's quality of life. It might help to introduce the service via day care, respite and complementary therapies.

Palliative care support may be available in different settings, including at home, in hospital, in MND care centres and networks or in hospices. They may offer day care, respite care and inpatient admission for symptom control or end of life care.

If palliative care includes referral to a hospice, it is important to stress this does not always mean that death is imminent, as many people mistakenly view hospices purely as places where people die.

Further information for you

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

MND in acute, urgent and emergency care

Information to share with people affected by MND

End of life: a guide for people with MND

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

Information sheet 8C - Withdrawal of ventilation with MND

Understanding my needs – A record of someone's needs to help professionals provide appropriate support.

See page 53 for details of how to order our publications.

Supporting carers and families

Many people providing unpaid care for someone with MND will not recognise themselves as a carer. They may not be aware that identifying as a carer will enable them to access specific support and benefits.

Carers can experience pressures on emotional and physical health, as well as financial difficulties. It may not be possible to provide solutions to every problem, but much can be achieved by listening to carers and their experiences.

Carers of people with MND need advice, support and information to help them make sense of what is happening, to enable them to continue in their caring role and to help them plan for the future. Good quality and timely care and support can have a positive effect on emotional wellbeing and help prevent a crisis.

Not every person with MND will have family or friends to support them. These people may have additional practical and emotional needs that cannot be met without external support.

Where a relationship was poor before the MND diagnosis, it can sometimes improve, but it may also get worse. Professionals should be aware that, in some cases, this can lead to a relationship breakdown. The person may need external care if family or friends cannot help and should be referred as promptly as possible to social care services.

MND forces changes in roles and relationships. Consider:

- mapping the social support system of the family using a genogram
- meeting the information needs of all family members
- counteracting isolation of individuals and promoting awareness of each other's needs
- offering early opportunities for short periods of respite to prevent over-dependence on a single carer
- other concurrent life events, such as moving house, financial difficulties etc and linking the family with supportive services
- exploring how MND changes relationships and acknowledge the strain of this, and also the ways in which they are strengthened

- creating opportunities for people to express negative feelings without feeling guilty
- the impact of other dependants, such as older relatives or children who the family may be supporting or caring for
- how carers may experience exhaustion from the caring role, exacerbated by powerlessness to prevent suffering and further deterioration
- the right of a carer to decide to stop carrying out that role, and how best social services can support the family in this situation.

Information to share with carers

Caring and MND: support for you - Comprehensive information designed to support individual needs during the caring role.

Information sheet 10B – *What is social care?*

See page 53 for details of how to order our publications.

Carer's assessments

Carers who provide a substantial amount of care on a regular basis have a legal right to an assessment of their needs. These are usually carried out by their local authority or health and social care trust. The assessment should anticipate the progression of MND and future needs so crisis points can be avoided.

Carers of people living with MND may need regular, planned breaks from caring. As a key feature of the disease is the speed of progression, many carers find themselves continually trying to meet unrelenting demands. Without breaks, carers will be less able to perform their caring role and their own health may suffer.

Respite may involve care at home, in a day centre or hospice day centre, or a residential setting. It can allow the carer to go out and retain social contact.

Carers of people affected by FTD and MND may require additional support if they wish to continue in their caring role.

Children and young people

The increasing needs of the person with MND, possible reduced family income and changed quality of life can all impact on children. A child or young person may experience:

- panicking at school
- falling behind with their studies
- an increased feeling of isolation and of being different
- reduced freedom to act on impulse, such as visiting friends
- missing out on activities that cost money
- limited social and recreational time due to caring responsibilities
- problems making and keeping friendships
- difficulties fitting in
- anxiety about situations where talk turns to MND
- inability to cope in social situations as self-esteem may be affected.

The person with MND may need support to manage their parental role, such as getting children ready in the morning and transport to school. Generally, support for disabled parents is provided by adult social care services. If this support is not sufficient to meet the child's needs, they may be able to access help from children's social care services. Adult social care services should work alongside children's social care services to help both the parent and child.

Further information for you

Supporting children and young people close to someone with MND

Information for children and young people

So what is MND anyway? - For young people, including young carers.

When someone close has MND - An interactive workbook for children aged four to ten

Why are things changing? - Storybook for children aged four to ten

MND Buddies – Our activity hub for children aged four to ten. Visit www.mndbuddies.org

See page 53 for details of how to order our publications.

Young carers

Depending on the family's circumstances, children and young people who live in a household where someone has MND may be involved in providing care, such as:

- offering emotional support and comfort
- helping the person with MND to communicate when speech is affected or absent, including telephone calls, emails and letters
- collecting prescriptions and administering medication
- managing household tasks such as shopping, housework, laundry, gardening and home maintenance
- caring for younger siblings
- preparing meals or assisting with tube feeding
- delivering personal care, such as bathing, dressing and feeding
- supporting a person who has cognitive changes or dementia
- providing care at night
- making appointments and accompanying the person with MND
- supporting the person with hobbies or leisure activities.

Young people who are caring for someone with MND are entitled to a young carer's needs assessment. Liaising with their school can also help to ensure they are receiving the support they need. An Early Help Assessment for children who are not providing care within the family will enable them to access targeted support, including emotional support.

Children and young people in the family may benefit from a referral to a specialist service such as the school nurse or Child and Adolescent Mental Health Service (CAMHS) in order to access appropriate therapies, such as emotional or psychological support or practical help with their education.

Psychological support for carers and family

The carers and families of those living with MND often experience considerable psychological and emotional distress. Assumptions, hopes, plans and expectations for the future may have to be reviewed.

Caring for someone with MND can be physically and emotionally challenging and often leads to feelings of isolation.

Allow carers time to talk about the impact MND has on them and their family. It may be more appropriate to talk to the carer separately from the person with MND, so they can be more open about their needs. Let them express and explore their feelings.

By asking questions, you will find out how safe it is to talk about particular issues. A carer may not discuss these feelings and fears spontaneously. Reassure the carer that it is natural to have intense and conflicting emotions about the situation they are in.

MND involves many losses: carers need time to grieve for the past and how things were, the present situation and their loss of a future with the person they care for. Discuss with the carer/family what type and frequency of support would help reduce anxiety and fear.

Carers may benefit from being in contact with other carers of people with MND. The MND Association can sometimes provide a volunteer Association visitor. Volunteer-led MND branches and groups run local support meetings for carers and families. See pages 22-24 for further information about these services.

It might help to talk to other carers through our online forum at <https://forum.mndassociation.org>

Bereavement

With MND, a sense of loss is often felt throughout the course of the disease. This is known as anticipatory grief. After the person with MND has died, their family and carers may experience a range of difficult emotions which can feel overwhelming.

Supporting the bereaved person to recognise the emotions felt with grief can be helpful. A bereavement counsellor can help the person to work through their feelings.

Support is available from:

GPs: They can carry out a health check and refer the person for specialist support if needed. They often have information about local grief support.

Palliative care professionals: If the person with MND was supported by palliative care specialists, eg in a hospice or hospital, they usually offer bereavement support to the person's immediate family.

MND Connect: Our helpline provides information, emotional support and help to access services.

Association visitor (AV): These are MND Association volunteers who support people with MND and their carers. If the person was supported by an AV, this can continue into bereavement if they agree. Many AVs have personal experience MND.

MND Association branches and groups: Our local branches and groups offer guidance and support, and often get together for meetings or events. Some bereaved carers may find this helpful. Some offer support meetings for past carers to share their experiences.

Support groups: Other groups may offer a chance to meet people in the same situation. These may be run by local hospices or local carer's organisations.

Voluntary organisations: Many charities offer bereavement support. Search online to find out what is available in your area. At a Loss offer signposting to local bereavement support. Visit www.ataloss.org for further information. Cruse Bereavement Care have a national helpline and offer local services. Visit www.cruse.org.uk or call 0808 808 1677.

MND Association forum: The MND Association has an online forum where people living with and affected by MND share experiences and support each other. It includes a section about bereavement. It can be accessed at <https://forum.mndassociation.org>

MND Association support grants: Our carer's support grant is available up to 12 months post-bereavement.

Information to share with family and carers

Visit our bereavement webpages:

www.mndassociation.org/bereavement

Finding your way with bereavement booklet

See page 53 for details of how to order our publications.

Checklist

The points below are not all directly part of a social worker's role or remit. However, social workers can help ensure people are receiving the best care possible by working closely with other professionals to ensure all bases are covered, including those that are the responsibility of other agencies.

Initial actions

- Does the person have a multidisciplinary MND care team you can liaise with?
- Are key health professionals, such as occupational therapist, speech and language therapist and dietitian in place?
- Has the CHC checklist been completed? If appropriate, has a fast track tool been completed by a relevant professional? Support should not be withheld while CHC is explored.
- Does the person and their family have enough information about MND and the support the MND Association can provide?
- Is urgent care required prior to undertaking a full assessment?
- Do I need further information about MND?
- Does the person have the mental capacity for the decisions they are being asked to make? If in doubt, arrange a mental capacity assessment.
- Does the person or their carer need information and advice about benefits? If so, signpost to MND Association Benefits Advice Service (see page 24).
- If any children are involved, approach children's social services to work together.

Mobility

- Is the home suitable for wheelchair and equipment use as MND progresses? Refer to occupational therapist.
- What support is needed for repositioning to maximise comfort and the avoidance of pressure sores? How will this be managed during the night? Refer to occupational therapist.

- What leisure or community activities is the person involved in? How can these be continued as physical disability progresses?
- What support is required for personal care, including oral care and toileting?
- How will the person manage tasks such shopping, cooking, holding cutlery and cleaning up?
- What additional support is required if the person lives alone?
- What needs does the carer have? Do they need support or training?
- What extra support will be needed if the person has cognitive change?

Speech and communication

- Do I need to allow additional time during home visits?
- How best can I communicate with the person to understand their wishes? Do they have a simple code for yes and no?
- Who can help with communication?
- Can the person contact me via email or text message instead of phone call?
- Can I send a questionnaire or self-assessment form in advance to allow the person to prepare?
- How will the person be able to summon help? Is telecare appropriate?
- Would environment controls help? If so, make a referral.

Eating and drinking

- What adaptations are needed for cooking and eating? Is an occupational therapist involved? If not, make a referral.
- If the person has a gastrostomy, how will care workers be trained to give feeds and medications, and how will it be kept clean?

Saliva and mucus

- How will care workers be trained to use suction units and machines to help with coughing?
- What is the social impact of drooling? How can this be managed?

Fatigue

- Explain to the person with MND that accepting external help with tasks will save their energy for the things that matter to them.
- Ensure support is flexible and can adapt to how the person is feeling and the activities they have planned.
- Is the person getting a good night's sleep? If they experience cramps and spasticity, or breathing issues, they should discuss this with their MND team. A profiling bed can make breathing and positioning easier at night.
- What support can I offer to help the person save their energy for the things that matter to them?

Breathing

- How will care workers be trained to manage ventilation and suction units?
- How will the person be supported to complete breathing exercises if they are used?
- How will the person manage to reposition their ventilation mask if it comes off?

Cognitive and behavioural change

- How can care workers be trained and supported to manage behaviour changes?
- Is a specialist care agency available?
- What contingency plan can be put in place in case of care plan breakdown?
- What measures are needed to ensure the person's safety?
- How can family members and carers be supported?

Psychological impact

- Signpost the person to counselling services, or other avenues for emotional support such as hospices.
- How can I support the person to maintain relationships, community involvement and leisure activities?

Carers

- Has a carer's assessment been arranged or completed?
- Has the carer been signposted to local carer organisations?
- Does the carer require any training, such as manual handling?
- Has the carer been signposted to the MND Association?
- How can the carer be supported to take a break?
- What psychological help may be needed?

Children and young people

- What support does the person with MND need with their parenting role?
- Has an early help assessment been arranged or completed?
- If appropriate, has a young carer's needs assessment been arranged or completed?
- Are the school aware of the situation? Is the family happy for them to be involved?
- What support is available locally from local young carer organisations?
- What psychological support may be needed?

Bereavement

- When appropriate**, has the family been made of aware of the support available and how to access this? See pages 47-48.
- Is support available from a local hospice or other local source?

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Denise Bell, Social Worker - Adult Care and Support, Sheffield
City Council

Philippa Graham, Head of Quality and Education, Mary Ann
Evans Hospice

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

MND Association

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