



6: What care is available?

This section identifies and explains the types of care on offer at end of life and who is involved.

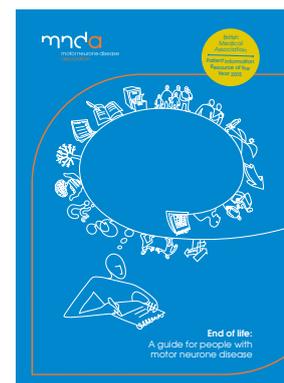
The following information is an extracted section from our full guide *End of life: A guide for people with motor neurone disease*.

All of the extracted sections, and the full guide, can be found online at: www.mndassociation.org/eolguide

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org



End of life:
A guide for people with
motor neurone disease

6: What care is available?

This section identifies and explains the types of care on offer at end of life and who is involved.



“ The difficulty for the family can sometimes be to know who to go to for what symptoms or difficulties. This may seem obvious to the health professionals involved... but often it is the first time the family has to cope with a serious illness and look after someone in the home.”

Types of care

There are five main types of care that you are likely to use when approaching end of life:

- your GP and community healthcare team
- Specialist and multidisciplinary healthcare for MND
- adult social care services
- specialist palliative care services
- support from other organisations.

These are described below.

See also the heading *What is NHS Continuing Healthcare?* later in this section.

“ One piece of advice I’d pass to other people living with MND and their carers would be to anticipate your needs. Have equipment or services set up and ready before you need them.”

Your GP and community healthcare team

Based either within a GP surgery or local clinic, this community team includes GPs and district/community nurses, but may also include professionals such as speech and language therapists, dietitians, occupational therapists and physiotherapists.

See the heading *Who is involved?* later in this section, for a list of professionals and what they do.

How can they help with end of life care?

Depending on their expertise, they can offer assistance through:

- referrals to specialists or services
- managing and monitoring symptoms
- advising on the management and prevention of health problems
- prescribing medicines (those who are authorised to prescribe)
- accessing specialist equipment
- support for you, your carer and your family.

How do I access this help?

These services are usually provided at a surgery or clinic. Towards the end of life, you are more likely to receive these services in your own home.

“ If I need any help I can call on the local community physiotherapist, occupational therapist, GP or MND volunteer...”

Help from a GP and community nursing team is also available on evenings and weekends, through your local out-of-hours service.

Do I have to pay for this?

The majority of NHS services are free at point of delivery, but exceptions include:

- some dental and optical services
- larger items of equipment and assistive aids provided by local authorities, for which you may be financially assessed to see if you are required to make a contribution
- some prescription fees, although you would usually qualify for exemption from payment (if you live in Northern Ireland or Wales, all prescriptions are free).

See Further information at the end of Part 2: *What is likely to happen?* for details about our information sheets. Prescription exemptions and help towards the cost of sight tests and dental charges are covered in Information sheet 10A *Benefits and entitlements*.

Specialist and multidisciplinary healthcare for MND

Specialist health care professionals cover a particular area of treatment. They often work in a team based at the same location, but can work as a virtual team in different settings. Where specialists from different areas of care work in a co-ordinated way, they are known as a multidisciplinary team.

See the heading *Who is involved?* later in this section, for a list of professionals and what they do within a multidisciplinary team.

How can they help with end of life care?

Specialists offer similar services to the community team, eg managing and monitoring of symptoms, but focused on a particular area, such as breathing support. This is likely to include help on planning ahead with regard to treatments, ways to cope, clinical equipment and your choices.

See Section 4: *What to expect as the disease progresses* and Section 9: *Advance care planning and advance decisions*.

In many areas, you may be able to get help and guidance from a co-ordinator who specialises in MND.

“ My MND co-ordinator is very thorough in keeping myself, and other medical practitioners involved in my care, informed of any new developments or findings, and answering any questions I may have.”

MND co-ordinators tend to be located at MND care centres and networks, as care centre co-ordinators, but this role sometimes exists through other neurological services, palliative care and hospices. Ask your GP or neurologist for guidance in your region.

How do I access this help?

You can be referred by your GP, or by another health and social care professional, according to your needs. Specialist services are provided in hospitals or clinics, and sometimes in your home.

Do I have to pay for this?

This type of NHS care is free.

Adult social care services

Normally based in local authority offices, adult social care services sometimes work within a surgery or clinic, alongside the local community health care team. In Northern Ireland, these services would be provided through the local health and social care trust. These services usually include social workers, care managers, care co-ordinators and occupational therapists (OTs).

See the heading *Who is involved?* later in this section, for a list of professionals and what they do.

How can they help with end of life care?

They can offer assistance through:

- assessing your existing and potential needs, through a needs assessment, to see what services and support you may require for everyday living
- assessing the needs of your carer, through a carer's assessment, to determine if they need support
- assessing the needs of children and young people, especially if they are involved as young carers
- arrangement of services to meet your needs, eg personal care to help with laundry, washing, dressing, food preparation and other daily tasks
- provision of small items of equipment
- advice on larger equipment, home adaptations and potential funding sources
- guidance on other services, benefits and emergency support
- psychological and family support
- guidance on selection and arrangements for residential and nursing care homes, should this be required.

How do I access this help?

Assessment for you, your carers or any young carers involved, may not happen automatically, but you can request this by contacting the adult social care team through your local authority or social services (or in Northern Ireland your health and social care trust). You can find local contact details online.

Assessment is usually done at your home. Ask for this as early as you can to help you and your carer feel prepared. As the disease progresses, you can ask for a review should your needs change.

Do I have to pay for this?

Some equipment may be free, but you may have to pay towards care services. Your income and savings will be considered to see how much you will be expected to contribute or if you will be funded.

If you live in Northern Ireland home care services are free, but there may be a charge for other services.

Care services can either be arranged for you or you can receive direct payments to make your own arrangements, if you are being funded. We provide Information sheet *10B - What is social care?* to help you understand these options.

See Further information at the end of Part 2: What is likely to happen? for details on how to access other publications.

Specialist palliative care services

Based in a hospital, hospice, day hospice or local clinic, specialist palliative care is provided by a wide range of health and social care professionals. These professionals have additional training and expertise in the management of care for people with life-shortening illnesses.

See the heading *Who is involved?* later in this section, for a list of professionals and what they do.

How can they help with end of life care?

Whether in a hospice or other setting, specialist palliative care services provide a more focused approach to end of life care, which considers the person's needs as a whole.



" We should have been told what a hospice is, that it's not just a place where you go to die. I wish someone had said this to us."

This includes symptom management, but also psychological, social, spiritual and practical support. This may range from clinical care and counselling, to the use of complementary therapies and guidance on financial support. They will also provide support for those close to you.

“ Death, especially your own death, can be a difficult subject to raise. But I found staff at the hospice were as willing to discuss death as they were willing to discuss the weather.”

How do I access this help?

Referral to these services is usually from your GP, but other health and social care professionals can also refer. Palliative care services can be provided where needed, whether in hospital, a hospice, your home or a residential or nursing care home.

Ask about early referral if possible. Depending on your progression, you may have to wait if services in your area are busy. However, the earlier you can build a relationship with a hospice or specialist palliative care services, the more benefit you are likely to receive. This also enables the professionals involved to get to know your needs, wishes and preferences. If you do have to be admitted to hospital for any reason, their knowledge of your case may help ensure you get the specialist help you need. This could mean a shorter stay.

Do I have to pay for this?

Palliative care services are usually free. These may be NHS funded or through charity funding (eg through independent hospice funding or charities involved with end of life care).

There may be some services you need to pay for. For example, you may be offered some complementary therapies free of charge, but if you wish to explore a wider selection, you may have to pay for these.

Support from other organisations

A variety of voluntary organisations can help support you and your family with end of life care. These may be local, regional or national organisations.

See Section 16: *Useful organisations for some suggestions.*

How can they help with end of life care?

Depending on the aim of the organisation, they can assist by:

- providing advice, guidance, information and resources
- directing you to other support to meet specific needs, such as respite care to give your carer time to rest
- offering direct help, such as equipment loan or financial support.

How do I access this help?

Contact the organisation direct. You can find contact details online or ask your local authority, as they may have their own directory of services. We can also help direct you to services and organisations, through our helpline MND Connect, our Association visitors, our regional care development advisers and our branches and groups.

See *Further information at the end of Part 2: What is likely to happen?* for contact details for our helpline MND Connect.

See also Section 16: *Useful organisations for a selection of organisations you may wish to contact.*

Do I have to pay for this?

Much of the help on offer will be free of charge, but this will depend on the organisation and the type of services they provide.

Who is involved?

“ We deal with so many people. We have a list on our fridge - there are around twenty of them: consultant, palliative care, occupational therapist...I see the consultant at the national neurological centre every four to six months. We are in very close contact with the MND specialist nurse and she's excellent. We're also in contact with our GP...I was also quickly referred to the hospice, even though it was early days.”

Most health services are accessed through your GP, who can help with symptom management and medication, or refer you to other support, such as:

- a symptom specialist, such as a respiratory consultant or speech and language therapist
- an MND care centre or network

See Section 15: Help from the MND Association for information about our part-funded MND care centres and networks.

- a local neurological clinic or MND service, normally within neurology, rehabilitation services or specialist palliative care. This is usually based in a local or regional hospital.

MND is not a common disease, so many health and social care professionals may only see a few cases in their career, or none at all. Specialist, co-ordinated care (from professionals familiar with the condition) is particularly helpful during the later stages, when care can be complex.

However, services can vary across regions. This is where referral to an MND care centre or network (part-funded by the MND Association), or to a local neurological service, is valuable.

The multidisciplinary team

“ I find it confusing that so many people are involved from specialisms which I don't really understand.”

A range of specialist support is needed with MND, usually through a multidisciplinary team (MDT). An MDT is specifically set up to provide a co-ordinated approach to care.

The team will probably include some or all of:

Consultant: for assessment, diagnosis, symptom management and guidance. This is usually a neurologist for MND, but you may also meet other consultants, such as a respiratory consultant for breathing problems or a palliative medicine consultant.

Specialist palliative care services: for symptom management, guidance and information, counselling, emotional and spiritual support, complementary therapies, and family and carer support too. Specialist palliative care is designed to support the best possible quality of life during a life-shortening illness. In many cases, these services can be received at home, but often at a hospice, hospital or day centre as an outpatient. Short stay admissions may be needed for assessment or palliative care support.

Neurology or MND specialist nurse: for specialist advice and information about neurological conditions, such as MND. Nurses may offer home visits, clinic appointments or a combination of both and will make referrals on your behalf as and when the need arises. Please be aware that there may not be neurology or MND specialist nursing staff in all areas.

MND co-ordinator: for linking your care through the MDT professionals involved. They answer questions and keep you informed. MND co-ordinators are usually located at MND care centres and networks, as care centre co-ordinators, but the role may exist in other neurological, palliative and hospice services. Ask your GP or neurologist for advice about MND co-ordinators in your region.

“ Our MND co-ordinator made an appointment with us to discuss end of life, particularly advance decisions and DNAR. We were okay that she raised this, but she was also experienced enough to do this at the right time.”

Community nurse: for nursing services, such as assistance with medication, monitoring and treatment of symptoms, prevention of pressure sores, continence advice and provision of home nursing equipment. Working closely with your GP, they may have regular contact with you towards end of life.

Speech and language therapist (SLT): for assessment of speech and communication, and swallowing difficulties. SLTs with experience of MND can advise on a range of suitable communication aids, which may be funded by the NHS. An independent assessment with a SLT is recommended if you consider purchasing any of these aids yourself, as they can be costly and not all solutions suit all people. Not all SLTs have experience with MND, but they can contact us for guidance. We provide a document called the *AAC Pathway* to help them assess people for alternative communication aids.

Dietitian: for advice on the most appropriate diet to help you maintain a healthy weight and for guidance where swallowing may be difficult. A dietitian will often work closely with your speech and language therapist.

Physiotherapist: for guidance on managing symptoms, such as fatigue, cramps and tightness in muscles. They can advise on appropriate exercise, passive or assisted, and positioning to maximise comfort. Physiotherapy and exercise cannot delay the progression of the disease, but they may help to maximise the use of muscles that are not yet affected and increase flexibility by maintaining movement of your joints. You may also be referred to a respiratory physiotherapist for help with any breathing problems.

Occupational therapist (OT): for advice on posture, equipment and access in your home, to help you continue daily routines with as much independence as possible.

Counselling and psychology services: for emotional and psychological support. Your GP can usually refer you to an appropriate service, counsellor or psychologist, but there may be a waiting list. Your local hospice, palliative care team or palliative care social worker may offer counselling as part of their palliative care support.

Pharmacist: for advice on the best types of medication in particular circumstances, eg many medicines can be dispensed in liquid form for ease of swallowing.

Complementary therapists: for a variety of complementary therapies, in conjunction with conventional medicine, eg massage, acupuncture, reflexology and others. For some people, the use of complementary therapies can help to alleviate symptoms and reduce feelings of stress.

Wheelchair services: for assessment of seating needs and co-ordination of provision for a wheelchair, as appropriate. Please be aware that there are often waiting lists for this provision. If you find this is the case in your area, our Support Services team at the MND Association can advise.

See Section 15: Help from the MND Association.

Social worker or care manager: for help with care assessments, advice, information and social care arrangements, including arranging care at home or advice regarding care homes.

Benefits adviser: for help on decisions and claims regarding benefits. The adviser may not be directly linked to a healthcare MDT, but there may need to be communication between members of the MDT and the benefits adviser, if medical evidence is needed to support a particular claim. Benefits advisers are usually contacted through your local Jobcentre Plus office or you may wish to search for government online information at www.gov.uk or in Northern Ireland at www.nidirect.gov.uk

What is NHS Continuing Healthcare?

This is often referred to as continuing care and is a package of funding and care for complex medical needs, provided by the NHS.

If you qualify, the full cost of all the care you need (whether for health or social care) will be funded by the NHS. However, in some cases, this will be provided as a 'shared care package' between the NHS and adult social care services.

In Northern Ireland there is no guidance on NHS continuing healthcare, but the health and social care trusts are encouraged to refer to the criteria used in the rest of the UK.

To be eligible for NHS Continuing Healthcare, your main or primary need must relate to your health. Your needs will be assessed against specific criteria to determine if you require a high level of healthcare and support for any of the following:

- complex medical conditions
- rapidly deteriorating conditions
- end of life care.

Initially, your healthcare needs will be identified by a qualified healthcare professional to determine if you should be referred for a full assessment. The full assessment will be carried out by a team of health and social care professionals. You and your main carer should be consulted as part of the assessment process.

See Further information at the end of Part 2: What is likely to happen? for details about Information sheet 10D - NHS Continuing Healthcare.

“ Your information sheet, 10D, helped me to engage with professionals, secure the fast track option and enable a better outcome for my stepson, who also had special needs.”

Key points

- Some health and social care professionals may feel uncomfortable about raising the subject. You may need to let them know you're ready to discuss end of life and options for health care or social care as symptoms progress.

See Section 3: Difficult conversations with professionals.

- Health and social care professionals can also contact our helpline, MND Connect, for guidance and information.

See Section 15: Help from the MND Association.

- Many different health and social care professionals may be involved in your care. It can be helpful to have one identified professional, such as a specialist nurse or MND co-ordinator, who can help act as a link between services on your behalf.

Impact from the coronavirus pandemic

You may experience some delays with assessments, appointments and treatments due to the pandemic. However, much work has been done to enable remote consultations by telephone, web chat or online video communication. Much can be accomplished this way.

When you do meet health and social care professionals, there may be rules and restrictions in place – these are needed to reduce the risks of you and the staff being infected with coronavirus.

Find our coronavirus information at: www.mndassociation.org/coronavirus

Further information

We produce a wide range of publications to help you gather information about MND and its management. The following may be useful in relation to the subjects covered in Part 2: *What is likely to happen?*

From our numbered information sheet range:

- 1A: NICE guideline on motor neurone disease
- 1B: Information about MND or Kennedy's disease in other languages or Braille
- 3A: MND care centres and networks
- 6A: Physiotherapy
- 6B: Complementary therapies
- 7A: Swallowing difficulties
- 7B: Tube feeding
- 7C: Speech and communication support
- 8A to 8D: our sheets on breathing with MND, ventilation support and withdrawal
- 10A to 10G: our range of sheets on benefits, social care and NHS Continuing Healthcare
- 11C: Equipment and wheelchairs
- 14A: Advance Decision to Refuse Treatment (ADRT)

From our other publications:

What you should expect from your care a pocket sized booklet to help you use the NICE guideline on MND at appointments.

Living with motor neurone disease a guide about MND to help you manage the impact from diagnosis onwards and maintain the best possible quality of life.

Understanding My Needs a write-on tool to enable you to record basic notes about your needs and how you would like to be cared for, if admitted to hospital or a hospice.

MND Alert Card a small card to keep in your purse, wallet or pocket, to alert hospital staff that you have MND and need specialist help, with space to record key contacts.

MND Alert Wristband to wear at all times, to let hospital and emergency staff know you have MND and may be at risk with oxygen.

Eating and drinking with motor neurone disease a guide including easy-swallow recipes and information about nutrition with MND.

Caring and MND - support for you a comprehensive pack focused on the wellbeing of family and unpaid carers.

Emotional and psychological support for suggestions and details about therapies.

Changes to thinking and behaviour with MND for ways to help manage these changes.

How to access publications and further information:

Most of our publications can be downloaded from our website: www.mndassociation.org or you can order them from MND Connect, our support and information helpline:

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Connect can also help you locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional staff.

See Section 15: Help from the MND Association, for details about our services.

Online forum:

Hosted by the MND Association at: <https://forum.mndassociation.org> for you to share information and experiences with other people affected by MND.

myMND website:

See this site for further information and video collections on tube feeding with **myTube** and assisted breathing with **myBreathing** at: www.mymnd.org.uk Developed by SITraN – the Sheffield Institute for Translational Neuroscience.

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This resource has been evidenced,
user tested and reviewed by experts.