motor neurone disease association

Types of care

for people with MND or Kennedy's disease

"It's strange having people here to care for me as I've lived alone for so long. But we get on and they're nice people."

Contents

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How can this booklet help me?

Everyone's experience of MND or Kennedy's disease will vary. You may not have exactly the same symptoms in the same order as someone else, so your care will be individual to you. To help manage symptoms, emotional impact and practical needs, you can access a wide range of health and social care.

This booklet explores the common types of professional care, who provides these and how you can access this support.

How do I download or order your information resources?

To help you explore further, you will see our information resources mentioned throughout this booklet, as relevant to a subject.

Download our resources at: **www.mndassociation.org/publications** or contact our MND Connect helpline to order printed copies:

Telephone: **0808 802 6262**
Email: **mndconnect@mndassociation.org**

See also section 5 *How do I find out more?*

If you have Kennedy's disease, you may also find our wider information on MND useful.

“ This symbol highlights quotes from people living with or affected by MND or Kennedy's disease.

You can ask health and social care services for their information in a different format, where needed for accessibility. For example, in Braille or as an audio recording. Provision of accessible information is now mandatory in England for Government funded health and social care services. Search for: *Accessible Information Standard* at: **www.england.nhs.uk**

1: What do we mean by types of care?

Depending on your symptoms, you and those close to you will have already found ways to tackle many challenges. However, there may come a time when you need professional support.

Getting the right type of care at the right time is important. It can help maintain independence for longer, increase wellbeing and reduce any time spent in hospital. Being informed about health and social care options can help everyone feel supported. If you have a partner, relative or friend acting as your main carer, accepting additional professional care may help them save time and energy.

Find resources and guidance for family and unpaid carers at: www.mndassociation.org/carers

Services, facilities and waiting lists vary across regions. If you live on the border of two counties, you may even find that your health care is delivered by one county and social care by the other. This can cause confusion, but your GP, care team or social worker can advise how systems work in your area.

See section 4: *How do I get the right care?*

The National Institute for Health and Care Excellence (NICE), recommends the care you should expect with MND in the NICE Guideline on the management of MND. These recommendations are a guideline rather than a legal document, but health and social care professionals are encouraged to follow them. The guideline can also help if you are living with Kennedy's disease.

See information sheet 1A - *About the NICE guideline on MND* and our pocket guide *What you should expect from your care.*

2: What types of care are available?

This section covers the following types of professional care:

Primary or community care
Multidisciplinary care
MND care centres and networks
Adult social care
Palliative care
Respite care
Emergency and urgent care
Residential and nursing care
NHS continuing healthcare (CHC)
End of life care

If you have any problems accessing these types of care, you have the right to appeal or complain.

See section 4: *How do I get the right care?*

Not all health and social care professionals have experience of MND, but we provide information to help them.

See resources for health and social care professionals at: www.mndassociation.org/professionals

Primary or community care

Local GPs and community nurses are often your first point of contact. They can refer you to specialists as your needs change and know how services work where you live.

Various professionals are involved in community care teams, but the following are likely to be the ones you see most:

General practitioner (GP): your GP is usually the first person you approach about symptoms. They prescribe medicines, maintain medical records and refer you to specialists and local services when needed, such as wheelchair services. If you're an unpaid carer ask your GP to add this to your records, so you can access further information and practical support.

Community or district nurse: a nurse who works closely with GPs and assists with medications. If your needs become urgent or you are unable to leave the house, they can support you at home. They help with practical tasks, like prevention of pressure sores, as well as arranging some items of home nursing equipment. They will have a wealth of knowledge on local services.

Pharmacist: for advice on medications and how best to take them. For example, some drugs are in liquid form for ease of swallowing.

For additional roles see *Multidisciplinary care* in this section.

Are there any medications for MND?

Various medications are available to help ease symptoms. Your GP or specialists will advise.

Riluzole is the only drug to be licensed for the treatment of MND in the UK. It is usually prescribed with the form of MND called amyotrophic lateral sclerosis (ALS). It is not a cure, but may slow the progression of the disease for a number of months. Ask your neurologist if riluzole would benefit you. Your GP and pharmacist will manage the prescription.

See information sheet 5A- *Riluzole*. See more about types of MND at: www.mndassociation.org/what-is-mnd

What is meant by secondary or tertiary care?

You receive secondary care if you are referred beyond primary care, to a specialist, such as a neurologist.

You receive tertiary care if you need highly specialised care in a hospital setting, such as surgery.

Multidisciplinary care

The NICE guideline recommends people with MND have access to a multidisciplinary team (MDT). An MDT is a group of different specialists who work together to provide care in a co-ordinated way. Where possible, this means you get the benefit of shared knowledge and attend fewer appointments. Your MDT usually connects with your primary care team too and social workers when needed.

MDTs are usually based in an MND care centre or network, or neurological clinic. You should be given one point of contact who can answer your questions.

Depending on your symptoms, you may see the following members of the team:

Consultant neurologist: a specialist doctor of the brain, spinal cord, nerves and muscles, with expertise in the diagnosis and management of MND or Kennedy's disease.

Neurology or MND specialist nurse: a nurse who can offer information, advice and guidance on services for neurological conditions, such as MND or Kennedy's disease.

MND care co-ordinator: a clinical specialist who helps connect you to the points of care you need. Usually through an MND care centre or network, but sometimes found at other neurological services.

Dietitian: a professional who provides guidance on nutrition, tube feeding, maintaining your weight and fluids for hydration. They often work closely with speech and language therapists.

See information sheet 7B – *Tube feeding* and our guide, *Eating and drinking with MND.*

Speech and language therapist (SLT): a therapist who provides guidance on speech and communication aids, through alternative and augmentative communication (AAC) if your speech is affected. They also assess swallowing and often work closely with dietitians on consistency of food and drink, and guidance on tube feeding.

See information sheets 7A, 7C and 7D on swallowing, speech and communication, and voicebanking. Also, our animation *What is voice banking?*

Physiotherapist: for support with physical symptoms, cramps, stiffness and the need for limb support. They can guide you, and your carer, on appropriate assisted exercises and positioning for you. Respiratory physiotherapists focus on breathing therapies.

See information sheet 6A – *Physiotherapy*

Occupational therapist (OT): a therapist who can assess your needs for daily living, assistive equipment and adapting your home. They may also connect with your physiotherapist and orthotics services, about items such as braces and splints to support limbs or spine, or services that can help with neck and head support.

See our information sheets and booklets on:
10C – *Disabled facilities grants and home accessibilty*
6A – *Physiotherapy*
6B – *Complementary therapies*
6C – *Managing pain*
11C – *Equipment and wheelchairs*
11E – *Environmental controls*
Personal care
Getting around

Respiratory consultant: to assess your breathing and give advice about breathing exercises, positioning, coughing techniques and the way that assisted ventilation can support breathing. They work within a team and with other specialists such as respiratory physiotherapists.

See sheets 8A, 8B, 8C and 8D on breathing and ventilation.

Neuro psychologist: for emotional and psychological support to help you and your family. They can also assess changes to thinking and behaviour, which happen for some people with MND.

See our booklets: *Emotional and psychological support* and *Changes to thinking and behaviour with MND*

Palliative care specialist: to help you achieve the best possible quality of life from diagnosis, including symptom management, counselling, complementary therapies, information and practical guidance, emotional or spiritual help, and access to support groups.

For more, see *Palliative care*, further on in this section.

MND care centres and networks

MND care centres and networks are dedicated MND clinics across England, Wales and Northern Ireland, that the MND Association part-funds. These clinics provide co-ordinated care, with a multidisciplinary team (MDT) that connects with your primary healthcare team. Find your nearest MND care centre or network at: **www.mndassociation.org/carecentres**

MND care centres are based in within hospitals or hospices, rather than purpose built clinics. If you find it difficult to travel to these clinics, video appointments may be possible.

An MND care network is an outreach service that covers larger regions and uses a variety of meeting places.

If you don't have access to an MND care centre or network, local neurology clinics and community healthcare also offer co-ordinated services for people living with MND or Kennedy's disease.

How can an MND care centre or network help me?

MND care centres and networks focus on providing you with specialist expertise in the management of MND. They don't replace your existing healthcare team but work with them to provide you with the co-ordinated care you need.

You will be helped by a care centre co-ordinator, who acts as a single point of contact between you, your MDT, your primary care and the MND Association.

Depending on your needs, they may offer:

- regular monitoring by a neurologist with expertise in MND, including blood tests
- breathing assessments and other specialist appointments, with access to more than one therapist at each visit
- planning for your future care, with referrals as needed
- advice and information, including support for your carer
- opportunities to be involved in research projects or clinical trials, where appropriate – ask your neurologist for advice.

See: **www.mndassociation.org/research/get-involved-in-research** to find out more about clinical trials or email our research team at: **research@mndassociation.org**

Do I have to pay for care at an MND care centre or network?

Access to multidisciplinary care in an MND care centre or network is free. You need to be referred by a GP, neurologist, or other healthcare professional.

What if I have Kennedy's disease?

Kennedy's disease has similar symptoms to MND and is sometimes misdiagnosed as MND at first. Find out more at:
www.mndassociation.org/kennedys

MND care centres and networks can also help if you have Kennedy's disease, but a specialist Kennedy's Disease Clinic is based at the National Hospital for Neurosurgery in Queens Square, London. You may need to be referred by your GP, but services at the clinic are free. This includes access to specialists, such as physiotherapists, occupational therapists, speech and language therapists, dietitians and a palliative care team experienced in support for people with neurological diseases.

> ***"A multidisciplinary team is equally as important for people with Kennedy's disease as it is for people with MND."***

The Kennedy's disease clinic offers the same multidisciplinary approach that is available to people living with MND. They can support co-ordination of care between the clinic and in the community, and provide support for family and friends too.

Telephone:	020 3108 7507
Website:	**www.ucl.ac.uk/ion/centres/queen-square-motor-neuron-disease-centre/about-centre**

Search for the *Kennedy's disease register* at: **www.ucl.ac.uk**

Adult social care

Social care is about getting help with everyday tasks or personal care. Adult social care services assess your needs and can arrange services to give support, as agreed with you. You may also need a home assessment by an occupational therapist, who can guide you on adaptations.

How do I get assessed?

You have a legal right to assessment. If you need extra support, and you have not been referred by your GP or another professional, you can ask to be assessed as follows.

In England and Wales search for your l*ocal authority* at: **www.gov.uk/find-local-council** Ask adult social care services for a needs assessment.

In Northern Ireland find your local health and social care trust at: **www.nidirect.gov.uk/articles/find-your-local-council** Ask adult social care services for a community care assessment.

Try not to wait until you are at point of need, as equipment and services can take time to arrange. Ask for your needs to be assessed as soon as symptoms begin to limit your independence. Your needs can be reviewed again if things change.

You don't have to be claiming benefits to have an assessment and it should be carried out in a language of your choice.

Your main unpaid carer can have a carer's assessment, even if you decide not to have an assessment for yourself.

How can social care help me and my carer?

Professional support can help free up time and energy, for you and your carer to preserve your existing relationship. It can also give your main carer time to rest or do other activities.

> ***"I often say to the patients I work with that sometimes 'just a little bit' of formal support helps maintain independence (and supports the carer too)."***
> **Diane Aldridge, Social Worker**

You may have care workers visit daily, overnight or several times a week. In some cases you may need 24-hour professional care.

If you do not have family and friends helping you, professional support will become essential in time.

Adult social care services can arrange for care workers, sometimes called care assistants, to help you at home with:

- eating, drinking and preparing meals
- household tasks such as laundry, cleaning and shopping
- moving about your home safely with mobility equipment
- personal care, such as washing, dressing and using the toilet.

Care workers can also help you:

- access work, training, further education or any volunteering opportunities you wish to try
- access community facilities, local services, public transport and leisure activities
- manage caring responsibilities for dependents
- find emotional support for you and those close to you.

You have the right to future reviews if your needs change. You can also appeal against decisions you don't agree with.

Accessing support services can also help your carer save time and energy. For example, you may qualify for the following:

- respite care or urgent professional care if your carer becomes unable to assist you
- regular support from a care worker at home
- laundry services or meals delivered at home
- home adaptations or equipment such as grab rails, ramps or hoists
- assistance with travel to appointments or day centres
- residential or nursing care.

See *Respite care* and *Residential and nursing care* in this section

Do I have to pay for adult social care services?

In England or Wales, your local authority will assess your finances. This is known as means testing to work out how much you need to pay towards any agreed services and how much they will fund. In Northern Ireland, means testing only applies if you are accepting a place in a nursing care home.

If you qualify for professional support once assessed, you can choose between having services arranged for you or managing your own care. If you wish to manage your own care, you will receive your personal budget as direct payments. This gives you greater control, but you will need to keep records and may have to accept the role of an employer if you hire a personal care assistant.

Social care systems vary across England, Wales and Northern Ireland. See more on assessments and direct payments in information sheet 10B – *What is social care?* and at:
www.mndassociation.org/healthandsocialcare
See also *NHS continuing healthcare* later in this section.

Palliative care

Palliative care aims to provide the best possible quality of life for people with life-shortening illnesses. Most healthcare professionals have some training in this type of care, but you can also be referred to specialist palliative care teams.

This type of care can be delivered at a hospital, hospice, clinic, nursing home or your own home if you cannot travel. They can help you manage your symptoms and offer emotional, practical and spiritual support as needed.

> ***"Put simply, the palliative care team didn't pick me up when I stumbled, they caught me before I fell and held me until I got my strength and fight back."***

Many people think palliative or hospice care is for the last stages of life only and this can cause worry if it's offered soon after diagnosis. Yet the earlier you seek out these services, the more they can support you. The aim of palliative care is to help you to live as well as possible.

There may be waiting lists in your area, so it's worth being added to the list if you can, even if you don't want to access it straight away. Ask your GP or another member of your health and social care team for guidance on what might be available.

> ***"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."***

See also *End of life care* later in this section.

How can palliative care help me?

Palliative care specialists can be:

- consultants in palliative care
- clinical nurse specialists
- community palliative care nurses
- hospice nursing, medical and enablement teams.

Palliative care helps wellbeing by treating you as a whole person instead of separate symptoms. Having this support team around you over a period of time builds their knowledge of your needs and those of your carer. If there is an emergency, this can reduce any time you spend in hospital.

> ***"It's nice when I'm treated as a whole person and not just an illness."***

“I’ve been attending St Richard’s Hospice for several years. Clearly it has been supporting me well. I have got into painting while there. They do aromatherapy, creative therapy, counselling, chaplaincy, and you can see a doctor, physio and occupational therapist. It is run by nurses and volunteers. I have also been an inpatient, including for symptom control... and they’re all just fantastic.”

Palliative services are provided through:

Day services: where palliative care professionals can assess your needs, help control symptoms and provide advice and guidance. You'll also be able to ask questions or raise concerns.

Outpatient services: usually at a clinic, where you can discuss long-term conditions with health and social care professionals, but you do not stay overnight.

Inpatient services: where you may be admitted for a short while to a hospice or hospital, sometimes overnight, for treatment or symptom monitoring as part of your palliative care.

Support groups: to help you and those close to you meet others in similar circumstances, who understand the challenges you face.

How can I get palliative care?

If you do not have a palliative care specialist as part of your MDT, ask your GP for a referral to palliative care services. If you have any issues with palliative care or other types of care, see: **www.mndassociation.org/mycare**

Do I have to pay for palliative care?

Palliative care through the NHS is free on referral. Hospice care may have some NHS funding, but often relies on charitable donations. This means volunteers help at hospices, but clinical care is always by specialist professionals. Hospice care is usually free, but some hospice services, such as complementary therapies, may be charged by a visiting professional. If unsure, ask about costs.

Our comprehensive guide, *End of life: a guide for people with motor neurone disease*, contains guidance on planning ahead and palliative care. See: www.mndassociation.org/eolguide

Respite care

Respite care is sometimes called replacement care and gives carers a break from usual routines. Although it can provide support in an emergency, it's usually planned in advance. It could be a break at a day centre for a complementary therapy, going to a regular social gathering or a longer period of time spent away from home. Respite care can happen in a range of locations, such as:

- your own home
- a residential or nursing care home
- a care centre
- a hospice.

See *Residential or nursing care* later in this section.

How can respite care help me and my carer?

Friends and family may offer regular support to allow your main carer time for shopping or appointments. However, if this support isn't available, then professional respite care may be the answer. This can help if your carer needs a longer break for a holiday, medical treatment or to visit family.

> ***"I feel stretched all the time and guilty that I cannot be both a carer and the best mother I can be."***

For more information on carer wellbeing see our guide, *Caring and MND: Support for you.*

Ask your GP, care team or social worker at any stage about respite care. It can be useful to explore respite options at your needs assessment with adult social care services.

See *Adult social care* in section 2: *What types of care are available?*

These services vary, so find out what might be available in your area before you need it. Add your name on waiting lists if necessary to access the services you prefer.

During respite care, you may also find new interests or hobbies, and strike up new friendships.

Try to ensure providers have adequate knowledge of how to support you, as they may not have experience with MND.

Accessing respite care early on can help services learn about your needs. If you need a provider's help again, they will know you and understand your care needs, preferences and wishes.

When using respite care, our *Understanding my needs* form can guide medical staff, care workers and carers. See *Forms and resources to help communicate your needs* at: www.mndassociation.org/careinfo

Do I have to pay for respite care?

If your needs assessment identifies that respite care could help, your financial assessment will decide how much funding you will receive and how much you need to pay towards any agreed services. You can also select and pay for your own chosen respite services.

You may be able to find grants to help with respite care - ask for guidance at your needs assessment.

See section 5: *Other types of support* to read about our MND Association grants which you can use towards respite care.

> ***"The grant enabled us to get additional nursing cover to allow a break for both of us, a small break will revitalise us to keep going."***

Emergency or urgent healthcare

Sometimes, even with detailed support in place, the unexpected can happen. Planning ahead can help everyone involved in your daily care feel more prepared, in case you need emergency or urgent care.

For example, keep up to date contact numbers for local out-of-hours services, such as your adult care services duty team. Make the details easy to find, such as on the fridge door or by the phone.

How can I prepare for emergency care?

Local care services often work in different ways depending on where you live.

Ask your GP or local authority about the urgent support services in your area and note down their addresses, telephone numbers and opening hours.

Consider the following:

- How do we access emergency treatment, or urgent care support when it's out of normal hours?
- How can I access supported transport?
- Who can I contact if my main carer is unable to support me at short notice?
- Where can I find suitable support if my main unpaid carer needs respite urgently?

See *Respite care* earlier in this section

Do I have to pay for emergency care?

There is no charge for emergency healthcare from the NHS.

How do I call for help in an emergency?

You may already have contact numbers for urgent or out of hours local support, as provided from your needs assessment or by your GP. However, if you need an emergency service, the following may be useful if you have communication difficulties:

Emergency SMS: If you need to call the emergency services on 999 but cannot speak, text them through Emergency SMS. You need to register your mobile phone in advance. For more information on this service see: **www.emergencysms.net**

The RelayUK app: can be downloaded to your phone and used to have a real time conversation with a person if you can't hear or speak. Once downloaded you'll be able to read what the caller is saying to you and type back your response. For more information see: **www.relayuk.bt.com/relay-uk-services**

Call alarms: there are many personal alarms you can wear to call for help in an emergency. Discuss which one could suit your needs with a member of your healthcare team.

What resources can help raise awareness of my needs?

Keep resources that guide your care in an obvious place, so that emergency teams can find them.

Power of Attorney is a legal process to give permission to someone else to make certain decisions on your behalf. This works differently in Northern Ireland to England and Wales. Find out more at:
www.mndassociation.org/planningahead

Advance care plans are a way of guiding everyone in your care about your wishes and preferences for future care, in case you become unable to communicate these for yourself. Your health and social care team can help you with advance care planning.

Advance decisions are choices about the refusal or withdrawal of treatments, and when you would want this to happen. When recorded correctly on an Advance Decision to Refuse Treatment (ADRT) form, your choices are legally binding. They guide healthcare professionals if you become unable to make decisions or communicate on your own behalf. An ADRT can also help those close to you understand your wishes and is sometimes referred to as a 'Living Will' or 'Advance Directive'.

See our information sheet 14A - *Advance Decision to Refuse Treatment (ADRT) and advance care planning*

Carer emergency cards can be carried by your main carer and are usually linked to a registration service. In the event of your carer having an accident, this service alerts authorities that someone at home needs care. Ask your local authority if they have a carer card scheme. In Northern Ireland ask your health and social care trust.

Message in a bottle these sticker and bottle sets are available free from chemists. Put the sticker on your fridge or inside your front door to show that your medical information is in the bottle in your fridge.

MedicAlert provide bracelets or necklets to purchase and wear, that identify your medical condition or allergy. The scheme includes a 24-hour emergency telephone service. See: **www.medicalert.org.uk**

Understanding my needs is a form from the MND Association to record your needs, to guide care workers and hospital staff in your care if you are unable to communicate.

MND Association Just in Case Kit is a box that your GP can order from the MND Association, for you to keep prescribed medications at home. The medicines can be used by emergency teams if you are breathless, or have feelings of choking or anxiety. Guidance is also given for carers. Contact our MND Connect helpline for more information or speak to your GP.

MND Alert Card is a small card available from the MND Association to carry in a pocket, purse or wallet, to flag that you have MND. There is room to write down your main contacts and it also explains that oxygen should be used with caution with MND.

MND Alert Wristband can be worn to alert medical staff that you have MND and may be at risk with oxygen. Order the band free of charge from the MND Association. The band includes a link for professionals to find other information about MND and urgent care.

Residential and nursing care

Residential and nursing care homes offer longer term, around the clock support by trained care workers and medical professionals:

Residential care homes: provide live in accommodation, usually with ensuite bathrooms. They provide all meals and help with daily personal care tasks, such as washing, dressing and going to the toilet, as well as communal and wellbeing activities.

Nursing care homes: provide the same services as a residential care home, but with qualified nursing care, available 24-hours a day.

Some homes offer a choice of both types of care, known as dual residential and nursing care.

How could a care home help me?

With MND, there may come a time when you need more support or medical help than either unpaid or paid carers can provide safely in your home.

Care homes provide a safe environment with trained staff, and the chance for companionship with other residents and supported activities. Those providing nursing care also manage medications and medical equipment.

Contact your local authority in England and Wales, or your local health and social care trust in Northern Ireland, for details about care homes in your area and how to access them. They can assess your needs and provide guidance on how to select a suitable residential or nursing care home. A health care professional may also need to be involved in your assessment.

See *Useful organisations* in section 5, for services that can help you research care home providers in your chosen area.

Do I have to pay for residential or nursing care?

You may have to pay towards care in a residential home. If this includes nursing care provided by the NHS, the nursing care element is not usually charged. A financial assessment by your local council will work out how much you might need to pay and how much will be funded.

If you qualify for NHS continuing healthcare (CHC), all your social care and medical care will be paid for.

NHS continuing healthcare (CHC)

If your primary healthcare needs become complex and your symptoms are changing rapidly, you may qualify for ongoing health and social care, arranged and funded by the NHS. This is known as NHS continuing healthcare (CHC).

You need to be assessed but if you qualify for CHC, they should fund support as appropriate. In England, this may also involve being assessed for a Personal Health Budget to develop a personalised care plan - see the next section for details about these budgets.

CHC works in a similar way in Wales. There are no guidelines for NHS CHC in Northern Ireland, but they often follow NHS guidance, so check with your health and social care trust if similar care is available in your area.

For more see Information sheet 10D - *NHS Continuing healthcare*. We also have an animation about CHC, with voice over and subtitles at: www.mndassociation.org/animations

> ***"We've gone through the CHC process, and we've got funding for the carers after being unsuccessful before, so now that we've got that, we definitely have the right amount of support."***

End of life care

End of life care is about identifying your needs, and those of your family and carers, during the last phase of life into bereavement. This usually means during the final 12 months and includes palliative care services.

See also *Palliative care* earlier in this section.

End of life decision making can feel emotional and difficult, but may help you and those close to you feel better prepared.

With most forms of MND, the disease is life-shortening. People with MND have told us that once they made their choices, they felt better able to get on with living and focus on the things they really wanted to do.

Our guide *Living with motor neurone disease* covers information about the disease and types of MND. See the full guide and each separate section at: www.mndassociation.org/lwmnd

The aim of end of life care is to support the needs, preferences and wishes of the person approaching death. It also helps all those involved in the care of that person, including family and close friends.

When you feel ready for more information, our comprehensive *End of life guide* can be read in full or accessed in separate sections. It contains candid guidance to help with informed choices.

> ***"There is a sense of relief that all the guidance is accessible in one document and covers everything we need to know."***

See our resource *End of life: a guide for people with motor neurone disease*, at: www.mndassociation.org/eolguide

3: Is there any other support?

MND symptoms change over time. Your care needs will increase and this means the support you receive needs to be regularly reviewed. You may need wider care options depending on your symptoms. Your health and social care professionals can advise, after assessment of your needs.

There are many other options for care, but these could include:

Intermediate care

If you are admitted to hospital, your needs and those of your carer must be assessed before discharge, usually by a dedicated discharge team. If needed, a care plan should be provided, usually by adult social care services. This support may include intermediate care in a temporary care home. You may not need this type of care for long, but if you receive this help, the first 6 weeks will be paid for. After this time you will be financially assessed by adult social care services for any further care services needed for return to your own home.

There are no charges for any medical care you may receive. If your needs are assessed as complex, you may qualify for NHS continuing healthcare (CHC) - see the previous section.

Personal health budgets (England only)

A personal health budget helps you create a personalised care and support plan. This offers more choice over the way your assessed health needs are met. You won't receive more support than needed or more expensive services, but you will be able to select the therapies you want, as agreed and available through the NHS.

A personal health budget is not used to cover primary or emergency health care in England, as these are already provided free through the NHS. If you live in Northern Ireland or Wales ask your healthcare team about therapies you feel could help.

See our information sheet 10F - *Personal health budgets*

Complementary therapies

Complementary therapies are non-medical treatments that can be used alongside conventional medical treatments. You will find a range of therapies on offer, including massage, acupuncture and reflexology. They cannot stop or slow down MND, but may help with symptom relief and promote a sense of wellbeing.

Some therapies may be available free through the NHS, so ask your GP what is available. Local hospices often provide complementary therapies, but these may be charged. Ask about costs before booking as these can vary.

See our information sheet 6B - *Complementary therapies*

Private healthcare

If you pay for a private healthcare scheme or you have membership through your workplace, you may be able to access a range of therapies. Private healthcare is often accessed through an NHS Trust or Foundation Trust, in an NHS building.

MND Association support

At the MND Association, we are dedicated to improving the lives of people affected by MND in England, Wales and Northern Ireland. We provide a variety of services, local support through branches and groups, and grants for financial help.

Scotland is supported by a different organisation called MND Scotland.

See section 5 *How do I find out more?* for guidance about services and our support.

Support from other organisations

You can search for specialist help on the internet, but you may find it helpful to ask your GP for advice. Your GP surgery may have lists of services, carer groups and support groups, sometimes started by people in similar circumstances. These may give you an opportunity to share tips on care, with people experiencing the same challenges.

Local libraries usually have community notice boards and your local authority may have a directory of other charities, organisations and services that offer support in your area. In Northern Ireland, ask your local health and social care trust for guidance.

See *Useful organisations* in section 5 *How do I find out more?*

4: How do I get the right care?

Standards of care often vary across regions. Sometimes this is due to limited resources or changes to systems. It may also depend on the numbers of people waiting for appointments or treatment, which can cause waiting lists.

Your local area may have excellent facilities, while another may have older buildings where accessibility is more difficult. If you face problems in getting timely or appropriate care, you have the right to challenge this or complain.

What can I do if I'm not getting the right care?

If you are not receiving the care or treatment you need, discuss this first with the relevant health or social care professional, or provider.

Use the NICE guideline to open discussions about how to access suitable support. The guideline provides recommendations to professionals on appropriate care with MND.

The NICE guideline recommends that people with MND should have access to a multidisciplinary team, including a professional with expertise in palliative care.

See our information sheet 1A - *About the NICE guideline on motor neurone disease* and our pocket guide *What you should expect from your care* which can help you use the guideline at appointments.

If your situation doesn't improve, make a formal complaint or appeal to the service involved. They can guide you on how to do this.

What can I do if I'm on a waiting list too long?

You may be on a lengthy waiting list or unable to get a referral. For example, you may be waiting to access hospice or palliative care. Ask your GP or another member of your health and social care team for guidance.

If your care needs are still not met following this discussion, it may help to make a formal complaint. We provide more information on how to check if your treatment and care are appropriate, including contact details for national services at:
www.mndassociation.org/mycare

See also *Useful organisations* in section 5: *How do I find out more?* for details about services that deal with queries and complaints from patients.

What is advocacy?

Advocacy is when someone supports your communication, to help you explain concerns, and ask questions at appointments.

An advocate doesn't give their own opinion but supports you to make your own decisions. In other words, they ensure your wishes and choices are heard in meetings about treatment and care.

You can find advocates through professional services or you can ask a trusted friend or family member to be your advocate.

See our booklet *Telling people about MND* for more on advocacy and how to raise awareness of your needs with those involved in your care.

Useful organisations

We cannot endorse organisations, but the following may help your search for further support and information. Find more links at **www.mndassociation.org/usefulorgs**

Contact details may change between revisions, but our MND Connect helpline can help you find services (see *Further information* in this section for contact details.)

Adult social care services

To arrange a needs assessment or carer's assessment, contact adult social care services.

In England and Wales this is through your local authority or council. Search for *find your local council* at: **www.gov.uk**

In Northern Ireland, search for *health and social care trusts* at: **www.nidirect.gov.uk**

Care Quality Commission (CQC) (England)

Contact the CQC if you are concerned about care from a provider in England. You can also use this site to search for a care service in England and read the ratings.

Telephone:	03000 616161
Website:	**www.cqc.org.uk**

Community Health Councils (Wales)

Confidential advice for complaints about health care in Wales.

Website:	**www.wales.nhs.uk/ourservices**

Care and Social Services Inspectorate Wales (CSSIW)

Contact the CSSIW if you are concerned about care from a provider in Wales. You can also use this site to search for a care service in Wales and read the ratings.

Telephone: 0300 7900 126
Website: **www.careinspectorate.wales**

Health and social care online (Northern Ireland)

Health and social care online information for Northern Ireland.

Email: through the website contact page
Website: **www.hscni.net**

Health in Wales

Online information on NHS services in Wales.

Website: **www.wales.nhs.uk**

Hospice UK

Guidance on palliative and end of life care.

Website: **www.hospiceuk.org**

MND Scotland

MND care, information and research funding for Scotland.

Telephone: 0141 332 3903
Email: info@mndscotland.org.uk
Website: **https://mndscotland.org.uk**

National Institute for Health and Care Excellence

An independent organisation providing national guidelines on appropriate treatment and care for certain conditions.

Telephone: 0300 323 0140
Website: **www.nice.org.uk**

NHS 111

The NHS online/telephone service if you need urgent, but not life-threatening medical help or advice. Available 24-hours a day, 365 days a year.

Telephone: 111 (England and some areas of Wales)
Website: **https://111.nhs.uk**

NHS online

The main online reference for the NHS.

Website: **www.nhs.uk**

Patient advice and liaison service (PALS)

Confidential advice for complaints about health care in England. In many hospitals, PALS teams are known as *Patient experience teams*.

Website: Search for PALS at: **www.nhs.uk**

Patient and Client Council (Northern Ireland)

For confidential advice and making a complaint about healthcare in Northern Ireland.

Telephone: 0800 917 0222
Website: **https://pcc-ni.net**

The Regulation and Quality Improvement Authority (RQIA)

Contact the RQIA if you are concerned about care from a provider in Northern Ireland. You can also use this site to search for a care service and read the ratings.

Telephone: 028 9536 1111
Website: **www.rqia.org.uk**

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Castle Practice, Ludgershall and Tidworth

References

References used to support this information are available on request from email: **infofeedback@mndassociation.org**

Or write to:

Information feedback, MND Association
Francis Crick House (2nd floor), 6 Summerhouse Road
Moulton Park, Northampton NN3 6BJ

Further information

Most of our information resources refer to aspects of care with MND or Kennedy's disease. Where relevant, we have referenced resources in this booklet, but you can find further reading on our website at:
www.mndassociation.org/careinfo

You can also use our *Care information finder* on our care web pages. This helps you to search by need, grouping together all resources on selected topics. You can access the finder at:
www.mndassociation.org/careinfofinder

Download wider information at:
www.mndassociation.org/publications

Find our information for health and social care professionals at:
www.mndassociation.org/professionals

If you would like to order printed copies of our publications, contact our MND Connect helpline:

MND Connect

Our helpline team can provide emotional support, guidance and information. They can help you search for other organisations, our local branches, groups and volunteers, and explain our services and grants for people with and affected by MND or Kennedy's disease.

Telephone:	**0808 802 6262**
Email:	**mndconnect@mndassociation.org**

MND Association website

Find support and information about membership, fundraising, campaigning, research and news at:
www.mndassociation.org

Benefits Advice Service

The MND Association Benefits Advice Service can help you identify available benefits and how to claim them. Find details at: **www.mndassociation.org/benefitsadvice** for England, Wales and Northern Ireland, or contact our MND Connect helpline for guidance.

Equipment loans and MND support grants

If statutory funding is not available or delayed, we may be able to provide a grant or certain equipment on loan. Grants may be given to help with aspects of care or quality of life, for people with MND or Kennedy's disease, their carers and younger members of the family.

Applications for some support grants or equipment loans need to be made by a relevant health or social care professional.

Telephone:	**0808 802 6262**
Email:	**support.services@mndassociation.org**
Website:	**www.mndassociation.org/getting-support**

Local and regional support

To find out our contacts in your area, go to **www.mndassociation.org/local-support** or ask MND Connect as shown in this section.

Local support may include:

Regional staff: have knowledge about the management and care of people with MND. They can work with volunteers and families affected by MND or help to influence local service providers. Their aim is to help ensure care and support is made available at the right time.

Association visitors (AVs): our trained volunteers, who provide information and guidance about MND and local services by phone, email or home visits. Contact MND Connect to find out if there is an AV near you.

> ***"There is a great benefit to be able to talk to someone who is not a family member, someone with whom you can share all your hopes and fears without worrying about the impact this might have as you would with one of the family."***

Branches and groups: are volunteer-led and provide local support, practical help and an opportunity to get together with others living with or affected by MND.

Communication Aids Service

Contact our service with queries about communication aids. We also provide some financial support. Certain items can be loaned if unavailable or delayed through health and social care services.

Telephone:	**0808 802 6262**
Email:	**communicationaids@mndassociation.org**

MND Association online forum

Our online forum is a safe place to share experiences with other people living with or affected by MND. You can just view if you wish or join the online chats. You can access the forum at: **https://forum.mndassociation.org**

Information in other languages

We provide introductory information in languages other than English, with a limited translation service for further care publications. Contact MND Connect or ask someone to contact them on your behalf for support. We can also arrange for an interpreter to join a call with MND Connect or our Benefits Advice Service, if needed: **www.mndassociation.org/languages**

We welcome your views

Let us know what you think of this booklet. We'd love to hear what you feel we did well and how we can improve this content for people with or affected by MND or Kennedy's disease. Your anonymous comments may also be used to support and influence, as they help us share real MND experiences and raise awareness in our resources, campaigns and applications for funding. Please use our online feedback form at: **www.smartsurvey.co.uk/s/MNDcare**

Email your comments to: **infofeedback@mndassociation.org**

or write to us:

MND Association Information feedback,
Francis Crick House (2nd floor), 6 Summerhouse Road
Moulton Park, Northampton NN3 6BJ

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