



## 5: What kind of support is available?

This section looks at the types of care and support available to help you in the caring role.

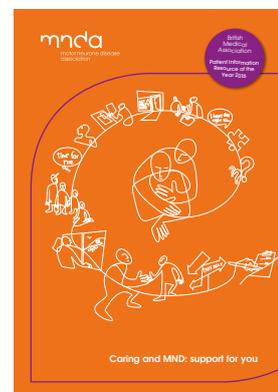
The following information is a section from our full guide *Caring and MND: support for you*.

Other sections, and the full guide, can be found online at: **[www.mndassociation.org/carerguide](http://www.mndassociation.org/carerguide)**

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

Telephone: **0808 802 6262**

Email: **[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)**



**Caring and MND:  
support for you**

# 5: What kind of support is available?



This section looks at the types of care and support available to help you in the caring role.

**“The main focus appears to always be on the person with MND. Carers appear to be left to carry on with little or no support.”**

## Types of care

MND support is wide ranging, but it is important to realise this can assist and guide carers too. You are an unpaid member of the health and social care team, so do ask questions if you need to and offer your viewpoint when you think it can help.

**“It’s difficult to find your own path and plan ahead if you are unaware or unprepared for what may or may not happen. Usually it happens before you realise it.”**

You understand how the disease is affecting daily life for the person with MND – and for yourself. Professionals should seek your input at appointments and the more they know, the more appropriate help and advice they can give.

The types of care include:

- your GP and community health team
- specialist healthcare for MND
- MND care centres and networks

- adult social care services
- specialist palliative and hospice care
- respite care
- residential and nursing care homes
- emergency and urgent support
- care following a hospital stay
- NHS continuing healthcare
- support from the MND Association
- support from other organisations
- support from other people affected by MND.

Health and social care services can vary across regions and sometimes there may be a waiting list for support. However, where possible, an early referral can help build a relationship. In urgent situations, this means needs and wishes will already be known.

This section provides an overview of available care, to explain:

- who is involved
- what each type of support does and how this can help
- how to access that help
- whether or not you need to pay.

## Who is involved?

Before looking at the types of care on offer, it may help to consider the different health and social care professionals who make up these services. You may have contact with a large number of professionals, which can be bewildering.

“It is extremely confusing as to who has responsibility for which service.”

The following list explains the main contacts usually involved with MND, but you may meet others depending on your needs.

They may be part of:

- the community healthcare team
- a multidisciplinary team linked to an MND care centre, network or other neurology service
- a specialist ward in a hospital or clinic.

Although their primary aim will be the care of the person with MND, they can also answer your questions as a carer.

“It should be stressed that often the carer knows more about the person with MND’s personal needs than the professionals.”

**GP:** Your local doctor or ‘general practitioner’, is a central medical contact. They can help diagnose, prescribe medicines, maintain medical records, provide information and guidance, and refer you or the person with MND to specialists when needed.

**Consultant neurologist:** A doctor who specialises in the brain, spinal cord, nerves and muscles. They are experts on conditions such as MND and usually work with other medical consultants to ensure people with MND receive the best possible medical care.

**Other consultants:** As well as seeing a neurologist, someone with MND may see other consultants as needed, such as a respiratory consultant about breathing support or a palliative medicine consultant.

**Specialist nurse:** A nurse who specialises in a relevant field – often in neurology, with expert knowledge of conditions such as MND.

**MND care centre co-ordinator:** The main contact at an MND care centre or network, often a specialist nurse or other health professional. They help link people with the multidisciplinary team, community services and the MND Association. A similar role may exist in other neurological teams.

**Community or district nurse:** A nurse who works closely with your GP and is likely to visit the person with MND as the disease progresses. They can assist with medication, monitor and treat symptoms, help with prevention of pressure sores, provide certain items of home nursing equipment and advise on local services.

**Speech and language therapist (SLT):** These therapists assess speech and communication difficulties. They also work with people who have problems with eating and swallowing. Following assessment, they can provide guidance, therapy and advise on communication aids.

**Dietitian:** An expert in nutrition who works closely with speech and language therapists. They can help someone with MND maintain weight if swallowing becomes difficult.

**Occupational therapist (OT):** A therapist who helps people remain as independent as possible through equipment for daily living or mobility, adapting the home environment and informing people of different ways to do everyday activities.

**Physiotherapist:** A therapist who can offer guidance on managing fatigue, cramps and stiffness in muscles and joints. They can advise someone with MND about suitable exercise and, where necessary, advise you how to help with assisted or passive exercise. Exercise cannot reverse damage to muscle groups weakened by MND, but can strengthen muscles not yet affected and help improve or maintain range of movement in joints. Physiotherapists can also advise on ways to prevent or manage falls.

See Information sheet 6A: *Physiotherapy*.

**Palliative care specialists:** These teams work to improve quality of life for people with life-shortening conditions. They provide a wide range of support, including symptom control and guidance on psychological, social, spiritual and practical needs.

**Respiratory team:** This may include a respiratory consultant and a specialist physiotherapist who are experts in breathing. They can assess the needs of the person with MND and offer guidance on therapy and treatment, including ventilation (mechanical breathing support).

**Counselling and psychology services:** A GP can refer the person with MND to an appropriate service, counsellor or neuro-psychologist for emotional and psychological support. This may be particularly important if the person experiences changes to thinking and behaviour with MND. There may be a waiting list, but a local hospice, palliative care team or social worker may also offer counselling as part of their palliative support.

**Pharmacist:** A professional who dispenses prescribed medicines. They can advise on the best types of medication in particular circumstances, including liquid medication for ease of swallowing.

**Complementary therapists:** These therapists can offer a variety of complementary therapies, such as massage, acupuncture, reflexology and others. These do not replace conventional medicine, but work alongside it. Some people find these therapies ease symptoms and reduce feelings of stress or anxiety.

**Wheelchair services:** These professionals can assess seating needs and help arrange wheelchair supply, as appropriate. There may be waiting lists for NHS provision.

*See Section 11: How the MND Association can help you for details about our services.*

**Social worker or care manager:** Working for adult social care services, these professionals provide information, needs assessments for people with MND and carers' assessments. They provide guidance on care services, including home help or advice on residential and nursing care homes.

**Benefits advisers:** An adviser who helps with benefits queries and claims for financial support. They do not work closely with other members of the health and social care team, but on occasion may need to ask members of the wider team for medical evidence to support a claim. You can also search for government online information at: [www.gov.uk](http://www.gov.uk) or for Northern Ireland at: [www.nidirect.gov.uk](http://www.nidirect.gov.uk)

**MND Association regional care staff:** Professionals who work for the MND Association across England, Wales and Northern Ireland. They work closely with local service providers to ensure care and support are available at the right time.

**MND Association visitor (AV):** One of our voluntary visitors, who provide free and confidential support to people living with MND, their carers, their family and close friends.

*See Section 11: How the MND Association can help you for details about our services.*

## Your GP and community health team

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

See the earlier heading *Who is involved?* for a list of professionals and what they do.

### How can they help?

Depending on their expertise, they can offer help with:

- referrals to other health and social care professionals or services
- managing and monitoring symptoms
- prevention of health problems and health checks (important for you as well as the person you support)
- accessing specialist equipment
- carer support, information and training
- prescribing of medicines (if authorised to do so).

See the heading, *Breathing support in Section 2: What to expect*, for details about GPs prescribing medicines for our MND Just in Case Kit.

### How do we access this help?

Contact your local GP surgery to register as a carer. This places a flag against your record and helps the professionals involved to remain aware of your needs as a carer. If the person you support attends a different surgery, ask if you can register as their carer at this surgery too.

As MND progresses, the person with MND may be able to get support and symptom monitoring through home visits, by a district or community nurse, and other professionals as appropriate.

Most surgeries operate an out-of-hours service during evenings and weekends.

## Do we have to pay for this?

The majority of NHS services are free, but exceptions may include:

- some dental and optical services
- larger items of equipment and assistive aids (the person with MND may be financially assessed to see if they need to contribute)
- some prescription fees in England, although the person with MND usually qualifies for exemption (prescriptions are free in Wales and Northern Ireland).

See Information sheet 10A: *Benefits and entitlements* for details about prescription exemption and costs for sight tests and dental treatment.

## Specialist healthcare for MND

Specialist healthcare professionals can be based at the same location or as a virtual team in different settings. Some may make home visits, but this is not always possible.

See earlier heading *Who is involved?* for a list of professionals and what they do.

### How can they help?

Specialists assess and monitor symptoms like the community healthcare team, but focus on provision of treatment for a particular area, such as breathing support.

As the carer, this can help you:

- plan ahead when symptoms first begin to show
- become more aware of interventions the person with MND does or does not want
- find out how to manage treatment, therapy or equipment within your daily routines.



“I would like more support to talk about the future and plan what can be done to help.”

In many regions, you may be able to get help from a co-ordinator who specialises in MND and can act as a main contact between specialists. They usually work for an MND care centre or network, but this role sometimes exists through other neurological clinics, palliative care services and hospices. GPs and neurological consultants can advise on MND co-ordinators in your area.

### How do we access this help?

GPs or other health and social care professionals can refer the person with MND, and yourself, to specialists as needed.

### Do we have to pay for this?

This type of NHS care is free.

## MND care centres and networks

The MND Association part-funds a national partnership programme of MND care centres and networks across England, Wales and Northern Ireland. These are dedicated MND clinics where health and social care professionals come together to improve the standard of care for people living with MND. They also give guidance to carers.

### How can they help?

Each team of specialist professionals (known as a multidisciplinary team) works in a co-ordinated way. They monitor and advise on symptoms and provide support and information. They do not replace the existing health and social care team for the person with MND, but work with them.

**See earlier heading *Who is involved?* for a list of professionals and what they do.**

It is important to note that most neurology clinics offer co-ordinated care and services for MND. The MND Association works in partnership with neurology and community services, as well as MND care centres and networks. Our aim is to improve services and help people with or affected by MND receive equal care at the highest possible standard.

**See Information sheet 3A: *MND care centres and networks*, for more detail about these services.**

### How do we access this help?

If the person with MND wishes to access an MND care centre or network, they will need to ask their GP or neurological consultant for a referral. The service focuses on the needs of the person with MND, but you can attend appointments with them, which can help you feel more informed.

MND care centres are not purpose-built buildings. Appointments usually take place in a hospital or hospice. In most cases you need to travel to these appointments, but some teams may provide an outreach service, as do MND network services.

### Do we have to pay for this?

Support from MND care centres and networks is free.

## Adult social care services

These services usually include social workers, care managers, care co-ordinators and occupational therapists.

**See the earlier heading *Who is involved?* for a list of professionals and what they do.**

### How can they help?

They can offer assistance through:

- a needs assessment for the person with MND to agree and arrange appropriate services, such as a care worker, or a personal budget to assist their needs
- a carer's assessment for yourself to agree and arrange appropriate services or a personal budget to assist your needs
- provision of small items of equipment
- advice on larger equipment, home adaptations and potential funding
- guidance on other services, benefits and emergency support
- psychological and family support

- guidance on selecting and arranging residential or nursing home care, should this be required, or working with healthcare professionals to provide care at home.

### How do we access this help?

Contact adult social care services through your local authority or, in Northern Ireland, through your local health and social care trust. Sometimes, social care professionals work at a GP surgery, alongside the local community healthcare team.

### Do we have to pay for this?

Some equipment may be free, but you may have to pay towards services. Income and savings will be considered to work out how much you may need to pay. In Northern Ireland, home care services are free, but you may have to pay for other help.

**See Section 4: Carer's assessment for more detail about financial assessment and how services can be arranged, including direct payments to purchase services of your choice.**

## Specialist palliative care

Based in a hospital, hospice, day hospice or local clinic, specialist palliative care is provided by a team of health and social care professionals with training and expertise in support for life-shortening illness. Services can also be provided by home visit or in a residential or nursing care home.

**“We have a good relationship with our local hospice...I keep telling people how good it is for living as well as end of life.”**

### How can they help?

This care looks at the person's needs as a whole. It includes symptom management, but also psychological, social, spiritual and practical support as required. The care given can range from clinical care and counselling, to complementary therapies and guidance on financial support. Carers and family members are also supported.

### How do we access this help?

GPs and other health and social care professionals can refer the person with MND and yourself to specialist palliative care. Ask for early referral as soon as you both feel ready.

You may have to wait if services are busy in your area, but early referral enables you to build a relationship with a hospice or specialist palliative care team. This can bring added benefit as these services focus on quality of life. It also helps professionals to understand everyone's needs, wishes and preferences. If the person with MND has to be admitted to hospital for any reason, detailed knowledge about their needs may result in a shorter stay.

### Do we have to pay for this?

Palliative care is usually free. These services are sometimes funded by the NHS, but also by charity funding (as with independent hospices). You may be charged for some services, such as complementary therapies.

## Respite care

Short-term alternative care that allows you to take a break or regular breaks, is known as respite care. Although this support can be provided by family and friends, there may come a time when you need to involve professional help.

**See Section 8: Looking after yourself for more about the benefits of respite and how to manage if the person you support does not want to receive this type of care.**

Where services allow, respite care can be provided at:

- home
- a residential or nursing care home
- a day care centre
- a hospital
- a hospice.

### How can they help?

In most cases, respite means that someone will sit with the person and support them for short, regular breaks. This could help you to go shopping, attend a course, make an appointment or visit family and friends.



**“We receive help from the local hospice for three hours a week, and weekly day care there.”**

Longer periods of respite can also be arranged so you can rest, take a holiday or receive treatment, if needed. This may mean someone coming into the home to provide care, or if care is complex or needed around the clock, the person with MND may be able to stay in a residential or nursing home for a week or two.

### How do we access this help?

We recommend looking at options in advance, as respite care is not easy to arrange at short notice. You may also need to identify suitable support for MND, as professional carers may not have previous experience of working with the disease.



**“My husband went into a care home for a week’s respite care at short notice and the care home was unprepared for dealing with his requirements and need for speedy attention.”**

With MND, needs can change over time and become more complex, so you may want to keep a variety of contact details to hand.

The first step is to contact adult social care services through your local authority or, in Northern Ireland, through your local health and social care trust. They can arrange an assessment for the person you support to work out their needs and a carer’s assessment for yourself. You can ask for advice about respite providers at the assessment.

**See Section 4: Carer’s assessment for details and our write-on forms at the end of this guide for tracking contacts.**

Local carer centres and hospices can direct to specialist respite providers, but may not be able to recommend one service above another.

If the person did not require respite care before, but their needs have increased, this can be reviewed. They can have their needs assessed again, as can you, with a focus on respite and other support.

Adult social care services can also advise about out-of-hours support, for care cover in urgent or emergency situations. It is worth finding out contact details for this service and keeping these in or near your telephone.

**See later heading, *Emergency and urgent support*.**

### Do we have to pay for this?

There is normally a charge for respite care, but you and the person you support may receive help towards this, depending on the outcome of your assessments.

If you seek respite care on your own, there will be a charge, but there may be local schemes to help with carer breaks. Ask about grants for carers during your own assessment, to find out what may be available and if this can be included in your care and support plan.

## Residential and nursing homes

There may come a time when the person you support needs more care than you can realistically provide at home. Respite care can help for short periods of time, but if the situation is ongoing, residential or nursing care may need to be considered.

Even where every effort has been made to enable the person with MND to stay at home, this sometimes has to change.

**“I know I won’t be able to do it all on my own soon. Right now there is no telling him that and I don’t know how to bridge the reality of his needs with my capability. It really worries me.”**

This can be a difficult decision for you both, but it does not reflect on the care you provide. Residential nursing care may be necessary where:

- there is a need for complex medical care
- a hospital admission for urgent or emergency care results in ongoing nursing care
- your own ill-health means you become unable to continue providing support
- you have children or other dependants who also need your support
- you do not have a personal or family network to help
- changes to thinking and behaviour have caused the person with MND to become aggressive or a risk to themselves.

### How can they help?

Both residential and nursing care homes provide accommodation, meals and personal care support, but nursing homes employ registered general nurses.

These nurses also work in a co-ordinated way with other healthcare professionals, to ensure medical needs are met.

Someone with MND is more likely to need nursing care, especially if their medical needs become complex and they need help with eating, drinking and breathing.

Some homes are dual registered, which means they can provide nursing care if needed.

### How do we access this help?

Adult social care services can assess if the person with MND requires residential care. Contact your local authority or, in Northern Ireland, your local health and social care trust.

Where nursing care may be required, an NHS healthcare professional will also need to assist with the assessment.

This may be a good time to apply for NHS continuing healthcare. This is often provided in a nursing care home, but can sometimes enable a person to remain in their own home with nursing support.

**See later heading, *NHS continuing healthcare.***

The person you support must agree to any care plans that are made. The only exception is where dementia or severe changes to thinking mean that the person is unable to make decisions on their own behalf. In this situation, a health or social care professional will need to assess their ability to make decisions (known as mental capacity). They will then work with you to make decisions based on the best interests of the person with MND.

**“We are just looking into residential care, but it’s difficult to find a place as his needs are so complex.”**

When selecting a care home, ask the following questions:

- Do they have the necessary experience with neurological conditions to provide suitable care for MND?
- How do they support needs such as speech and communication, mobility and help at mealtimes, including tube feeding if required?
- Can they support advance care planning and end of life plans?
- When are you allowed to visit?
- Are you allowed to help with care tasks if that is something you and the person with MND would like?

You can read inspection reports to see how a home is rated:

- for England, see the Care Quality Commission website at: [www.cqc.org.uk](http://www.cqc.org.uk)
- for Wales, see the Care Inspectorate for Wales website at: <https://careinspectorate.wales>
- for Northern Ireland, see the Regulation and Quality Improvement Authority website at: [www.rqia.org.uk](http://www.rqia.org.uk)

See also Section 12: *Useful organisations and [www.mndassociation.org/mycare](http://www.mndassociation.org/mycare)*

### Do we have to pay for this?

In a nursing care home, registered nurses are usually employed by the care home itself, but the NHS makes a payment to the care home to fund this. If someone is paying for this care themselves, the fees should be reduced by the amount the NHS pay.

For residential care without NHS-funded nursing care, a financial assessment will be arranged to see if the person with MND needs help to pay or must pay for this themselves. Most people are expected to contribute towards care in a residential home, depending on capital and savings.

If the person qualifies for NHS continuing healthcare, all of their personal and medical care will be fully funded.

## Emergency and urgent support

No matter how well you plan, or how much support you have in place, something unexpected may happen. We provide a *Motor neurone disease checklist* to help people think ahead.

See *Further information at the end of this section for details about how to order our publications.*

It is important to identify out-of-hours support and emergency services, so that you feel prepared.

### How can they help?

Out-of-hours support and emergency services can provide:

- emergency care cover if you suddenly find yourself unable to support for any reason
- emergency medical care for the person with MND, if needed, (this may require hospital admission).

### How do we access this help?

If you have a carer's assessment, ask about emergency care cover services. You can also contact your local authority at any time to find out more. In Northern Ireland, contact your local health and social care trust.

The GP and members of the health and social care team who support the person with MND can also advise about emergency and urgent support. The GP will usually add the person with MND to an electronic end of life register, which can help professionals remain aware of particular needs in emergency situations.

Keep all contact numbers for emergency assistance in or near your telephone. In urgent medical situations, call 999 for assistance.

### Do we have to pay for this?

Emergency healthcare is free, however, there may be a charge for emergency care cover. Depending on the services arranged, some contribution may be required and the person with MND may be financially assessed, as part of their own needs assessment.

There are various ways to alert emergency teams about the needs of the person with MND. The following may help bring peace of mind in urgent situations:

Ways to raise an alert	What this provides
<b>Carer emergency card</b>	A card to carry in case you are involved in an emergency and unable to communicate. Usually linked to a registration service, the card alerts authorities that you are a carer and means the person you support will receive help. Ask your local authority if they have a carer card scheme, or your local health and social care trust in Northern Ireland.
<b>Message in a bottle</b>	A sticker on the fridge and inside of the front door where the person with MND lives, tells paramedics an alert bottle can be found in the fridge. This can contain essential personal and medical details. Bottles are free of charge from your local chemist. You can find details through the Lions Club. Search for <i>message in a bottle</i> at: <a href="https://lionsclubs.co">https://lionsclubs.co</a>
<b>MND Alert Card</b>	We provide this small card for the person with MND to carry in a purse, wallet or pocket. This helps to alert hospital staff that they need specialist help for MND, with space to record key contacts.
<b>Understanding My Needs</b>	We provide this write-on booklet to help someone with MND record their needs and personal background. This can help guide care workers, or hospital or hospice staff.
<b>MedicAlert</b>	This registered charity provides an identification system for individuals with medical conditions and allergies. Usually in the form of a bracelet or necklet, which you purchase, the scheme is supported by a 24-hour emergency telephone service. You can find details at: <a href="http://www.medicalert.org.uk">www.medicalert.org.uk</a>
<b>MND Association Just in Case Kit</b>	A box designed to hold medication to relieve sudden breathlessness and anxiety. This can be ordered from the MND Association by a GP, who will prescribe suitable medication and discuss usage with the person and yourself, as their carer. The box is kept at home 'just in case'.

Ways to raise an alert	What this provides
<b>Important care documents</b>	If the person with MND has advance care plans, end of life care plans or an Advance Decision to Refuse Treatment (ADRT), ensure these documents are easy to find in an emergency. For example, it is not advisable to lock them away in a safe, which may be difficult to access when needed. Paramedics and medical teams need to be able to see these documents if they are to respect the wishes of the individual. If you use the Message in a bottle scheme, the bottle may not be big enough to hold all these documents, but you could add a note of where to locate them to raise awareness.
<b>Telecare and telehealth</b>	When the person with MND is being assessed for their care needs, ask about equipment to send messages to a health monitoring service. If you cannot be with the person at all times, this can ensure assistance in case of a fall or other urgent situation. There may be a charge for this.

## Care following a hospital stay

If the person you support has been admitted to hospital for symptom control or urgent care, both their needs and yours should be assessed before discharge. A care plan should then be provided, usually by adult social care services. Many hospitals have dedicated discharge teams who do this.

### How can they help?

Where an increased level of care will be required as a result of the treatment, services should be arranged promptly to help you in your care tasks.

### How do we access this help?

If the person you support is going to be discharged and you have not been approached about a care plan, you have the right to ask when it will be carried out. Feel confident about making this request, as care plans are a requirement for the hospital and adult social care services. It is important that you both receive adequate support.

### Do we have to pay for this?

Depending on the services arranged, some contribution may be required and the person with MND and yourself may be financially assessed, as for a needs or carer's assessment. However, there are no charges for medical care.

## NHS continuing healthcare

If the needs of the person with MND become complex and require medical help, they may be eligible for NHS continuing healthcare. This funds and organises appropriate care and support, which can relieve pressure on you as the carer.

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

**See Information sheet 10D: *NHS continuing healthcare* for details about the assessment required for this service.**

## How can they help?

If the person with MND qualifies, all of their care needs will be met by professional care support (whether personal or medical). The care package is sometimes provided at home, but may need to take place in a nursing care home if the person's needs are very complex.

## How do I access this help?

The person with MND must require a high level of healthcare and support to qualify. If their symptoms are progressing rapidly or they need end of life care, they are more likely to receive NHS continuing healthcare. They may also qualify for 'fast tracking' which can speed up the application process.

Ask any member of the health and social care team for guidance about referral for NHS continuing healthcare. A team of professionals will be involved in the assessment process and as the main carer, you should be consulted.

## Do we have to pay for this?

If the person with MND qualifies for this type of care, it will be funded entirely by the NHS. In some cases, a 'shared care package' may be provided between the NHS and adult social care services.

## Support from other organisations

A variety of local, regional or national organisations may be able to offer guidance, information, support or funding to you and the person with MND.

*See Section 12: Useful organisations for suggested services and contact details.*

## Support from the MND Association

We offer a range of support for people with MND, their carers, families and the professionals who provide care.

*See Section 11: How the MND Association can help you.*

## Support from people affected by MND

You may wish to seek support from others affected by MND. Our branches and groups offer the chance for get-togethers and often host meetings specifically for carers. If this does not feel appropriate for you now, it may be useful in the future.

A purple speech bubble containing a quote. The quote is: "I would like a carers' group so I could share experience, as we are very rural and there aren't many carers nearby."

"I would like a carers' group so I could share experience, as we are very rural and there aren't many carers nearby."

You may also find our online forum useful at: <https://forum.mndassociation.org> which provides a safe place to share experiences with others affected by MND.

A purple speech bubble containing a quote. The quote is: "I regularly read the problems and comments on the forum and find these very helpful, although I have never joined in or posted anything myself."

"I regularly read the problems and comments on the forum and find these very helpful, although I have never joined in or posted anything myself."

*See Section 11: How the MND Association can help you for details about these services.*

## Key points

- Find out about out-of-hours and emergency support as soon as you can – it is always better to be prepared. Having this information to hand can bring peace of mind.
- If you need to, ask questions when supporting the person with MND at appointments. You need guidance too.
- The health and social care team supporting the person with MND should include you in discussions about care arrangements, where this affects you and the support you provide.
- You can note questions to ask at appointments and answers given using our *Appointment queries* form at the end of this guide.

## Further information

We produce a wide range of publications about MND and the support that may be needed. The following may be useful in relation to this section:

### From our information sheet range:

**3A: MND care centres and networks**

**6A: Physiotherapy**

**6B: Complementary therapies**

### From our other publications:

**MND Alert Card:** a small card for the person with MND to carry in a purse, wallet or pocket. This helps to alert hospital staff that they need specialist help for MND, with space to record key contacts.

**Understanding My Needs:** a write-on booklet to help someone with MND record their needs and personal background. This can help guide care workers, or hospital or hospice staff.

**Motor neurone disease checklist:** to help someone with MND think about their wellbeing and the support they may need.

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

**End of life: a guide for people with motor neurone disease:** a candid and comprehensive guide about planning ahead for the later stages of MND and wishes for future care.

**Personal care:** our booklet about managing daily routines.

**Emotional and psychological support:** our booklet about available therapies.

**Changes to thinking and behaviour with MND:** our booklet on how to seek support if these changes are experienced by the person with MND.

## How to access publications and further information:

Most of our publications can be downloaded at: **[www.mndassociation.org/publications](http://www.mndassociation.org/publications)** or you can order them from our MND Connect helpline:

Telephone: **0808 802 6262**

Email: **[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)**

MND Connect can also help direct you to external services and providers, and introduce you to our services as available in your area, including branches and groups, Association visitors and regional staff.

*See Section 11: How the MND Association can help you for details about our services.*

### **Online forum:**

The forum provides an opportunity to share information and experiences with other people affected by MND. Hosted by the MND Association at:

**<https://forum.mndassociation.org>**

### **Information for professionals**

We provide information to help professionals support people with MND, their families and carers. This can be accessed at:

**[www.mndassociation.org/professionals](http://www.mndassociation.org/professionals)**

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Motor Neurone Disease Association  
Francis Crick House, 6 Summerhouse Road,  
Moulton Park, Northampton NN3 6BJ

Tel: 01604 250505

Website: [www.mndassociation.org](http://www.mndassociation.org)

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For references and acknowledgements  
please refer to the full guide, *Caring and  
MND: support for you*.

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from our helpline, MND Connect:

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



*Patient Information Forum*