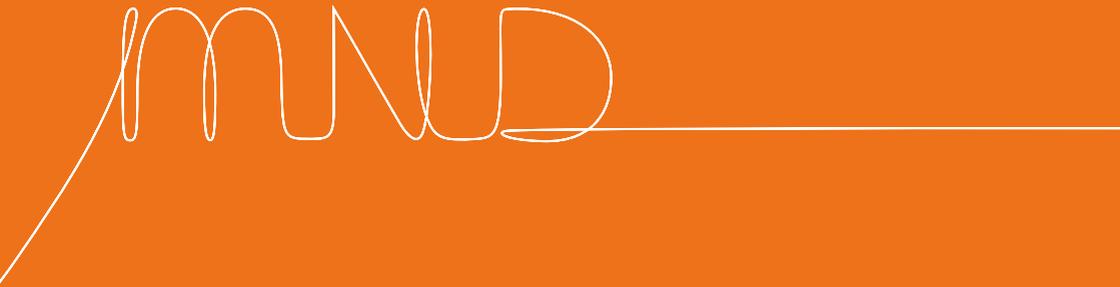


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motor neurone disease
association



Caring and MND: quick guide



Registered Charity No. 294354
Company Limited by Guarantee No. 2007023

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The MND Association would like to thank The Pixel Fund, The Hedley Foundation and the Hazel and Leslie Peskin Charitable Trust for their kind support, which has made possible the production of *Caring and MND: quick guide* and our full carer guide, *Caring and MND: support for you*.



<https://piftick.org.uk>

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



This guide has been endorsed by Carers UK

How this guide can help you

If you are a family or unpaid carer for someone with motor neurone disease (MND), this quick guide suggests ways to find support for you. It can also help if you support someone with Kennedy's disease.

It is designed for:

- those new to a caring role
- anyone who needs a simple introduction.

We offer more detailed help in our full carer's guide *Caring and MND: support for you*. At the end of each section in this quick guide, we highlight where to find relevant information in *Caring and MND: support for you*, and other useful publications.

The full guide contains additional write-on pages to help you keep notes of contacts and other details.

You can obtain the full guide, spare write-on pages and our other publications through the MND Connect helpline: **0808 802 6262**, **mndconnect@mndassociation.org**. The helpline team can also provide a listening ear and help you find appropriate services.

All of our publications are listed on our *Publications list* and most can be downloaded instantly from our website:

www.mndassociation.org/publications

The quotes used in this quick guide are from carers who have supported a person with MND or Kennedy's disease.

1: New to caring?



If someone close to you has been diagnosed with MND or Kennedy's disease, you may be providing both practical and emotional support. You may be any age, a partner, a family member or a friend, who provides either part-time or full-time care. However, you may not recognise yourself as a carer.

"I love him, so I care for him."



Yet the term 'carer' is important, as it is used to describe family or unpaid carers by most support organisations.

Describing yourself as a carer can help open doors to the support you may need.

With MND, the person's care needs are likely to increase over time and this may feel overwhelming.

"I don't feel there is a me anymore, you live your life to keep everyone else happy."



Register as a carer with your GP as soon as possible. The surgery team may be able to help with more timely appointments and checks to monitor your health when facing the demands of a caring role.

However, you do have a choice on the amount and type of care you are able to provide. There is no right or wrong way. You may find tasks such as personal care or managing another person's finances become too much.

Ask about assessment from your local authority in England and Wales, or your local health and social care trust in Northern Ireland. You can then discuss concerns and find out the options available. You can have a carer's assessment and the person with MND or Kennedy's disease can have a needs assessment. For details see 4: *Carer's assessment* later in this quick guide. In Northern Ireland a needs assessment is called a community care assessment.

Although everyone's situation is different, there are people you can talk to who will understand what you are going through.

For suggested contacts, see 8: *How the MND Association can help you* in this quick guide. You may also wish to visit our online forum at **<https://forum.mndassociation.org>**

The MND Association supports people with or affected by MND or Kennedy's disease in England, Wales and Northern Ireland.

While every effort is made to ensure our information is relevant to each country, there may be differences across regional services. Always check with your local providers for guidance.

Further information from the MND Association:

See our full guide – *Caring and MND: support for you* (Section 1) which contains information and the following write-on pages to help you keep track:

- 1 Care summary
- 2 Carer's assessment preparation
- 3 Appointment queries
- 4 Contact record

See the previous section *How this guide can help you* for order details.

2: What to expect



MND is a neurological disease affecting the nerves in the brain and spinal cord. As the nerves become damaged, the muscles they control weaken and waste.

Everyone's journey with MND is different. Symptoms and speed of progression can differ greatly, but it can be rapid and care needs increase over time. Planning ahead is an important aspect of the caring role.

"I have no idea if what is happening to my partner is normal."



Not all symptoms happen to everyone with MND and it is unlikely they will all happen at the same time. However, MND can affect how the person walks, talks, eats, drinks, breathes, thinks and behaves.

Fatigue can limit activity and your routines may need to be flexible, including mealtimes. Swallowing difficulties can cause weight loss if eating becomes difficult, but a dietitian and a speech and language therapist can advise on diet, eating techniques or support.

A speech and language therapist can also help with speech and communication problems and suggest appropriate communication aids and therapy. Early assessment is recommended.

The bladder and bowel are not usually affected, but problems with mobility and dexterity may make it harder to get to the toilet and remove clothing in time. In some cases there may be a sense of an urgency to pee. Breathing problems can make it harder to push, which can lead to constipation - ask a GP for advice.

Some people with MND may experience emotional lability (inappropriate bouts of laughter and tears), or anxiety and depression.

Up to half of those living with MND may show changes to thinking and behaviour, but that number increases during the later stages of the disease. The effects are usually mild and only a small number develop severe changes to behaviour. This is due to a type of dementia called frontotemporal dementia (FTD). Changes to thinking and behaviour may make it difficult for the person with MND to process anything new. For example, they may refuse external care. Ask the supporting health and social care professionals for advice if needed.

See our booklet, *Changes to thinking and behaviour with MND*.

Symptom control and managing care tasks

There are many ways to help manage the disease. Section 2 of the full carer's guide *Caring and MND: support for you* looks at symptom control and support to help with care tasks.

Ask the health team supporting the person living with MND if you are worried about any symptoms or medication. It is not acceptable for you to be asked to manage medical equipment without being shown how by the relevant healthcare professional.

Encourage the person you are supporting to inform their doctor that they are happy for their medical information to be shared with you. Make sure that you are recognised as an equal partner in the care team and don't be afraid to speak up if something worries you.

Before buying equipment or aids to help the person with MND, have their needs assessed by a relevant professional, such as an occupational therapist. Equipment may not be suitable for everyone. Mistakes can be costly and frustrating, as needs can change before equipment arrives. Some items may be free or available on loan through health or social care services.

Urgent or emergency support

It is important to find out how to access appropriate support in case you are unable to provide care for any reason. It can be difficult to find professional care appropriate for MND. However, you can ask about emergency care during a carer's assessment (see 4: *Carer's assessment* in this quick guide). The following may be helpful:

Emergency Duty Team (EDT): adult social care services run this out-of-hours service to include bank holidays and weekends. EDT contact details can be obtained from your local authority in England and Wales. Contact your local health and social care trust to find out about out-of-hours assistance in Northern Ireland.

Emergency card scheme: many local authorities have a carer's card you can carry, so the person you care for gets support if you cannot be with them. It gives a trusted contact, but don't add the person's address in case the card is stolen. In Northern Ireland, ask your local health and social care trust about alerts.

Message in a bottle: a sticker on the fridge door tells paramedics that a bottle in the fridge contains essential details about the person needing support. Contact your local Lion's Club or through the website: <https://lionsclubs.co/Public>

MedicAlert: an identification system for people with medical conditions, usually in the form of bracelets or necklets. The scheme is supported by a 24-hour emergency telephone service. Details can be found at: www.medicalert.org.uk

Understanding my needs: our form for people with MND to record their needs, and use in hospital or at home to help anyone providing care.

MND Alert Card: our alert card for people with MND to carry in a purse, wallet or pocket, with important contact details.

MND Alert Wristband: our wristband alerts emergency professionals that the person has MND and may be at risk with oxygen, with a web address for the professional to find out more.

Recognising your own needs

Try to think about your needs, even if difficult when giving support. Your own wellbeing matters and this can help you continue providing care, if that's your wish.

See 7: *Your own wellbeing in this quick guide.*

Though symptoms and speed of progression vary, the physical and emotional impact of MND or Kennedy's disease can make it harder to stay involved socially. This may feel isolating for yourself as well as the person you support. Balancing your own social needs with a caring role can be difficult. Try to encourage opportunities where both of you can socialise. If the person you support has speech problems, explain to others that communication can take longer.

Further information from the MND Association:

Full guide – *Caring and MND: support for you*

Personal care a guide on support for daily routines with MND.

Making the most of life with MND a booklet on maintaining interests when living with MND.

Living with motor neurone disease.

When someone close has MND

a workbook for children aged 4 to 10.

So what is MND, anyway?

A guide for young people affected by motor neurone disease.

End of life: a guide for people with motor neurone disease.

Information sheets 1 to 14 on symptoms and support, including help for Kennedy's disease.

See *How this guide can help you for order details.*

3: Your rights as a carer



The wish to provide support should not leave you unsupported.

“I just hope that I will be able to maintain the care that I am managing at the moment.”

The carer’s role is recognised in law. If you provide care, you have certain entitlements and should be aware of how these can support you.

Talk to adult social care services to explore what is available and how services work in your area. Any financial or social care provision may depend on your circumstances and income.

In brief, you have the right to:

- have your views taken into consideration when the person you support is having their needs assessed
- an assessment of your needs as a carer
- benefits and financial support, where applicable
- request flexible working from your employer.

If you have your needs assessed as a carer, your interests, work, family life and life ‘outside’ of caring should be recognised and considered. This should include looking at ways to take a break from caring when needed.

Contact your local carers' centre, which may be able to support your rights as a carer. To find your nearest carers' centre, contact MND Connect on **0808 802 6262**, or contact organisations such as Carers UK and Carers Trust (see 9: *Useful organisations* in this quick guide).

Legislation for carers is controlled through various Acts and Orders. If required, details of these can be found in the full carer's guide, *Caring and MND: support for you*.

Further information from the MND Association:

Full guide – *Caring and MND: support for you* (Section 3).

See How this guide can help you for order details.

4: Carer's assessment



A carer's assessment enables you to tell adult social care services how your caring role could be made easier.

You should be offered an assessment once you have been identified as a carer, or you can ask for one. Contact your local authority or, in Northern Ireland, your local health and social care trust.

You have a right to a carer's assessment whether or not you live with the person you support. You may provide care full-time or part-time, or combine care with paid work.

An assessment will help you find out about:

- care services, benefits advice and local voluntary organisations
- planning for respite, urgent or emergency care
- assistance with travel
- how to maintain your own interests, studies or activities while caring
- suggestions for counselling or support groups.

Please remember, the assessment does not judge your capability as a carer, but allows you to review your caring role:

- Do you need help and are there services that could support?
- Are you willing and able to carry on caring?
- Can you continue to give increasing levels of care?

You can be assessed jointly with the person you support or separately.

“I wouldn’t want to talk about it in front of him.”



If it is difficult to leave the person you support, you may be able to arrange for the assessment at home. A friend, advocate or interpreter can also be there.

“I had to tell them what would help me.”



You may find it helpful to log some of the issues and daily tasks you face. The tools in the full carer’s guide *Caring and MND: support for you* can help with this and are also available separately (see *How this guide can help you* for order details).

At the assessment, try to consider the following:

- your health, wellbeing, hobbies and interests
- work, benefits, housing issues and adaptations
- relationships and the needs of other family members
- how to access urgent and emergency support.

Do not put on a brave face, or it is unlikely you will receive appropriate support. Emphasise how support and services made available to you now, could prevent your caring role breaking down in the future. This is important, as MND symptoms will progress and the person’s care needs will increase.

Following the meeting, you should receive a care and support plan identifying your needs and the types of information, support or services that could be provided. You may be financially assessed to work out if you need to pay towards to any agreed services.

The person you support is likely to have a needs assessment, called a community care assessment in Northern Ireland. They may be offered a range of services, respite care, equipment and aids. These can all help you as the carer, too. However, they will have their own financial assessment and you would not be expected to pay towards any of their costs as the carer.

Young people (aged under 18) who provide care to adult family members are also entitled to a young carer's needs assessment, which forms part of a 'whole family' approach.

You may want to ask for support when it will help you most. For example, at night if this worries you more. If your needs change, you may need extra support. You can ask for a review if this happens.

“At the time of the assessment (long time ago) my needs were not as great as now. Extra help in different forms has come gradually as needs arise.”



If you are not happy with any part of the assessment process, please refer to Section 4: of the full carer guide *Caring and MND: support for you* for more detail.

You can also contact our MND Connect helpline for guidance:
0808 802 6262, mndconnect@mndassociation.org

Further information from the MND Association:

See our full guide – *Caring and MND: support for you* (Section 4 and 9) for information and notes pages:

- 1 Care summary
- 2 Carer's assessment preparation
- 3 Appointment queries
- 4 Contact record

See *How this guide can help you for order details.*

5: What kind of support is available?



Support for people with MND can be complex. However, the care available can help you as the carer, as well as the person with MND.

When a person with MND requires external support, it is not a reflection on you or the care you provide. They may have complex needs and without rest, you may reach a point where you become unable to support.

The following overview shows the range of support services and professionals involved. You can find more detail in our full carer's guide, *Caring and MND: support for you*.

Please note that the person you support must agree to any referral, treatment, care or external support, unless they have become unable to make decisions on their own behalf. Only a health or social care professional can make this decision after a formal assessment to test their mental capacity. Every effort must be taken to ensure the person can communicate during this assessment (even if this requires a communication aid).

General and social care support

GP and community or district nurse: Your general practitioner or local doctor is your central medical contact. They can monitor symptoms, prescribe medicines, maintain medical records, and provide information and guidance. They can also arrange referrals to other health and social care professionals when needed. A community or district nurse is likely to visit someone with MND as the disease progresses. They work closely with the GP and assist with medication, monitoring and treatment of symptoms, prevention of pressure sores, certain items of home nursing equipment and advice on local services.

Urgent and emergency support: Identify out-of-hours support and emergency services, so that you feel prepared and keep them to hand. This way you will know how to access emergency medical help or urgent care cover if you cannot provide support for any reason. Ask for advice at your carer's assessment or the needs assessment for the person with MND (see Section 4: *Carer's assessment*), or ask your GP for guidance.

Care following a hospital stay: If the person you support has spent time in hospital, both their needs, and yours, should be assessed before discharge by social services or a dedicated discharge team. If required, a care plan should be drawn up and services arranged to assist with care tasks.

Social worker or care manager: Working for adult social care services, these professionals help provide information, support, and needs assessments for people with MND and carers' assessments. They can provide guidance on care services, including arrangements for home help or advice on residential and nursing care homes. Contact your local authority or, in Northern Ireland, your local health and social care trust. See Section 4: *Carer's assessment*.

Respite care professionals: Short-term alternative care, that allows you to take a break or regular breaks, is known as respite care. Although this support can sometimes be provided by family and friends, there may come a time when you need professional help. Where relevant and available, respite care can be provided at home, in a residential or nursing care home, a day centre, hospital or hospice. Check the provider can meet the needs of the person with MND. It can be helpful to discuss this during a needs assessment for the person with MND or a carer's assessment for yourself (see 4: *Carer's assessment* in this quick guide).

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: Providers of therapies such as massage, acupuncture, reflexology and more. These work alongside conventional medicine and some people find they ease symptoms and anxiety.

Benefits adviser: An adviser who helps with queries and claims, for benefits and financial support. They may need to ask supporting health professionals for medical evidence to support a claim. You can also search for government online information at: **www.gov.uk** or for Northern Ireland at: **www.nidirect.gov.uk**

See Section 8: How the MND Association can help you for details about our Benefits Advice Service.

Residential and nursing home care: Sometimes a person with MND requires nursing care, where medical needs are complex. Adult social care services provide information about local care homes. Contact your local authority or, in Northern Ireland, your local health and social care trust.

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 9: *Useful organisations*).

Specialist MND support

Consultants: Specialist doctors. With MND, a neurologist deals with the brain, spinal cord, nerves and muscles. They often work with other consultants, such as a respiratory consultant for 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 or network co-ordinator: A health professional with expertise in MND, sometimes a specialist nurse, and the main contact at an MND care centre or network. A similar role may be available in other neurological teams. The co-ordinator helps to link people with specialists, community services and the MND Association.

See Section 8: How the MND Association can help you.

Speech and language therapist (SLT): These therapists assess speech and communication difficulties. Following assessment, they can provide guidance on therapies, communication aids, and voice and message banking (to use your recorded voice on computer-based communication aids). They also help with eating and swallowing problems and work closely with dietitians.

Dietitian: An expert in nutrition who works closely with speech and language therapists. They can help someone with MND maintain a healthy weight where swallowing becomes difficult, provide guidance on safe eating and drinking, and advise about tube feeding.

Occupational therapist (OT): A therapist who helps people remain as independent as possible with equipment, home adaptations and different ways to do everyday activities.

Physiotherapist: A therapist who can advise on fatigue, cramps, stiffness, managing falls, and assisted or passive exercise. Exercise cannot reverse muscle damage caused by MND, but can strengthen unaffected muscles and improve range of movement.

Specialist palliative or hospice care: These teams help improve quality of life for people with life-shortening conditions, including symptom control and guidance on psychological, social, spiritual and practical needs. Support is also given to family and carers. Services can be provided at home, in hospital, at a hospice, or in residential and nursing homes. Early referral is recommended to get maximum benefit.

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 neuropsychologist 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 in most cases local hospices, palliative care teams or social workers also offer similar support.

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

NHS continuing healthcare (CHC): This is fully funded care by the NHS to meet complex needs, where the primary need is healthcare. See *Further information* at the end of this section. NHS continuing healthcare works in a similar way in England and Wales, but there is no guidance for Northern Ireland. Contact your local health and social care trust in Northern Ireland for advice if required.

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 8: *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 get-togethers and often host meetings specifically for carers. If this does not feel appropriate now, it may be useful in the future (see Section 8: *How the MND Association can help you*). You may also find our online forum helpful at: <https://forum.mndassociation.org> which provides a safe place to share experiences with others affected by MND.

Further information from the MND Association:

Full guide – *Caring and MND: support for you* (Section 5).

Information sheets:

- 3A MND care centres and networks
- 3D Hospice and palliative care
- 6A Physiotherapy
- 6B Complementary therapies
- 7C Speech and communication support
- 10A Benefits and entitlements
- 10D NHS continuing healthcare
- 11C Equipment and wheelchairs

See *How this guide can help you for order details*.

6: Work and financial support



If you or the person with MND are in paid work at the point of diagnosis, the first big decision might be whether to continue or leave employment.

“I had to struggle being a full-time carer and hold down a full-time job.”



This can be a difficult time, as decisions about work may affect:

- how you perceive your roles in life and sense of purpose
- your daily routines and social network
- your standard of living and approach to financial support.

Your first contact for advice is usually your employer, unless you are self-employed. If self-employed, seek advice from an independent financial adviser to review your income, tax liabilities and any financial investments. You may need advice from a legal expert in self-employment or company law.

If you are employed, some organisations offer an employee assistance programme, company policy or similar scheme, that may support you as a carer. You may also be able to take a short career break.

As the care demands increase with MND, you may find it useful to discuss options with:

- your employer or your trade union
- a social worker from your local authority, health and social care trust in Northern Ireland, local care services or your local Jobcentre Plus (with regard to possible benefits)

- the person you are supporting, family and friends.

Some of the options to consider are:

- paid and unpaid leave
- shorter or flexible hours, or working from home if possible
- using care services while you are working
- sharing care responsibilities between family and friends
- adapting the home or using specialist equipment to prolong independent living for the person with MND, for as long as it is safe to do so
- voluntary redundancy or leaving work
- exploring the benefits and entitlements you may be entitled to if you leave work
- early retirement (always take advice from a pensions adviser, as this can impact on other financial aspects, such as benefits)
- residential or nursing care for the person you support, for short breaks or longer term if the care needs become particularly complex.

Further information from the MND Association:

Full guide – *Caring and MND: support for you* (Section 6).

Information sheets 10A-10G on benefits, social care, work and MND, and other financial support.

See How this guide can help you for order details.

7: Your own wellbeing



As a carer it is often difficult to find time to look after your own needs. This can result in a situation where you are no longer able to continue your caring role, even if this is still your wish.

No one can be on the go 24 hours a day, seven days a week. Staff in care homes and hospitals share care and go home at the end of their shift. Don't be afraid or ashamed to ask for help.

“Accept help when it is offered. I am getting better at this. I want to be able to do it all by myself, but I just can't. I won't be able to survive if I do.”



There may be times when you feel overwhelmed.

“I have good days and bad days. Sometimes I think I'm doing okay and feel I can cope. Other times I feel lost.”



If the caring role begins to take its toll, you may find it helpful to refer to our full carer's guide *Caring and MND: support for you*. This contains a wealth of information to help you to:

- identify the multiple emotions you may experience
- work out ways to deal with these feelings
- consider ways to look after yourself as a carer
- explore how to make time to do this
- find appropriate support for younger family members
- find support when the caring role decreases or stops.

A carer's assessment will help you find out about available support (see Section 4: *Carer's assessment* in this quick guide). If you find it difficult to cope emotionally, ask your GP for advice. Help is available. Please remember, you are not to blame, you are not alone and your feelings are normal. Carers cope in different ways. There is no right or wrong way. If you are in contact with an Association visitor, they can support you, or your local branch or group can help.

Or contact our helpline MND Connect, **0808 802 6262**, or email **mndconnect@mndassociation.org**

Children and young people close to the person with MND will notice the physical effects of the disease. If this isn't explained to them, they can become confused and may even blame themselves. See below for publications to help communicate sensitive issues to children.

Further information from the MND Association:

Full guide - **Caring and MND: support for you** (Sections 7 to 10).

Our booklet **Telling people about MND** has suggestions about communicating with family, children, young people and professionals.

Our booklet on **Sex and relationships** for people with or affected by MND or Kennedy's disease.

www.mndassociation.org/cyp our web pages about support for children, young people, parents and guardians.

www.mndbuddies.org - our activity hub for younger children to gently find out about MND through games, stories and things to do.

Why is everything changing? Our storybook for young children.

When someone close has MND an interactive workbook for children aged 4 to 10 to help a trusted adult communicate about MND.

So what is MND anyway? A guide and web app for young people and young carers.

See How this guide can help you for order details.

If you would like to contact other people affected by MND, see our online forum at: **<https://forum.mndassociation.org>**

8: How the MND Association can help you



The MND Association offers a range of services at no cost to people with or affected by MND, or Kennedy's disease, including carers. Our services cover England, Wales and Northern Ireland.

MND Connect: our helpline can provide information and emotional support, and connect you with our own or other appropriate services. Contact **0808 802 6262** or email **mndconnect@mndassociation.org** Monday to Friday, 9am to 5pm and 7pm to 10.30pm.

MND Association Benefits Advice Service: we can provide free, confidential and impartial advice on any benefits you may be entitled to. Find current contact details for England, Wales and Northern Ireland at: **www.mndassociation.org/benefitsadvice** or contact our MND Connect helpline for guidance.

Association visitors: trained volunteers who can provide information and guidance about MND and local services. They can offer this support by phone, email or home visit.

Regional staff for local support: our regional staff have knowledge about care and management of MND. They work with volunteers and affected families, and influence local service providers to help ensure the right support is available, when needed.

Branches and groups: for guidance and support, including meetings for carers to share experiences and information. Our branches are listed at: **www.mndassociation.org/branchesandgroups**

MND care centres and networks: we part-fund a national partnership programme of MND care centres and networks across England, Wales and Northern Ireland. These are dedicated clinics where professionals from a range of disciplines work together in a co-ordinated way to provide specialist care. They also provide guidance to carers. They are usually based in hospitals or hospices, but some may provide an outreach service.

It's important to note that most neurology clinics also 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 to ensure people with or affected by MND receive equal care at the highest possible standard.

Equipment loan and MND support grants: We may be able to provide certain items of equipment on loan or support grants (including grants for carers and young carers). All statutory funding and services should be explored first. Contact on **0808 802 6262** or email: **support.services@mndassociation.org**

Communication Aids Service: our service can help with queries and where delays are experienced through health and social care provision, we also offer limited financial support and loans for communication aids. Contact on **0808 802 6262** or email: **communicationaids@mndassociation.org**

Website: find online help at: **www.mndassociation.org**

Care information: publications about the disease and its management can be ordered in print from MND Connect or downloaded from: **www.mndassociation.org/publications** You can also find some of our publications in other languages at: **www.mndassociation.org/languages**

Forum: a safe place to share experiences with other people affected by MND, at **https://forum.mndassociation.org**

Membership: means opportunities to help towards a common goal and to have your voice heard. You'll be the first to know when we take steps forward. You'll receive our regular Thumb Print magazine, and ways to get involved in exclusive membership events. To join, see: **membership@mndassociation.org**

Thumb Print: our member's magazine, informing on care, research and the work of the Association.

Support for everyone who is affected by MND or Kennedy's disease: We understand that people have varied needs, backgrounds, culture and faiths. Please ask the service you are dealing with if you have any particular needs or preferences you wish to be considered. If you would like guidance on how to get one of our resources in a language other than English or a different format, please contact our MND Connect helpline, as listed in this section. You can also find a range of our resources in other languages at: **www.mndassociation.org/languages**

Further information from the MND Association:

Full guide – *Caring and MND: support for you* (Section 11).

9: Useful organisations



We do not necessarily endorse the organisations listed here, but hope they provide a starting point to access further support. For extended listings and address details, see Section 12 of the full carer's guide *Caring and MND: support for you*. Contact details are correct at time of print.

Age UK

Information and advocacy services for people in later life.

Telephone: **0800 055 6112**

Website: **www.ageuk.org.uk**

The Carers Trust

Support for carers and young carers. Use the search facility on their website to find support through their wide network of Carers' Centres, including a variety of services for young carers.

Email: **info@carers.org**

Website: **<https://carers.org>**

Carers UK

Providing family carers with information and advice.

Telephone: **020 7378 4999** (England)

029 2081 1370 (Wales)

02890 439 843 (Northern Ireland)

Website: **www.carersuk.org**

Citizens Advice Bureau

Free guidance to resolve legal, money and other problems. Search for your local branch on the Get Advice page of the website.

Telephone: **0800 144 8848** (England)
0800 702 2020 (Wales)
See website for Northern Ireland
Website: **www.citizensadvice.org.uk**

Community Law Service

Independent advice or representation for areas such as benefits and housing. Find your local service through your telephone directory or search for Community Law Service online.

GOV.UK

Online government information about financial help and benefits, including Carer's Allowance.

Website: **www.gov.uk** (England and Wales)
www.nidirect.gov.uk (Northern Ireland)

MND Scotland

Providing support for people affected by MND in Scotland.

Telephone: **0141 332 3903**
Website: **www.mndscotland.org.uk**

NHS UK

Online health information according to need.

Website: **www.nhs.uk**

NHS 111

The NHS online/telephone help and support service, providing health advice and information, 24-hours a day, 365 days a year.

Telephone: **111** for urgent, but nonemergency medical advice

Website: **www.nhs.uk**

NHS 111 Wales

Similar to NHS 111, but for Wales.

Telephone: **111** if available in your area or **0845 46 47**

Website: **<https://111.wales.nhs.uk>**

NHS Northern Ireland

Online information about NHS services in Northern Ireland.

Website: **<http://online.hscni.net>**

Pension Service

For queries and claims regarding pensions and pension credit.

Telephone: **0800 731 7898**

0800 731 7339 (text phone)

Website: search for *pensions* at: **www.gov.uk**

www.nidirect.gov.uk (for Northern Ireland)

Further information from the MND Association:

Full guide – *Caring and MND: support for you* (Section 12).

See How this guide can help you for order details.

Acknowledgements

Full acknowledgements are listed in the full carer's guide, *Caring and MND: support for you*.

We would like to thank the following for their additional support with this quick guide:

Dr Usha Boolaky, Institute of Public Care, Oxford Brookes University

Pauline Callagher, MND Specialist Nurse and MND Care Centre Co-ordinator, Preston Care Centre, Royal Preston Hospital

Helen Copsey, MND Care and Research Network Co-ordinator Norfolk and Norwich University Hospital, Norfolk

Lesley Johnston, Advice and Information Officer, Carers Northern Ireland

Rachael Marsden, Care Centre Co-ordinator, Oxford MND Care Centre

Dorinda Moffatt, Specialist Neuro-Respiratory Physiotherapist and Frailty Therapist, Prospect Hospice, Swindon

References

References used to support this information are available on request from:

Email: **infofeedback@mndassociation.org**

Or write to:

MND Association

Francis Crick House (2nd Floor)
6 Summerhouse Road
Moulton Park
Northampton NN3 6BJ

We welcome your views

Let us know what you think of this booklet. We'd love to hear what you think we did well and where we can improve the content for people with or affected by MND.

Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

If you would like to provide feedback about our *Caring and MND: quick guide*, please use our online feedback form at:

www.smartsurvey.co.uk/s/carersquickguide

or alternatively, please contact us at:

infofeedback@mndassociation.org

or by post to:

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Document dates:

Last revised: March 2022

Next review: March 2025

Version: 1

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Registered Charity No. 294354

Company Limited by Guarantee No. 2007023

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