

11: How the MND Association can help you

This section will help you access services and support from the MND Association.

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/MNDguides**

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

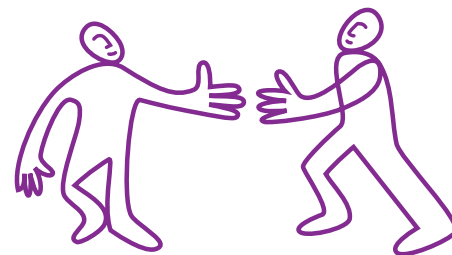
Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**



**Caring and MND:
support for you**

11: How the MND Association can help you



This section will help you access services and support from the MND Association.

What does the MND Association do?

We are a charity dedicated to improving the lives of people affected by MND in England, Wales and Northern Ireland. Scotland is supported by a different organisation called MND Scotland.

See Section 12: *Useful organisations for contact details.*

Our overall vision is a world free from MND.

Our mission is to:

- improve care and support for people with MND, their families and carers
- fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND
- campaign and raise awareness, so the needs of people with MND and everyone who cares for them, are recognised and addressed by wider society.

The earlier we can help you, the more we can accomplish on your behalf. You may at times feel very isolated, but you are not alone in this.

“The MND Association is there at the end of a phone or email...and with them I’m a member of a community with similar problems; we can provide each other with help and offer solutions.”

How does the MND Association help carers?

In a caring role, you need to achieve the best possible quality of life for yourself and the person you support. This means access to appropriate services and information.

We work towards this goal by:

- building and improving our range of information for carers
- informing carers of available support, benefits and care options to enable greater choice and control
- providing local guidance through regional staff and volunteers
- enabling peer support through local branches and groups and our online forum
- providing MND Support Grants, Carers’ Grants, a young person’s grant and equipment loans as appropriate
- directing carers to opportunities for training in care tasks
- raising awareness about carers and the demands of MND within regional health and social care systems
- campaigning and influencing government and health and social care services.

We recognise the huge demands on you when you support someone with MND. You need specific support tailored to your individual and changing situation. We are constantly seeking ways to help you access appropriate services and to improve the support we provide.

MND Association services

The following headings list our services, with contact details.

MND Connect helpline

Our helpline provides support and information for people living with MND, their carers and families, our volunteers, and health and social care professionals.

If you are concerned about any aspect of care or how to manage the caring role, contact MND Connect.

The team can direct you to practical support, including our own services and appropriate external organisations. If you simply need to talk to someone, they can listen.

“I found the helpline invaluable...We were able to gain knowledge about the condition, and were prepared (as much as you can be) for each stage of the illness and the options available.”

The service is available Monday to Friday, from 9am to 5pm and 7pm to 10.30pm.

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

MND Association,
PO Box 246, Northampton NN1 2PR

MND Connect is accredited by the Helplines Standard.



Association visitors (AVs)

AVs are volunteers who provide free and confidential personal guidance to people with MND, their carers, and close family and friends. An AV can help you identify problems as they arise, answer questions and discuss how you might get support.

All AVs are carefully selected, undergo a thorough training programme and a Disclosure and Barring Service (DBS) check. They are based in the local community as members of a team and can make contact with you by phone, email or visiting you at home.

“My Association visitor has been really, really helpful. She’s been prepared to help and support whenever I’ve asked and has been very good at keeping one eye on the future.”

If you would like to be supported by an AV, your local regional care development adviser (RCDA) can help arrange this where an AV is available (see next heading).

If an AV is not available in your area, we can offer ongoing support and help through our helpline or your local branch or group. Please see other headings in this list for details of these services.

Our work with volunteers is accredited by the Investing in Volunteers standard.



Regional care development advisers (RCDAs)

RCDAs have expert knowledge of the management and care of people with MND. They work closely with local service providers to ensure care and support is available at the right time.

“The regional care development adviser was excellent in helping when there was a problem with no support for my wife, who is my carer.”

RCDAs either have a professional health and social care background or significant experience that will help them in this role. They also manage a regional team of Association visitors (AVs), where available.

Our RCDAs are listed on our website at www.mndassociation.org/rcda or contact our MND Connect helpline:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

Local branches and support groups

We have a network of around 90 branches and groups, run by volunteers, throughout England, Wales and Northern Ireland. They provide a warm welcome, friendship and the opportunity to meet others affected by MND.

“The camaraderie between carers is so important to us all in our support group. We are there for each other through thick and thin.”

Our branches and groups offer guidance and support, including get-togethers and group meetings specifically for carers. People can share emotional and practical support, and exchange information.

Our branches are listed on our website at: www.mndassociation.org/branchesandgroups or contact our MND Connect helpline to help you find the nearest location:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

MND care centres and networks

We part-fund MND care centres and networks across the UK, with more planned. These offer specialist help to manage the complexity of the disease, supporting people with MND, their carers and families.

If you cannot get to a care centre or network easily, you and the person you support can still receive co-ordinated care through regional neurological services and local specialist palliative care services.

All of the care centres and networks bring together a range of health and social care professionals to provide co-ordinated care. They are usually referred to as a multi-disciplinary team.

“The care centre staff are all brilliant. It’s a great place to go to get help with medical problems.”

Care centres are not a ‘building’ and usually take place in an established clinic area in one place, such as a hospital. Networks work in a similar way, but do not have a fixed location, in order to provide a service across a wide geographical area.

Care centres and networks sometimes run clinical drug trials and undertake clinical

research about MND. They also help to educate colleagues in the community and share good practice to improve MND care and support.

To find your nearest MND care centre or network, contact our MND Connect helpline:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Equipment loan and MND support grants

Our Support Services team may be able to provide certain items of equipment and communication aids on loan, or consider requests for MND support grants.

All statutory funding and services should be explored first. However, loaned items can be provided if you have to wait for health and social care services to arrange equipment or if they are unable to provide an item.

The following types of grant are available:

MND Care Grants

Provided to: people living with MND, of any age.

Amount provided: depends on the type of spend and the value of any previous grants provided.

Application: by a health or social care professional following assessment of need, where this need cannot be met through the services they link to, or where provision will be delayed.

Can be used for: a variety of purposes, such as home adaptations, equipment or respite care.

Carer's Grant

Provided to: carers who are not paid for the support they give and who are 19 or older.

Amount provided: up to £500 is available in any one year.

Application: by the carer, or on their behalf by one of our Association visitors or a health and social care professional.

Can be used for: a variety of purposes, such as driving lessons, towards a carer break or for respite care.

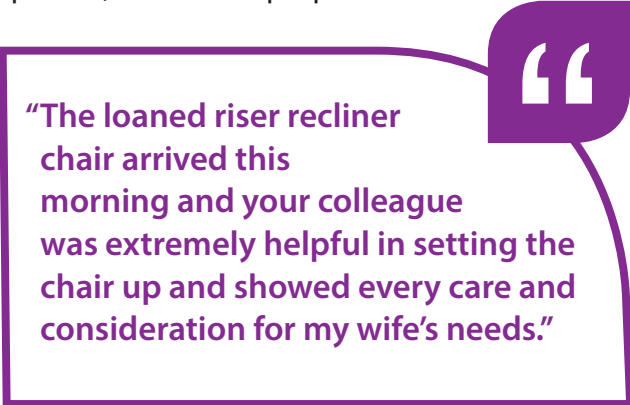
Young Person's Grant

Provided to: a child or young person aged 18 or under, who is affected by MND in their immediate or close family.

Amount provided: up to £250 is available in any one year.

Application: by a family member for the young person, or on their behalf by one of our Association visitors or a health or social care professional.

Can be used for: a variety of purposes, such as decorating their room at home, a family day out or for equipment to help the young person, such as a laptop.



“The loaned riser recliner chair arrived this morning and your colleague was extremely helpful in setting the chair up and showed every care and consideration for my wife’s needs.”

If you have any queries, please contact our Support Services team:

Telephone: **01604 611802**

Email: **support.services@mndassociation.org**

See information sheets 22A to 22E, which provide details about benefits and other financial support.

MND Association Wheelchair Service

The MND Association's wheelchair service consists of MND specialist wheelchair therapists and a wheelchair co-ordinator. The therapists link into MND care centres and networks, and NHS or other external wheelchair services. They provide posture and mobility assessments to determine people's wheelchair needs. They also support

other wheelchair services through education and training, and joint assessments.

The co-ordinator develops links with external wheelchair services and helps progress reported problems with delays, service or provision. The co-ordinator also processes applications for support grants to fund wheelchair top-ups for non-standard features or additional equipment.

For further information, please contact:
Email: wheelchairs@mndassociation.org

“My wheelchair has really changed my life, I can’t thank you enough.”

Communication Aids Service

Our Communication Aids Service helps people with MND, carers, families, and health and social care professionals, with queries about communication aids.

The service provides limited financial support for communication aids or some items on loan, if unavailable or delayed through health and social care services.

Our aim is to improve provision and information on a local and national level, through collaboration with health and social care professionals.

“Now I know there is help out there about voice banking and communication aids, with people willing to do all they can. This is very comforting. Thank you.”

Telephone: **01604 611767**
Email: communicationaids@mndassociation.org

Our website

Please visit the MND Association website to find out more about MND, our services and the MND Association at :

www.mndassociation.org including news about our research, volunteering, fundraising and campaigning activities.

“Well-targeted and accurate, the website provides a wealth of very useful information.”

Care information and publications

Our wide range of care information is developed and revised under The Information Standard, an accreditation run by NHS England. This means it is considered trustworthy, relevant and up-to-date. Look for the marker:



You can download the majority of our information from our website at:
www.mndassociation.org/publications

or contact our MND Connect helpline to order printed copies:

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

“I am about to finish reading Caring and MND: support for you, which gives wonderful advice from the very first page...exactly what’s needed. I am learning to be kind to myself.”

Online forum

Our online forum is a safe place to share experiences, ideas and a wealth of information, with other people affected by MND.

“The forum is so useful for all of us as carers, it’s a lifeline... I still can’t leave it, even though I no longer need it for advice.”

You can access the forum from our website or by using the following internet address:
<http://forum.mndassociation.org>

Membership

Membership of the MND Association is free for people living with MND, their spouses, partners and carers. It enables you to join a community of people who all share the same vision of a world free from MND. As a unified force, our membership creates a powerful voice to support lobbying and campaigns on behalf of all people affected by MND.

By becoming a member, you can access the following benefits:

- our quarterly magazine, Thumb Print, which features the latest news on care and research as well as inspirational stories from others affected by MND
- an introduction to your nearest branch or group
- our Annual Impact Report, which demonstrates the difference made by us over the last financial year
- invitations to conferences and seminars, including our regional conferences
- the authority to vote at national and local AGMs, including the election of MND Association Trustees.

“At the AGM last September, we met people from all over the country. There were also people from the MND Association and a doctor from Sheffield talking about the latest research.”

To become a member, contact us by:

Telephone: **01604 611855**

Email: **membership@mndassociation.org**

Support for minority and ethnic groups

We are here for everyone living with or affected by MND.

We acknowledge that people have differing needs, backgrounds, culture and faiths. Other aspects of diversity may also influence the way care and support should be offered and provided.

The MND Association supports equality in all of its services. Please ask the service you are dealing with if you have any particular preferences or needs that you wish to be taken into consideration.

“I don’t have family here in the UK, neither does my son, so we feel very lonely without money, moral support or information. Help!”

Information in other languages

We provide introductory information in additional languages to English and a limited translation service for further care publications. You can find out more at: **www.mndassociation.org/languages**

If you need further help, contact our MND Connect helpline or ask someone to contact the team on your behalf. They can help answer your questions or direct you to appropriate support.

See earlier heading in this section, *MND Connect helpline*.

Key points

- We support everyone with or affected by MND in England, Wales and Northern Ireland (support is provided in Scotland by MND Scotland).
- Our services are free for people with MND, their partners and carers.
- If you need assistance to contact any of our services or external services, contact our MND Connect helpline:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Document dates:

Created: 01/16

Next revision: 01/19

Version: 1

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Registered Charity No. 294354

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

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Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**



The MND Association has been certified as a producer of reliable health and social care information.

www.england.nhs.uk/tis