

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/carerguide**

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

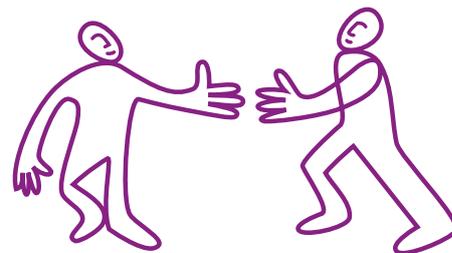
Telephone: **0808 802 6262**

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.

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.

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

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Benefits Advice Service

The MND Association Benefits Advice Service provides free, confidential and impartial advice on any benefits you may be entitled to.

Telephone: **0808 801 0620**

(England & Wales)

0808 802 0020

(Northern Ireland)

Email: Through the website contact page, at: **www.mndassociation.org/benefitsadvice**

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.

If you would like to be supported by an AV, contact our MND Connect helpline. Our regional staff can then put you in contact with an AV, where available.

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.

Regional staff for local support

Our regional staff for local support have knowledge about care for people with MND and how to support carers. They work with affected families, our volunteers and services. Their aim is to help ensure that appropriate care is made available at the right time.

Find out more about our services and local support at: www.mndassociation.org/support-and-information

Or contact our MND Connect helpline as shown in this section.

Local branches and support groups

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

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.

Care centres are not a 'building' and usually take place in an established clinic 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 see:

www.mndassociation.org/carecentres or contact our MND Connect helpline:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

Equipment loan and grants

We may be able to provide certain items of equipment and communication aids on loan, or consider requests for financial support through 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 support (care) grant

Provided to: people living with MND or Kennedy's disease, 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.

MND quality of life grant

Provided to: people living with MND or Kennedy's disease, of any age.

Amount provided: depends on the type of spend and the value of any previous grants provided, up to £500 in any one grant.

Application: by any family member, Association visitor, health or social care professional or a regional care staff contact.

Can be used for: improving quality of life for the person diagnosed, or for equipment that does not require a health or social care assessment.

MND carer's and young carer's grant

Provided to: family or non-professional carers, who are 16 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 break from caring, as with a pamper day, a short break or to support a hobby.

Young person's grant

Provided to: a child or young person aged 18 or under, who has a parent with MND or Kennedy's disease, or who lives in the same household with someone who has been diagnosed.

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, a regional care staff contact 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.

If you have any queries about grants or equipment loans, please contact our MND Connect helpline, as shown in this list.

Communication Aids Service

Help with queries about communication aids, for people with or affected by MND, and health and social care professionals.

A limited amount of financial support can be provided, and some items on loan (if unavailable or delayed through health and social care services).

Telephone: **0808 802 6262**

Email:

communicationaids@mndassociation.org

Our website

The MND Association makes every effort to ensure it provides trustworthy information (see *Care information and publications* heading). Please visit the MND Association website to find out more about MND, our services and the Association at:

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

Our online forum

A safe place to share experiences and tips with others affected by MND.

Access the forum on our website, or at:

https://forum.mndassociation.org

Care information and publications

We provide a wide range of information, developed and revised under the PIF Tick kitemark scheme: **https://piftick.org.uk**

This means our content is considered trustworthy. Look for the following kitemark:



Patient Information Forum

You can download the majority of our care information from our website, including our publications list, using the following address: **www.mndassociation.org/publications**

Or contact MND Connect to order printed copies (see previous *MND Connect helpline* heading).

Membership

Membership of the MND Association enables you to join a community of 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 will:

- have opportunities to influence the work of the Association
- be sent a welcome pack, including membership card
- be able to link to your nearest branch or group.
- receive Thumb Print, our Quarterly magazine
- be able to attend and vote at our AGMs
- have invitations to our conferences and events
- have access to a collectible pin badge every year.

To become a member, contact us by:

Telephone: **01604 611860**

Email: **membership@mndassociation.org**

Support for everyone and other languages

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

We are aware that not everyone will have the same needs, as everyone's experience of MND will be unique. Culture and religion may also influence the way care and support should be provided and the MND Association supports diversity and 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.

We offer a limited translation service for our health and social care information, other formats and telephone interpreters. Contact our MND Connect helpline for details (see previous heading *MND Connect Helpline*).

Getting involved

Many people with or affected by MND or Kennedy's disease ask how they can get involved with our activities. If you would like to know more, see the following web pages:

Volunteering:

www.mndassociation.org/volunteering

Fundraising:

www.mndassociation.org/fundraising

Campaigning:

www.mndassociation.org/campaigning

Research:

www.mndassociation.org/research

Or contact enquiries:

Telephone: **01604 250505**

Email: **enquiries@mndassociation.org**

Key points

- We support everyone with or affected by MND or Kennedy's disease in England, Wales and Northern Ireland (support is provided in Scotland by MND Scotland).
- Our services are free for people with MND or Kennedy's disease, 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**

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

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

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

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



Patient Information Forum