Where can I find the information I need?

Information for people with or affected by motor neurone disease, or Kennedy’s disease

Finding appropriate information is important, as needs can change quickly. However, there is a lot of information available out there, and this can feel overwhelming.

This information map can guide you to appropriate resources to help you access suitable support. You don’t need to read every publication on offer, but you may wish to use this information sheet to start your search, or for further information at a later date.

There are three sections:

1: The information map

2: Our support

3: Further support

We have included a number of websites, email addresses and telephone numbers. If you do not have internet access or need further help, contact our MND Connect helpline (see Our services in section 2: Our support for contact details).

This symbol is used to highlight our other publications. To find out how to access these, see Further information at the end of this sheet.

This symbol is used to highlight quotes from other people with or affected by MND.

This information has been evidenced, user tested and reviewed by experts.
1: The information map

Our support

- MND Connect
- Regional services
- MND care centres and networks
- Support services
- Communication aids service
- Benefits Advice Service
- Membership

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Further support

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Our information

- Our website
- Information for people with and affected by MND
- Information for children and young people
- Information for professionals
- Information about MND research
- Social media and online

Our services

- Our website
- Information for people with and affected by MND
- Information for children and young people
- Information for professionals
- Information about MND research
- Social media and online
2: Our support

The MND Association supports anyone living with or affected by MND or Kennedy’s disease, in England, Wales and Northern Ireland.

“If I’d gone to the MND Association site first, it would have saved me a lot of stress”

Our information

We provide a wide range of resources. You are unlikely to have exactly the same symptoms in the same order as someone else, so you don’t have to read everything at once. Return to our information as and when needed.

Our short booklet *An introduction to motor neurone disease* provides a simple overview of MND and the support available. This is an ideal place to start.

When you feel ready, you can find more detail in our comprehensive guide *Living with motor neurone disease*

If you are living with Kennedy’s disease, you may wish to start with Information sheet 2B – *Kennedy’s disease*

We also provide other resources and a wide range of information sheets to help with specific symptoms and needs. To order any of our publications in print, contact our MND Connect helpline (see Our services), or download them from our website:

Our website
www.mndassociation.org

All our information resources and our publications list
www.mndassociation.org/publications

Our guides, information sheets, forms and resources for people living with or affected by MND
www.mndassociation.org/careinfo

Information in other languages
www.mndassociation.org/languages

Information for carers
www.mndassociation.org/carers

Information for children and young people
www.mndassociation.org/ypinfo
Information for health and social care professionals
www.mndassociation.org/professionals

Our information about MND research
www.mndassociation.org/research

You can keep up to date with others living with or affected by MND by visiting our online forum and social media pages.

Online forum for people with or affected by MND
http://forum.mndassociation.org

Facebook
www.facebook.com/mndassociation

Twitter
www.twitter.com/mndassoc

Our services

“When I was diagnosed, I had no knowledge of MND. A friend gave me your number. It was the most important call of my life.”

Our services include:

MND Connect
MND Connect provides information and support for those with and affected by MND or Kennedy’s disease. This includes support for carers and health and social care professionals. The team can also direct you to our own and other services. If you speak little or no English and don’t have anyone to speak on your behalf, we can arrange for an interpreter to join your call.

Telephone: 0808 802 6262 (Freephone)
Email: mndconnect@mndassociation.org
Website: www.mndassociation.org/mndconnect

Regional services
We provide a variety of regional services:

- Our volunteer Association visitors (AVs) may be able to provide guidance by telephone, email or home visit. There is limited availability for AVs in some areas, contact MND Connect to find out if this service is available in your area.
- Our regional staff help influence and co-ordinate local services.
- Branches and groups in local areas may hold support groups and regular meetings where you can meet others living with or affected by MND. If this does not feel right for you now, you can join at any time.
Find more information about regional services, at:
www.mndassociation.org/local-support

or contact MND Connect:
Telephone: 0808 802 6262
Email: mndconnect@mndassociation.org

**MND care centres and networks**
We part fund a programme of care centres and networks that support people with MND, their carers and families by providing specialist help and access to a range of health and social care professionals. This type of care is also available through regional neurological services and local palliative care services.

For more information, see:
Information sheet 3A – *MND care centres and networks*

Find out if there is an MND care centre or network near you at:
www.mndassociation.org/carecentres

or contact MND Connect:
Telephone: 0808 802 6262
Email: mndconnect@mndassociation.org

**Support services**
If you cannot get the equipment or support you need through health or social care, we may be able to provide certain equipment on loan. We also provide MND support grants for a variety of needs. There are four types of MND support grant available, for support and care, quality of life, carers and young people affected by MND or Kennedy’s disease.

Applications for some grants need to be submitted by a relevant health and social care professional, following an assessment of your needs.

Telephone: 0808 802 6262
Email: support.services@mndassociation.org
Support Grants: www.mndassociation.org/financialsupport
Equipment loan: www.mndassociation.org/equipmentloan
**Communication aids**
If your speech and communication are affected, our communication aids service provides guidance about appropriate services and equipment. The service may also be able to provide limited financial assistance and communication aids loans if they are unavailable or delayed through social services.

Telephone: 0808 802 6262  
Email: communicationaids@mndassociation.org  
Web page: [www.mndassociation.org/communicationaids](http://www.mndassociation.org/communicationaids)

For more information on speech and communication with MND, see:  
Information sheet 7C – *Speech and communication support*  
Information sheet 7D – *Voice banking*

**Benefits Advice Service**
We provide a welfare benefits advice service for people living with or affected by MND. This is in partnership with Citizens Advice Cardiff and the Vale for people living in England or Wales and Advice NI for people living in Northern Ireland. The service provides free, impartial and confidential advice, and is available over the phone and by email. If you speak little or no English and don’t have anyone to speak on your behalf, we can arrange for an interpreter to join your call with the Benefits Advice Service. There is also a live web chat service on our website, available for people in England and Wales. Find out more at: [www.mndassociation.org/benefitsadvice](http://www.mndassociation.org/benefitsadvice)

Telephone: 0808 801 0620 *England and Wales*  
0808 802 0020 *Northern Ireland*  
Email: Through the contact form for our Benefits Advice Service at: [www.mndassociation.org/benefitsadvice](http://www.mndassociation.org/benefitsadvice)

**Membership with the MND Association**
Membership is free for people with MND or Kennedy’s disease, their carers and partners. A variety of benefits are available including Thumb Print, our quarterly magazine.

Telephone: 01604 611 855  
Web page: [www.mndassociation.org/membership](http://www.mndassociation.org/membership)
How we can help you

MND Connect
0808 8026262
mndconnect@mndassociation.org
MND Connect available
Monday - Friday
9am - 5pm and 7pm - 10.30pm

www.mndassociation.org

Whether you’re a person with MND, carer, family member, friend or volunteer... WE ARE HERE TO HELP
3: Further support

There are many organisations and services that provide support and information. With healthcare, social care and benefits, providers have legal responsibilities to provide certain services. The following may be able to help you.

**NICE Guideline on MND**

The National Institute for Health and Care Excellence (NICE) guideline on motor neurone disease sets out recommendations for health and social care professionals, about the treatment and care of people with MND. Using this guideline may help you achieve a better standard of care and provide supporting evidence if you need to make a complaint.

For more information about the guideline, see:
Information sheet 1A - *About the NICE guideline on motor neurone disease*

For information on how to use the NICE guideline, see our pocket sized booklet: *What you should expect from your care*

You can also find more information about checking if your treatment and care are appropriate, and what to do if you need to make a complaint at:
[www.mndassociation.org/mycare](http://www.mndassociation.org/mycare)

Always ask if you need any kind of health and social care information at a relevant appointment. If you are disabled, you may require this information in a particular format, such as Braille or easy-read. It is now compulsory in England for health and social care services to provide a format you can access. For more details, search for *accessible information standard* at: [www.england.nhs.uk](http://www.england.nhs.uk)

**Healthcare**

The complexity of MND and Kennedy’s disease means a range of health and social care professionals may be involved in your care. Ask your GP or another member of your health and social care team for a referral to a specialist, for example a speech and language therapist, physiotherapist or palliative care specialist. The co-ordinator or point of contact at MND care centres, networks or local neurological services can also help make arrangements.

Find general information about healthcare services at:
England: [www.nhs.uk](http://www.nhs.uk)
Wales: [www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)
Northern Ireland: [www.hscni.net](http://www.hscni.net)
Social care

Find out if you are eligible for care services, equipment, emergency care support or carer support by having your needs assessed by adult social care services. Ask for a needs assessment if you have any problems with disability. If you provide support, ask for a carer’s assessment. Contact your local authority for arrangements in England and Wales, or your local health and social care trust in Northern Ireland.

Search for needs assessment or carer’s assessment at:

England and Wales: www.gov.uk
Northern Ireland: www.nidirect.gov.uk

For more information about social care see: Information sheet 10B – What is social care?

Find our information sheets about social care at: www.mndassociation.org/careinfo

Benefits, finance and work

If you are disabled, have a long-term illness or provide support as a carer, there are a range of benefits, entitlements, grants and financial support you may be qualified to claim.

Find information about benefits, financial support and work at:

England and Wales: www.gov.uk
Northern Ireland: www.nidirect.gov.uk

For more information about benefits and other entitlements, see: Information sheet 10A – Benefits and entitlements

Find our information sheets about benefits, social care and work with MND at: www.mndassociation.org/careinfo

The MND Association Benefits Advice Service can also provide free, impartial advice and information on any benefits you may be entitled to. See Our services in section 2: Our support for details.
Low cost apps

There are a number of apps for phones, computers or tablet devices designed to help make life with a disability a little easier. We provide a list of free or low cost apps like this on our website:

www.mndassociation.org/apps

Useful organisations

There are many organisations out there that provide further information on a wide range of subjects that may be useful to you. We provide a list of some useful organisations on our website:

www.mndassociation.org/usefulorgs

We welcome your views

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them. If you would like to provide feedback on any of our information sheets, you can access an online form at:

www.smartsurvey.co.uk/s/infoheets_1-25

You can request a paper version of the form or provide direct feedback by email:
infofeedback@mndassociation.org

Or write to: Information feedback, MND Association, PO Box 246 Northampton NN1 2PR