



1C

Where can I find the information I need?

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


If you have been diagnosed with motor neurone disease (MND) or Kennedy's disease, finding appropriate information is important, as needs can change quickly. However, there is a lot of information available, which can feel overwhelming. This information map can help you identify available support and information you may need following diagnosis.

Not every resource will apply to you now, as your needs will be individual, but some may become relevant at a later date.

There are three sections:

- 1: The information map**
- 2: Our support**
- 3: Further support**

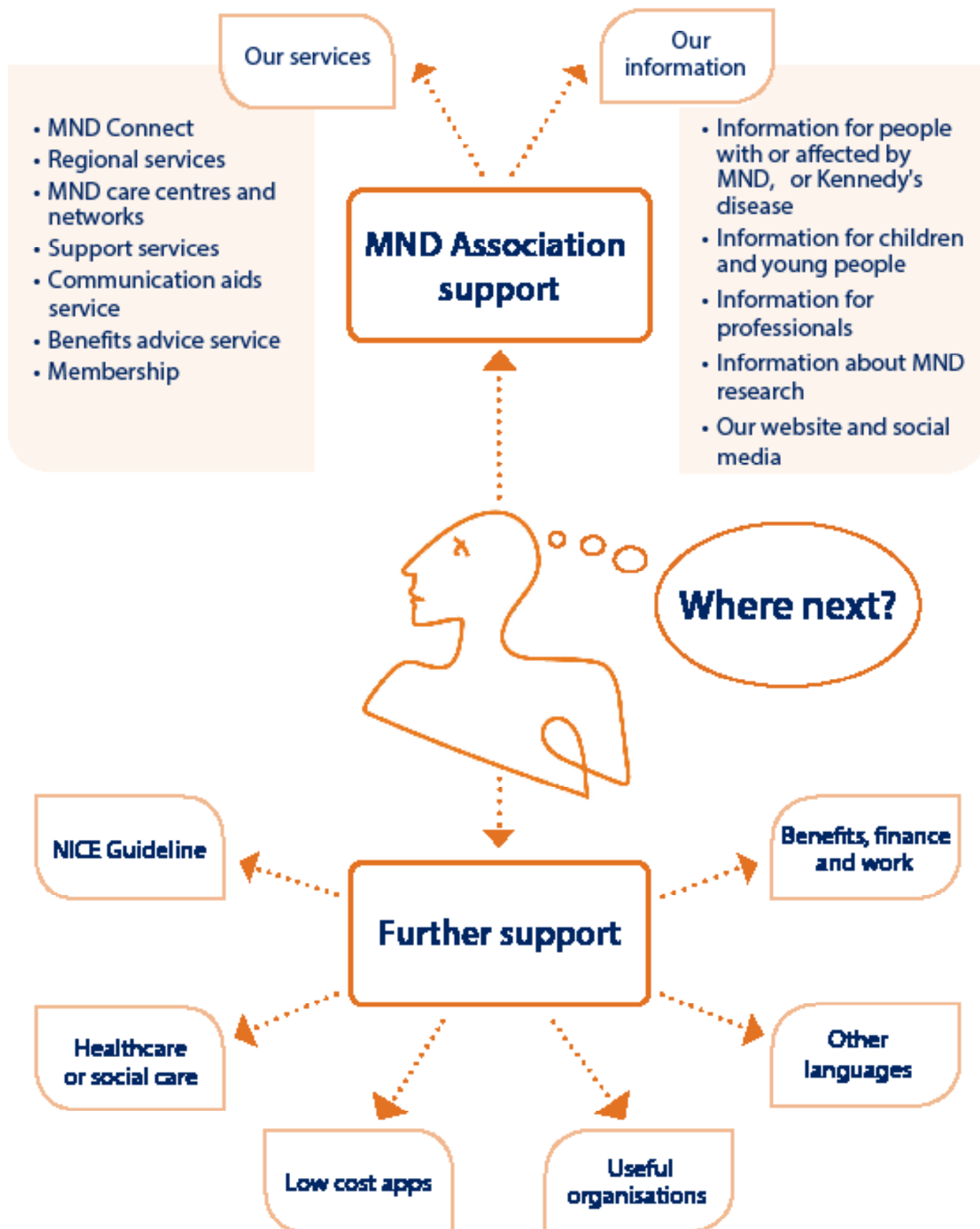
We have included a number of websites, email addresses and telephone numbers. If you do not have internet access or need further help, contact our MND Connect helpline. (See section 2: Our support for contact details.)

 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.



Our information resources are evidenced, user tested and reviewed by experts.

1: The information map



2: Our support



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

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. Access more information as you need it.



An *introduction to motor neurone disease* is an ideal place to start, with a simple overview of MND and the support available.

-  *Living with motor neurone disease (MND)* gives more detail about the disease and ways to manage daily routines.
-  Information sheet 2B – *Kennedy's disease* provides facts and available support with this condition. Kennedy's disease can be confused with MND as they share some similar symptoms, but much of our information for MND will also be helpful.

We have many other resources to help with symptoms and needs. Contact our MND Connect helpline to order printed publications (see Our services), or download them from our website:

Our website

www.mndassociation.org/apps

Our Care Information Finder can help you search for resources by need and share the links with other people

www.mndassociation.org/careinfofinder

Our care guides, information sheets and other resources for people living with or affected by MND or Kennedy's disease

www.mndassociation.org/careinfo

Our full list of all the information resources we provide, including those for professionals and research

www.mndassociation.org/publications

Information in other languages

www.mndassociation.org/languages

Information for carers

www.mndassociation.org/carers

Information for children, young people, parents and guardians
www.mndassociation.org/cyp


Online forum for people with or affected by MND
<https://forum.mndassociation.org>

Facebook
www.facebook.com/mndassociation

Twitter
<https://twitter.com/mndassoc>
<https://twitter.com/mndeducation>

Instagram
www.instagram.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 helpline

Our helpline 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 range of services in regions across England, Wales and Northern Ireland:

- 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. We also have regional campaigning and fundraising staff.
- 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 MND care centres and networks that support people with MND or Kennedy's disease, their carers and families. This specialist help gives access to a range of health and social care professionals, also available through regional neurological services and local palliative care services.

 **3A – MND care centres and networks** – our information sheet about our 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 service

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**



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

Find current contact details for England, Wales and Northern Ireland at:

www.mndassociation.org/benefitsadvice

or contact our MND Connect helpline for guidance: **0808 802 6262**

Membership with the MND Association

As a member you'll be alongside others, each working together towards a common goal and having your voices heard. You'll also be the first to know whenever we take steps forward. You'll receive our regular Thumb Print magazine and ways to get involved in exclusive membership events.

Telephone: **01604 611 855**

Web page: **www.mndassociation.org/membership**

How we can help you

PEOPLE AFFECTED BY MND

Using with MND

Carers

To ally

MIND CONNECT HELPLINE

mndconnect
0808 802 6262
mndconnect@mndassociation.org

MND Connect available
Monday - Friday
9am - 5pm and 7pm - 10.30pm

INFORMATION AND SUPPORT

Thumb Print

Information published online

Online forum

Communication Aids Service

Benefit advice service

Ergonomic loan

Wheelchair support

Grants

EVERYDAY LIVING

Replaced social events

Also offers via our online support Co-ordinator

22 MND Core Centres and Networks

LOCAL SUPPORT

89 branches and groups providing local support

www.mndassociation.org

Website

40 years of care, research and support for people affected by MND, their families and carers



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 help.

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, with supporting evidence if you need to make a complaint.



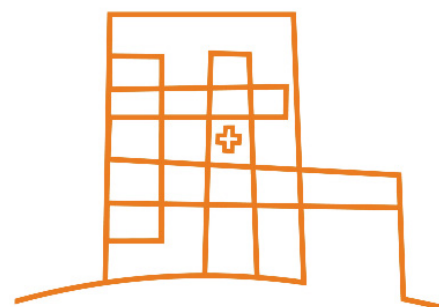
-  *What you should expect from your care - our pocket sized booklet on how to use the NICE guideline.*
-  *1A – About the NICE guideline on motor neurone disease – our information sheet about the guideline.*

You can also find more information about how to check if your treatment and care are appropriate, and how to make a complaint at: **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/**

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 support and general information at:

- England: **www.nhs.uk**
- Wales: **<https://111.wales.nhs.uk>**
- Northern Ireland: **<http://online.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

 10B - *What is social care?* – our information sheet about social care.


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

 10A – *Benefits and entitlements* – our information sheet about benefits and claims.

The MND Association Benefits Advice Service can also provide free, impartial advice and information on any benefits you may be entitled to. See 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 at:
www.mndassociation.org/apps



Useful organisations

Many organisations provide specialist support and information. We provide a list of useful organisations at: www.mndassociation.org/usefulorgs

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with or affected by MND, or Kennedy's disease. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding. To feedback on any of our information sheets, access our online form at: www.smartsurvey.co.uk/s/infosheets_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, Francis Crick House, 6 Summerhouse Rd, Moulton Park, Northampton NN3 6BJ



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