



1B

Health information in other languages or formats

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

If English is not your first language or you are sight impaired, it may be difficult to access information about motor neurone disease or Kennedy's disease and the type of support available.

This information sheet explains how to find accurate information in other languages or alternative formats, such as Braille, large print or audio. This sheet is currently available in a range of languages.

The content includes the following sections:

- 1: How do I get information in other languages?
- 2: Can I get information in other formats?
- 3: What else could help me?
- 4: How can the MND Association support me in the future?
- 5: How do I find out more?



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.



Patient Information Forum

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

1: How do I get information in other languages?

From the MND Association

Contact our MND Connect helpline if you need our support in a chosen language. You may need someone who speaks English to assist at first, so the helpline team can understand your needs. However, they should then be able to arrange a telephone call with an interpreter, who can translate for you.

MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

We offer introductory resources in a range of languages including information sheets on the main clinical decisions you may have to think about with MND or Kennedy's disease.

Download our translated publications at: www.mndassociation.org/languages or order them in print from MND Connect. Please note, we use reputable translation services, but cannot take responsibility for any errors in translation.

Let MND Connect know if you need any of the items in a different language to those we already provide. We may also be able to translate another information sheet, or a section from a larger guide, to help you make an important decision about treatment or care.



“Your information helped me to engage, even challenge doctors and nurses in discussions about treatment.”

Our translated resources are listed by language to help readers find what's available. The way the translation service works is explained in each language.

At health and social care appointments

When making decisions about treatment and care, it is important to discuss options with the health and social care professionals who support you. This can be difficult if they do not speak your language. However, healthcare providers must make reasonable changes to help people understand these conversations.

They may be able to arrange for a translator to help at appointments, particularly medical appointments. Many GP surgeries and hospitals offer interpretation services as standard, but others will only provide them on request

If you feel your doctor does not always understand your problems due to language needs, ask your GP surgery to arrange for an interpreter to be present at your appointment. You will need to do this in advance, so arrangements can be made. Let them know if it is important to you to have either a male or female interpreter.

It is the legal responsibility of the health service to provide trained interpreters. You also have the right to have an advocate with you. This is someone who you trust to help you communicate your needs and wishes, in an unbiased way. An advocate can be an adult friend or family member, or a professional advocate. This may be useful if you have problems with speech and communication, or if you get very tired at appointments.



For more information on advocacy and communicating about your diagnosis, see our booklet *Telling people about MND*

If written information is provided by your GP or hospital, this can also be requested in your first language.

If you are having a social care assessment in England, Wales or Scotland, ask your local authority about interpreters. In Northern Ireland ask your local health and social care trust. In most cases they will try to make arrangements for this, to ensure your assessment is fair and meets your needs.

From other organisations and websites

Automatic translation on websites can sometimes help, but may not be accurate and could be misleading. Some organisations provide information in a range of languages. Look on their website or ask someone to contact an organisation for you.

2: Can I get information in other formats?

From the MND Association

Contact our helpline, MND Connect, for guidance about our information and the formats available. They can help you access the following:

Braille:

As with our translated resources, you can request copies of our information sheets or sections of guides in Braille. Please note, we use reputable Braille services, but cannot take responsibility for any errors in production.

Large print:

Apart from our small cards and mini-booklets, all of our information uses the minimum of 12pt font and can be accessed online where you can increase the viewing size.

The following items are produced in large print (16pt or above):

- *An introduction to motor neurone disease (MND)*
- *An easy read guide to motor neurone disease (MND)*

If you need more help, contact our MND Connect helpline (find details in *Further information* at the end of this sheet).

Audio:

We offer introductory information in audio format in English. You can access these resources on Soundcloud at:

<https://soundcloud.com/mndassoc/mnd-audiobook>

At health and social care appointments

Information produced by GP surgeries, health services or at social care assessments may also be available in Braille, large print or other formats.

Explain your needs if you have any form of disability that makes it difficult for you to read and use guidance to get support. In this situation, health and social care services usually have a duty of care to ensure you can access and understand the decision-making information they offer.

The following resources give details in English about how this duty of care is governed:

For England

See the *Accessible Information Standard* at:
www.england.nhs.uk/ourwork/accessibleinfo

For Wales

Search for the *Sensory loss communication needs (Accessible Information Standard)*. This is available in both English and Welsh at:
<https://www.gov.wales/health-social-care>

For Northern Ireland

Search for *Making communication accessible* at:
<https://online.hscni.net>

For Scotland

Search for *Accessible information policy* in the publications search field at:
<https://publichealthscotland.scot/publications>



“To know that translation services should be available and that the info could be provided in an easier to read format is very helpful.”

3: What else could help me?

Speech and communication assessment

MND can affect speech and communication, making it more difficult to talk or use gesture and facial expression. Kennedy's disease can also affect the way you speak.

If you begin to have problems, ask your doctor for a referral to a speech and language therapist for assessment. They can advise on therapy and communication aids, which may range from simple items such as picture and text boards, to more detailed help from computer software.

You may also wish to seek guidance on voice banking and message banking, so that you can use your recorded voice to speak phrases through computer devices.



For more detail about speech and communication with MND, see:

- Section 8: *Speech and communication*, from our *Living with motor neurone disease* guide
- Information sheet 7C – *Speech and communication support*
- Information sheet 7D - *Voice banking*
- Our voice banking animation at www.mndassociation.org/animations

Providing written notes

If your speech is affected or you cannot speak English, you may find it helpful to provide pre-written notes to help people understand your needs. You may wish to have these notes in both your preferred language and in English to help all those involved in your care. You may need to ask a relative, friend or a translator to assist you.

Notes like this can be useful when:

- attending appointments
- travelling or following your usual routine
- at social events.

The following two pieces of text may be useful:

I find it difficult to communicate because I have motor neurone disease/Kennedy's disease. I also speak in: (insert the name of your preferred language here).

If you cannot speak my language and need to communicate with me, my carer/relative/doctor can help. Please contact: (add contact details here).

Here is a version of these two pieces of text in English, to help readers of English understand your needs. There is one for MND and one for Kennedy's disease, as appropriate. Just add the name of your language and contact details into the blank spaces. Use this sheet or copy to a notepad:

For motor neurone disease:

I find it difficult to communicate because I have motor neurone disease. I also speak in:

Insert name of your preferred language here:

If you cannot speak my language and need to communicate with me, my carer/relative/doctor can help. Please contact:

Add chosen contact details here:

For Kennedy's disease:

I find it difficult to communicate because I have Kennedy's disease. I also speak in:

Insert name of your preferred language here:

If you cannot speak my language and need to communicate with me, my carer/relative/doctor can help. Please contact:

Add chosen contact details here:

Easy read

Our publication *An easy read guide to motor neurone disease* can be helpful if you:

- want to read simple text in English
- need large print and short sentences
- have learning difficulties or know someone who does.

Select *guides* at: www.mndassociation.org/careinfo to download the *Easy read guide* or order in print from our MND Connect helpline (see end of sheet for contact details).

4: How can the MND Association support me in the future?

We are a charity dedicated to improving the lives of everyone with or affected by MND in England, Wales and Northern Ireland. We also support people with or affected by Kennedy's disease, who share similar symptoms.

If you live in Scotland, you can find support from MND Scotland (see *Useful organisations* near the end of this sheet for contact details).

If you contact us, let our services know if you need help provided in a specific way. If we don't speak your language, you may need someone to contact our MND Connect helpline in English.

Our helpline team may be able to arrange for a telephone interpreter to help them communicate with you. You can also ask for this support to communicate with our Benefits Advice Service.

We cannot provide a telephone interpreter for health or social care appointments or for calls between you and another external person. However, if you're having problems accessing an interpreter or translation through a health and social care service, our helpline team may be able to help. They can contact the service on your behalf to find out why and seek a solution.

Our services include:

- local branches or groups, where you can meet others affected by MND
- regional care staff and volunteers, who can help with guidance
- our support services team, who may be able to provide certain items of equipment on loan, or some financial support, where health and social care services cannot supply (in most cases, requests must come through a health and social care professional, following assessment of your needs)
- our Benefits Advice Service to help you identify claims you can make, at: www.mndassociation.org/benefitsadvice
- part-funded MND care centres and networks, offering specialist help and co-ordinated care (also provided through regional neurological services)
- our website and information resources: www.mndassociation.org

- our online forum: <https://forum.mndassociation.org> which provides a safe place to share experiences and support with others affected by MND (this is in English, so you may need someone to help you read or write forum posts)
- membership with us, within a supportive community, working together towards a common goal and having your voices heard. You'll receive our regular Thumb Print magazine, and you'll have the chance to get involved in exclusive membership events.



“I think this resource will empower people to know there is additional help out there and how to acquire it. To realise not to struggle and seek help.”

5: How do I find out more?

Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information. If they do not speak your language, you may need to ask someone to contact them on your behalf.

The contact details are correct at time of print, but may change between revisions. If you need help to find an organisation, contact our MND Connect helpline (see the end of this sheet for details).

Advicenow

Online information on rights and legal issues.

Website: www.advicenow.org.uk

Citizens Advice

Free, confidential advice to help resolve legal, money and other problems. Search for local branches on the website.

Telephone: England – 0800 144 8848
 Wales – 0800 702 2020
 Northern Ireland – See website for area numbers

Website: www.citizensadvice.org.uk

Disability Action

A Northern Ireland charity working for the rights of disabled people.

Telephone: 028 9029 7880
 Email: hq@disabilityaction.org
 Website: www.disabilityaction.org

GOV.UK

Online government information about benefits and support in England and Wales.

Website: www.gov.uk

NHS and UK healthcare

Information about NHS services and healthcare across the UK.

Website: www.nhs.uk

For England

Telephone: 111 (for urgent medical advice, available 24/7)
Website: <https://111.nhs.uk>

For Wales

Telephone: 111 (for urgent medical advice, available 24/7)
Website: <https://111.wales.nhs.uk>

For Northern Ireland

Telephone: Available via individual trusts website contact page
Website: www.hscni.net

NI Direct

Government information about health and social care in Northern Ireland.

Email: through the website contact page

Website: www.nidirect.gov.uk

For Scotland

Telephone: 111 (for urgent medical advice, available 24/7)
Website: www.nhs24.scot

Relay UK

Helping people with hearing and speech difficulties communicate with anyone over the phone, using the national relay service.

Telephone: Use the Relay app, or call 0800 500 888

Website: <https://www.relayuk.bt.com>

Translation services

Translation services can be expensive. If you are considering paying for a translation, ask your doctor's surgery, local authority, or your health and social care trust for Northern Ireland first. They may have preferred suppliers that they use.

References

References used to support this information are available on request from:
email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park, Northampton NN3 6BJ

Acknowledgements

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Further information

We provide information sheets and publications on a range of subjects.

You can download most of our publications from our website at:

www.mndassociation.org/publications or order in print from the MND Connect helpline. The helpline team can answer questions about our information, discuss your language needs, direct you to our services and other support. If they do not speak your language, you may wish to ask someone to contact them on your behalf:

MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association website and online forum

Website: **www.mndassociation.org**

Online forum: **<https://forum.mndassociation.org>** or through the website

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 Industrial Estate, Moulton Park, Northampton NN3 6BJ

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