MND Association

1B

Health information in other languages and formats

Information for people with or affected by Motor Neurone Disease (MND) or Kennedy's disease

If English is not your first language or you are sight impaired, it may be difficult to access information about MND or Kennedy's disease and the type of support available. This sheet explains how to find information in other languages or formats, such as Braille, large print or audio. This information sheet is available in a range of languages and the content includes:

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 do I find out more?**

Trusted Information Creator
Patient Information Forum

This content has been evidenced, user tested and reviewed by experts. See: piftick.org.uk

This symbol highlights quotes from people living with or affected by MND or Kennedy's disease.

This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in section 4 **How do I find out more?**

1. How do I get information in other languages?

From the MND Association

If you contact us, let our services know if you need help provided in a specific way or another language. If we don't speak your language, you may need someone who speaks English to assist at first. If they contact our MND Connect helpline, they can help our team understand your needs.

MND Connect
Tel: 0808 802 6262
Email: mndconnect@mndassociation.org

However, our helpline team can then arrange a telephone call with an interpreter, who can translate for 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.

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

We offer introductory resources in a range of languages. This includes information sheets on the main clinical decisions you may have to think about.

Download our translated publications at: **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 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.

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 health problems due to your 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 speech difficulties or if you get very tired at appointments.

See our booklet: **Telling people about MND** for more on advocacy and communicating about your diagnosis.

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 language support, 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 a minimum of 12pt font. If you access our resources on our website, you can increase the viewing size of the text.

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)**

Audio

We offer introductory information in audio format in English. You can access these resources on Soundcloud at: **soundcloud.com/mndassoc/mnd-audiobook**

Animations

Our animations about MND, Kennedy's disease, and health and social care, use a combination of images, voiceover and subtitles for accessibility. These short items are easy to share with other people too, as simple overviews.

Find our animation range at: **mndassociation.org/animations**

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.

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

Explain your needs if you have a disability that makes it difficult for you to read and use guidance to get support.

Health and social care services have a duty of care to make sure you can access and understand the decision making information they offer. The following resources give more details in English how duty of care is governed:

For England

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

For Wales

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

For Northern Ireland

Search for: Making communication accessible at: **online.hscni.net**

For Scotland

Using the publications search field, search for: Accessible information policy at: **publichealthscotland.scot/publications**

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.

> **“I just found it amazing that they have technology that allows him to speak in his own voice, which knowing my dad the way he is and being very nervous about changes and things, I thought this would just be perfect for him because he’d still feel like he’s in control and he still has his voice, even when he doesn’t. ”**

See our resources:

- information sheet **7C Speech and communication support**
- information sheet **7D Voice banking**
- our voice banking animation at: **mndassociation.org/animations**

Providing written notes

You may find it helpful to provide pre-written notes to help people understand your needs and preferences.

It can be useful 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 you are:

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

You may find the following pieces of text useful.

They are given 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.

For MND:

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 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 details here:

Easy read

Easy read uses a combination of images and simple sentences in large print.

It can be helpful if you:

- want to read simple text in English
- need basic facts about a subject
- have learning difficulties or know someone who does.

See our booklet: **An easy read guide to Motor Neurone Disease (MND)**.

Translation services

Translation services can be expensive.

If you are considering personally paying for a translation, ask your professionals for guidance first.

This may be through your:

- doctor's surgery
- MND care centre or network
- neurology service
- local authority or council (England, Wales or Scotland)
- local health and social care trust (Northern Ireland).

If they cannot help directly, these professionals and services may have preferred suppliers that they use. If they can't recommend, they may have some guidance.

See section 1 **How to get information in other languages?** about our MND Association transation service. See more about our wider support in section 4 **How do I find out more?**

4. How do I find out more?

Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

Advicenow
Online information on rights and legal issues.
Website: **advicenow.org.uk**

Citizens Advice
Free, confidential advice to help resolve legal, money and other problems.
Tel: 0800 144 8848 (England)
0344 477 2020 (Wales)
Website: **citizensadvice.org.uk (England)**
citizensadvice.org.uk/wales (Wales)
citizensadvice.org.uk/nireland (Northern Ireland)

Disability Action
A Northern Ireland charity working for the rights of disabled people.
Tel: 028 9029 7880
Email: hq@disabilityaction.org
Website: **disabilityaction.org**

Government information
Online government information about benefits and support.
Website: **gov.uk** (England and Wales)
nidirect.gov.uk (Northern Ireland)
gov.scot (Scotland)

NHS and UK healthcare
Information about NHS Services and healthcare across the UK.
Tel: 111 (England, Wales and Scotland)
See individual trusts website contact page (Northern Ireland)
Website: **111.nhs.uk** (England)
111.wales.nhs.uk (Wales)
hscni.net (Northern Ireland)
nhs24.scot (Scotland)

Relay UK
National service helping people with hearing and speech difficulties communicate.
Tel: Use the Relay app or call, 0800 500 888
Website: **relayuk.bt.com**

Acknowledgements

With thanks to our User review group for kindly sharing their experiences.

Thank you also to the following for their kind review during the development or revision of this booklet:

Ruth Glew	Network Lead Coordinator for MND, Morriston Hospital, Swansea, Wales.
Lesley Johnston	Advice and Information Officer, Carers Northern Ireland
Elizabeth Rogers,	Clinical Specialist Occupational Therapist, Motor Neurone Disease, University Hospitals of Derby and Burton NHS Foundation Trust

> **"I think this resource will empower people to know there's additional help out there and how to acquire it. To not to struggle and seek help."**

References

References used to support this resource are available on request:
Email: **infofeedback@mndassociation.org**

Or write to:
Information feedback,
Motor Neurone Disease Association,
Francis Crick House,
6 Summerhouse Road,
Moulton Park,
Northampton, NN3 6BJ

Further information

We offer a wide range of information about MND and Kennedy's disease.

As a starting point, we offer the following resources in a range of languages.

Other titles may become available at: **mndassociation.org/languages** along with those requested through our translation service.

Information sheets

1B Information in other languages and formats (this sheet)

7A Swallowing difficulties

7B Tube feeding

8A Support for breathing problems

8B Ventilation for Motor Neurone Disease

Booklets

An introduction to Motor Neurone Disease

Search for information by need at: **mndassociation.org/careinfofinder**

Find information for professionals at: **mndassociation.org/professionals**

Download our information at: **mndassociation.org/publications**

Find information in other languages at: **mndassociation.org/languages**

Order printed copies from our MND Connect helpline (see Our support next).

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy’s disease.

MND Connect
Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: **mndassociation.org/mndconnect**
Tel: 0808 802 6262
Email: mndconnect@mndassociation.org

Support services
Find out about our support services at: **mndassociation.org/our-services**

Local and regional support
Find out about our branches and groups at: **mndassociation.org/local-support**

MND Association Benefits Advice Service
For help to identify claims and how to apply, visit: **mndassociation.org/benefitsadvice** or call our MND Connect helpline.
Tel: 0808 802 6262

MND Association website and online forum
Website: **mndassociation.org**
Online forum: **forum.mndassociation.org**

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 MND or Kennedy's disease, their families and carers.

Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns, and applications for funding.

To give feedback on any of our information sheets, access our online form at:
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
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton, NN3 6BJ

Would you like to help with user review of our information?

If you are living with MND or Kennedy's disease, or a carer, contact us at
infofeedback@mndassociation.org

Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton, NN3 6BJ

Tel: 01604 250505
Email: enquiries@mndassociation.org
Website: mndassociation.org

Registered Charity no. 294354

Revised: January 2026
Next review: February 2028
Version: 1