



1B

# Health information in other languages or formats

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## 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 Braille, large print or 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?**
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 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.

# 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](mailto:mndconnect@mndassociation.org)

We offer our resource *An introduction to motor neurone disease* in a range of languages. This overview of the disease includes information about types of support available across England, Wales and Northern Ireland.

If you have Kennedy's disease and would like Information sheet 2B - *Kennedy's disease* in another language, contact MND Connect for assistance.

As well as this sheet, we provide the following information sheets in other languages:

- 7A – *Swallowing difficulties*
- 7B – *Tube feeding*
- 8A – *Support for breathing problems*
- 8B – *Ventilation for motor neurone disease (MND)*

Download our translated publications at: [www.mndassociation.org/languages](http://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 shown above 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."*

## 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.

Although it is the legal responsibility of the health service to provide trained interpreters, you may prefer a family member to interpret for you. Your wishes will be respected. 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 or Wales, 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.

If you live in Scotland, you may wish to contact MND Scotland for further guidance. See *Further information* at the end of this sheet for contact details.

## **From other organisations and websites**

Automatic translation on websites can sometimes help, but may not be accurate and could be misleading. However, 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 Braille, large print or other formats?**

### **From the MND Association**

Contact our helpline, MND Connect, for guidance about our information and the formats available.

Telephone: 0808 802 6262

Email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

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)*

### **Audio:**

*An introduction to motor neurone disease (MND)* is available in English as an audio recording. You can access this on Soundcloud at:

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

Further recordings of our resources will be made available in 2019.

### **E-read:**

We will introduce an e-readable format in 2019, for our information sheets and various other resources. This format can be easily read on smart phones, tablets or laptops, as when you increase the text size, the flow of text automatically changes to fit the page.

## **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 apply information. 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](http://www.england.nhs.uk/ourwork/accessibleinfo)**

### **For Wales**

See the *All Wales Standards for communication and information for people with sensory loss*. This is available in both English and Welsh at:

**[gov.wales/topics/health/publications/health/guidance/standards/?lang=en](http://gov.wales/topics/health/publications/health/guidance/standards/?lang=en)**

### **For Northern Ireland**

See *Making communication accessible for all – a guide for Health and Social Care (HSC) staff* at:

**[www.belfasttrust.hscni.net/pdf/making\\_communication\\_accessible\\_to\\_all.pdf](http://www.belfasttrust.hscni.net/pdf/making_communication_accessible_to_all.pdf)**


### 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*

#### 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](http://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. We understand people have different preferences, circumstances and beliefs, that influence how you want care and support to be provided. Let our service teams know if you need specific help. As we may not speak your language, you may need someone to contact us on your behalf.

Our MND Connect helpline (see end of sheet for contact details) can introduce you to our services, as available, including:

- voluntary Association visitors, who can offer information and support by telephone, email or home visit, where available
- local branches or groups, where you can meet others affected by MND
- regional care development advisers, who help influence local health and social care services
- our support services team, who may be able to provide certain items of equipment on loan, or a support grant, 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)
- 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](http://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, which is free to people living with MND or Kennedy's disease, or their spouses, partners and carers (this includes voting rights at our Annual General Meeting).

## 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](http://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: 03444 111 444 (England, or contact your local Citizens Advice Bureau)  
0344 477 2020 (Wales)

Website: **[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)** (England)  
**[www.citizensadvice.org.uk/wales](http://www.citizensadvice.org.uk/wales)** (Wales)  
**[www.citizensadvice.org.uk/nireland](http://www.citizensadvice.org.uk/nireland)** (Northern Ireland)

#### Disability Action

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

Telephone: 028 9029 7880  
Email: [hq@disabilityaction.org](mailto:hq@disabilityaction.org)  
Website: **[www.disabilityaction.org](http://www.disabilityaction.org)**

#### Disability Law Service

Assistance on disability law.

Telephone: 020 7791 9800  
Email: [advice@dls.org.uk](mailto:advice@dls.org.uk)  
Website: **[www.dls.org.uk](http://www.dls.org.uk)**

#### GOV.UK

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

Website: **[www.gov.uk](http://www.gov.uk)**



### **NHS Choices**

For health and advice and information, 24 hours a day, 365 days a year.

Telephone: 111 for urgent, but non-emergency medical advice in England and some parts of Wales

Website: **[www.nhs.uk](http://www.nhs.uk)**

### **NHS Direct Wales**

Similar to NHS 111, but for Wales.

Telephone: 0845 4647, or 111 if available in your area

Website: **[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)**

### **Health and Social Care Northern Ireland** (NHS Northern Ireland)

Online information about health and social care services in Northern Ireland.

Email: through the website contact page

Website: **[www.hscni.net](http://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](http://www.nidirect.gov.uk)**

### **Translation services**

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

## **References**

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

## **Acknowledgements**

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Ruth Glew, Network Lead Coordinator for MND, Morriston Hospital, Swansea, Wales

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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](http://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](mailto:mndconnect@mndassociation.org)

MND Association, Francis Crick House, 6 Summerhouse Rd,  
Moulton Park Industrial Estate, Moulton Park, Northampton NN3 6BJ

### **MND Association website and online forum**

Website: [www.mndassociation.org](http://www.mndassociation.org)

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

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