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Environmental controls

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

Motor neurone disease (MND) can affect the movement and strength in your arms, hands and legs. This can make everyday tasks difficult.

If you are living with Kennedy's disease, you may have similar symptoms and also find this information helpful.

This information sheet explains how environmental controls can help you remain independent around your home, and provides information on how to access this technology.

The content is split into the following sections:

- 1: How can environmental controls help me?**
 - 2: How do I get environmental controls?**
 - 3: What else might help?**
 - 4: 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.

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



1: How can environmental controls help me?

Motor neurone disease (MND) causes weakness and stiffness of the muscles, causing them to lose mass (known as wasting). This means it becomes harder to move parts of your body, such as your arms, hands and legs.

This can make daily tasks around your home more difficult, including:

- turning lamps on and off
- controlling your television
- using a computer.

Environmental control (EC) systems usually consist of:

- a device that can be controlled
- a controller
- a way to access or use the controller.

Different types of controller are available which can be operated using different parts of the body. This can help you remain independent around your home and may help your carer save energy too.

Controllers may be operated using:

Direct touch by any part of your body: you can operate a controller using any part of your body that has movement.

Your voice: if you find movement difficult, some controllers are voice activated.

Switches: you can use a scan and switch system, where options appear on a screen or controller and you use a switch to select the option you want to control when it appears. You can also use a switch to directly activate a device, such as a lamp. Switches are usually like a large button, which can be placed near any part of your body that has movement. Electromyography (EMG) switches now exist, which are placed on your body and activated when they sense the smallest movement in the muscles. Switches can also be operated using your breath.

Head operated mouse: if your neck muscles are not weakened by MND, you can use your head as a computer mouse, where a receiver on the computer follows the movement of your head, which will control a cursor on the computer screen. The computer can also act as an EC controller, which can be connected to devices around the home.

Eye movement: this is where a computer system tracks the movement of your eyes, which act like a computer mouse. The computer can also act as an EC controller, which can be connected to devices around your home.

What can I use environmental controls for?



"I have a switch to operate my tablet, which allows me to work and control some things around the house, for instance heating."

You can use EC to control things around your home, including:

- door entry intercom and access
- mobile phones
- television, radio and other media devices
- lighting, heating and electrical devices, such as lamps or fans
- powered chairs or beds
- powered curtains, blinds, doors or windows
- emergency call alarms and 'lifeline' telephones.

EC can also help you access a computer, if using the keyboard and mouse become difficult. Adaptations to help with computer access include:

- adapted keyboards, including large keys, guarded keyboards or on screen keyboards
- adapted mice, including joystick, trackball, touchpad, mouth or foot controlled mice and head or eye movement operated mice
- speech recognition, where you can control a computer using your voice.

Some communication aids have Environmental controls built into them. For example, a computer controlled by your eye movements which has communication software installed.



"I use a computer controlled by my eye movements and can surf the web, write and read emails, even use spreadsheets... I lead an active life thanks to this new technology which is improving all the time."

2: How do I get environmental controls?

If you think environmental controls (EC) may be helpful, ask your local occupational therapist for an assessment. If you don't currently have an occupational therapist, ask your GP for a referral.

The local occupational therapist will assess your needs and should suggest equipment that may be helpful now and in the future. If you qualify, they will refer you for assessment for EC provision by a specialist EC service. The referral or assessment may also involve a specialist speech and language therapist (SLT).

If the person assessing you is not familiar with MND and how it may affect you, they can contact our helpline team MND Connect, who can provide guidance. See *Further information* in section 4: *How do I find out more?* for contact details.

The National Institute for Health and Care Excellence (NICE) guideline on MND (NG42) recommends that you should be assessed for environmental control systems without delay, and provided with these if you qualify. The guideline also recommends that health and social care professionals should co-ordinate with each other to see if the EC system can be combined with a wheelchair and communication aid, if you also need these for support.

The NICE guideline covers England. However, the standards and recommendations in the guideline are also recognised in Wales and Northern Ireland.



For more information, see:

What you should expect from your care

Information sheet 1A – About the NICE guideline on motor neurone disease



"In my area I was referred to the specialist Electronic Assistive Technology Service and they made an initial visit to assess my situation and give me an outline of how they would be able to help in the future. They make regular contact to discuss any changes. This is very important to me."

How you get EC may differ across England, Wales and Northern Ireland. If you are living in Scotland, contact MND Scotland for advice (see *Useful organisations* in section 4: *How do I find out more?* for contact details).

Who will show me how to use the equipment?



"It's rather difficult if you are older and not very technically minded, although I know the occupational therapist is there to help."

The person providing you with the equipment can train you and your carer in using it. You may also be able to trial a piece of EC equipment to see how you get on with it, before deciding whether to accept this as ongoing support.

England and Wales

In England and Wales, you can usually trial equipment in your home. The occupational therapist or other professional from the specialist EC service team can provide you with this trial equipment. If this is not possible, you may be able to trial equipment from a private environmental controls company.

The assessor from the specialist EC service will advise you on what can be controlled by an EC controller and what equipment can be loaned to you. They will also discuss with you any safety aspects of relying on control through an EC system.

Northern Ireland

In Northern Ireland, ask your health and social care trust for guidance, as services may differ across regions.

The Design Innovation and Assisted Living (DIAL) centre at North West Regional College in Derry-Londonderry has a range of assisted living products on demonstration that provide support for people in their own home. You can make a clinic appointment by contacting the DIAL manager. For contact details, see *Useful organisations* at the end of this sheet.

Who pays for the equipment?

With EC, you will be loaned the equipment for however long you need it.

England and Wales

Through specialist EC services, the NHS pays for the assessment, equipment and ongoing support of EC systems for people who are eligible. They will lend you the EC equipment, but not the 'controlled' devices. For example, if you need EC to control a lamp, the NHS will lend you the controller, but not the lamp it controls. If the controlled device and the controller are all part of one system, the NHS will loan the whole system.

In some cases, your home may need to be adapted to allow for EC systems to work, such as door, window and curtain openers, and locks that can be controlled by EC. You may also need to have additional plug sockets in place to power the equipment.

Adult social care services are responsible for these aspects and may fund these adaptations. However, you may need to pay for these yourself, depending on your income and savings. Contact your local authority for more information (see *Useful organisations* at the end of this sheet for how to find contact details).



For more information on adapting your home, see:
Information sheet 10C – Disabled Facilities Grants and home accessibility (DFGs)

Northern Ireland

In Northern Ireland, your local health and social care trust will usually fund the assessment, equipment and ongoing support of an EC system. However, ask your occupational therapist for guidance, as funding may be different depending on where you live.

Sometimes installing EC equipment counts as an adaptation to your home, as with door, window and curtain openers and locks that can be controlled by EC. In this case, the Northern Ireland Housing Executive (NIHE) is responsible and may fund these items. However, you may need to pay for these yourself, depending on your income and savings. Contact the NIHE for more information (see *Useful organisations* at the end of this sheet for contact details).



For more information on adapting your home, see:
Information sheet 10C – Disabled Facilities Grants and home accessibility (DFGs)

Should I buy my own equipment?

If the equipment cannot be funded for any reason, the MND Association may be able to help in the form of an MND Support (Care) Grant. A relevant health and social care professional will need to apply for you. For more information, see:

www.mndassociation.org/financialsupport

Ask for an assessment from an occupational therapist or other health and social care professional, even if you are planning on buying your own equipment. Certain pieces of equipment may only be helpful for a short time, but an assessment can look at your needs now and in the future, which can help prevent costly mistakes.

Contact MND Connect if you have been assessed as not eligible for environmental controls and are thinking about buying equipment yourself. The team can discuss your case with the environmental controls service, if needed. See *Further information* in section 4: *How do I find out more?* for contact details.

Are environmental controls available on the high street?

Although not designed for MND, many pieces of technology are now available on the high street and online which work in a similar way to environmental control systems and may be helpful. Most of these are controlled by voice. If your voice is affected by MND, you may be able to control this technology using a computerised voice, such as those that come on powered communication aids. If you do not use a powered communication aid, this technology may still be helpful for your carer, to help them save energy.



For more information on powered communication aids, see information sheets:
7C – Speech and communication support
7D – Voice banking

Most smartphones, tablets and computers come with a built in or app-based ‘virtual assistant’, which works through voice control. These assistants can perform simple tasks like:

- making hands free telephone calls
- setting reminders for appointments or taking medication
- performing internet searches.

Popular virtual assistants include:

- Google Assistant, which is available on most smartphones as an app, or comes built-in on some Android phones
- Siri, which comes built-in on iPhones and Apple products
- Alexa, an app that can be downloaded onto most smartphones and tablets
- Bixby, which comes built-in on newer Samsung phones and tablets
- Cortana, which comes built-into on Windows phones, computers and other Windows products.

Your smartphone, tablet or computer will usually have instructions on how to use these.

These virtual assistants also work through a ‘smart speaker’, available for purchase on the high street and online, which can perform tasks you tell it to. For the smart speaker to work, you will need:

- a wireless internet connection in your home
- a smartphone or tablet with the correct app needed to control the speaker (virtual assistant apps are usually free).

The smart speaker works in the same way as a virtual assistant and is always ready to help. This means that you say a command out loud and the speaker will respond. You do not need to use your phone or tablet when asking the speaker to perform a task.

Common smart speakers currently on the market include:

- Amazon Echo, which works with the Alexa app (you may hear some people call the speaker an ‘Alexa’)
- Google Home, which works with the Google Assistant app
- Apple HomePod, which works with Siri through an iPhone.



“I got an Alexa so my husband could ask it to play music or the news, it was a great investment as he could not move.”

Other similar devices and apps may be available, and new versions are likely to come to the market as this technology advances.

These smart speakers and apps can connect to other ‘smart’ systems around the home by wireless signals, including:

- heating and lighting systems
- television and entertainment systems
- security cameras that enable you to see and speak to someone at your front door.

However, the system you want to control through the smart speaker or app needs to be compatible. For example, if you want to control your heating using a smart speaker or an app on your smartphone, you will need to have a thermostat that can connect wirelessly. Ask your occupational therapist for guidance.

Some smart systems around the home can send information to chosen family members and carers, so that they know what devices you have used throughout the day. This technology can inform your chosen contacts if anything unusual happens, or you are not following your usual routine. This may help reassure you that help is on hand even if you live alone.

3: What else might help?

You should be eligible for environmental controls if using your hands and arms is difficult, but this will depend on the outcome of your assessment. The occupational therapist may feel there are other ways for you to remain independent around your home, such as with other pieces of equipment or larger adaptations. It may also be more suitable to have care support from adult social care services or your main unpaid carer instead.



- For more information on social care, see Information sheets:
10B – *What is social care?*
10C – *Disabled Facilities Grants and home accessibility (DFGs)*
10F – *Personal health budgets*

What other equipment might I need?

With MND, you may need a range of assistive equipment to help you live independently, depending on your symptoms. Your assessment should look into how EC systems can work together with a wheelchair and communication aid, if you already use these or are assessed as needing them too.



- For detailed information, see:
Information sheet 11C – *Equipment and wheelchairs*

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

AbilityNet

Supports disabled people and older people by helping them to use digital technology at work, at home or in education. IT Support at Home volunteers can help you make the most of your computer, smartphone or tablet device.

Address: Microsoft Campus, Thames Valley Park, Reading, Berkshire RG6 1WG
Telephone: 0800 048 7642
Email: enquiries@abilitynet.org.uk
Website: www.abilitynet.org.uk

Adult social care services

Adult social care services can be contacted through your local authority, or health and social care trust in Northern Ireland. You can find your local council online at:

Website: www.gov.uk/find-your-local-council

Or for Northern Ireland, search for *health and social care trusts* at:

Website: www.nidirect.gov.uk

Age UK

Tips and advice for using the internet if you haven't used it before.

Address: 7th Floor, One America Square, 17 Crosswall, London, EC3N 2LB
Phone: 0800 169 80 80
Website: www.ageuk.org.uk

Design Innovation and Assisted Living (DIAL) centre (Northern Ireland)

A centre showcasing different pieces of assistive equipment for people to see and try out.

Telephone: 028 7127 6411
Email: veronica.mcwilliams@nwrc.ac.uk
Website: <http://dial.nwrc.ac.uk>

GOV.UK

Online government advice on a variety of welfare topics, including how to find your local council, in England and Wales.

Website: www.gov.uk

Health and Social Care Online (NHS Northern Ireland)

Online information on NHS services in Northern Ireland.

Website: <http://online.hscni.net/>

Health in Wales

Information on NHS services in Wales, including a directory of the Welsh health boards.

Website: www.wales.nhs.uk

MND Scotland

MND Scotland provides support and information for people affected by MND in Scotland.

Address: Unit 8, 76 Firhill Rd, Glasgow G20 7BA

Telephone: 0141 332 3903

Email: info@mndscotland.org.uk

Website: www.mndscotland.org.uk

National Centre for Electronic Assistive Technology (Wales)

The main contact for EC services in Wales.

Address: The Lodge, Rookwood Hospital, Fairwater Road, Llandaff, Cardiff CF5 2YN

Telephone: 029 2031 3976

Website: www.alas.wales.nhs.uk/electronic-assistive-technology

NHS UK

The main online reference for the NHS.

Website: www.nhs.uk

NHS 111

The NHS telephone service for urgent, but not life-threatening medical help or advice. Available 24-hours a day, 365 days a year.

Telephone: 111 in England (and some areas of Wales)

NI Direct

Providing government information for Northern Ireland on a variety of welfare subjects, including health services and support for disability.

Website: www.nidirect.gov.uk

NHS England Specialised AAC and EC Services

NHS Information about getting Specialised Assistive Technology Services for people of all ages in England.

Website: <https://assistivetechology.org.uk>

Northern Ireland Housing Executive (NIHE)

Northern Ireland's housing authority, offering a range of services to people living in socially rented, privately rented and owner occupied accommodation.

Telephone: 03448 920 900

Website: www.nihe.gov.uk

References

References used to support this document are available on request from:

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

Acknowledgements

Our thanks to the following for their kind support in the development of this information sheet:

Lynne Allsopp, Lead Occupational Therapist – Environmental Control, Access to Communication and Technology, Birmingham

Vonnie McWilliams, DIAL Manager, North West Regional College, Derry-Londonderry

Arek Szamocki MSc RCT, Clinical Technologist, Environmental Controls Service Team Leader, National Centre for Electronic Assistive Technology Wales, Rookwood Hospital, Cardiff

Further information

You may find these information sheets from the MND Association helpful:

1A – About the NICE guideline on motor neurone disease

7C – Speech and communication support

7D – Voice banking

10B – What is social care?

10C – Disabled Facilities Grants and home accessibility (DFGs)

10F – Personal health budgets

11C – Equipment and wheelchairs

We also provide the following resources that you may find useful:

Living with motor neurone disease – our main guide to help you manage the impact of the disease

Personal care with MND – information on prolonging independence with daily routines.

Getting around with MND – information on transport, driving and travelling with MND.

Making the most of life with MND – our booklet on quality of life with MND, which focuses on how adapting your approach may help you continue doing the things you want to do

What you should expect from your care – Our pocket sized booklet to support discussions with health and social care professionals. This may help lead to better outcomes for treatment and care with MND and contains the main points from the NICE guideline on motor neurone disease.

Caring and MND: support for you – comprehensive information for unpaid or family carers, who support someone living with MND

Caring and MND: quick guide – the summary version of our information for carers

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

www.mndassociation.org/publications or order in print from the MND Connect helpline, who can provide further information and support.

MND Connect can also help locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional MND Association staff.

MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

Motor Neurone Disease Association

Francis Crick House

6 Summerhouse Road

Northampton NN3 6BJ

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



Created: March 2022
Next review: March 2025
Version: 1

Registered Charity No. 294354
Company Limited by Guarantee No. 2007023
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