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Environmental controls

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

Both motor neurone disease (MND) and Kennedy's disease can affect movement and strength, making daily tasks difficult. This information sheet explores how environmental controls can help you control facilities around your home. Using this remote or smart technology can prolong independence and improve quality of life. The content includes:

- 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?**



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 can environmental controls help me?

Motor neurone disease (MND) and Kennedy's disease cause weakness in muscles, which leads to wasting (loss of muscle mass).

This makes it harder to move parts of your body and carry out daily tasks around your home, including operating facilities such as:

- turning lights on or off
- controlling your television
- opening windows or doors
- using a computer.

Environmental control (EC) systems can help you do these things remotely. These systems include:

- a facility or function that is set up to 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 can 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

Adapted switches or large buttons can be placed near any part of your body to activate a device. You can also use a scan and switch system, where options appear on a screen and you select the option you want to control. 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.



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

Head operated mouse

If your neck muscles haven't weakened, a special receiver on the computer can follow the movement of your head to control the cursor on the computer screen. With appropriate software apps, this means your computer can act like a remote control for devices around the home.

Eye movement

This is where a computer system tracks the movement of your eyes to select options on the screen. As with head movement, this enables your computer to act like a remote control for devices around the home.



“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.”

What can I use environmental controls for?

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 related telephone services.

If you find it gets harder to use a keyboard, EC can also help you access your computer. Adaptations that can help include:

- adapted keyboards, including large keys, guarded keyboards or on-screen keyboards
- adapted mice, including joysticks, trackballs, touchpads, 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.

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.



“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.”

The local occupational therapist (OT) will assess your needs and suggest ways to adapt or equipment that may be helpful. They'll explore your needs now and likely needs 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).



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

If anyone assessing your needs isn't familiar with MND or Kennedy's disease, they can contact our MND Connect helpline for guidance.



See section 4: **How do I find out more?** for our support details.

The National Institute for Health and Care Excellence (NICE) has produced NICE guideline NG42 for the management of MND. This recommends that, if you qualify, you should be assessed and provided with environmental control systems without delay.

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.



See the following resources for more on the NICE guideline:

- **What you should expect from your care**
- **information sheet 1A - About the NICE guideline on MND**

How you get EC may differ across England, Wales and Northern Ireland. If you are living in Scotland, contact MND Scotland for advice.



See section 4: **How do I find out more?** for other organisation details.

Who will show me how to use the equipment?

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 available for demonstration. Make a clinic appointment by contacting the DIAL manager.



See section 4: **How do I find out more?** for other organisation details.

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 qualify.

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. 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 about assessment.



See information sheet: **10C Disabled Facilities Grants and home accessibility (DFGs)** for more about adapting your home.

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 section 4: **How do I find out more?** for other organisation details.

Should I buy my own equipment?

If the equipment cannot be provided, the MND Association may be able to help with some funding. A relevant health and social care professional will need to apply for you. See: www.mndassociation.org/financialsupport We can also help discuss your case with the environmental controls service, if you do not qualify for environmental controls after assessment.

If you are planning on buying your own equipment, still ask for an assessment from an occupational therapist or relevant health and social care professional. Certain pieces of equipment may only be helpful for a short time. An assessment can look at your needs both now and in the future to help prevent costly mistakes.

Are environmental controls available on the high street?

Although not designed for MND, smart technology devices from high street and online providers can also be helpful. They provide a lot of functions and can work like environmental control systems.

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. These are available on powered communication aids.



For more about communication aids, see:
– **7C Speech and communication support**
– **7D Voice banking and message banking**

Smart technology can also be helpful for your carer, to help them save energy.

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.

Smartphones, tablets and computers usually have instructions on how to use these.



“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.”

A virtual assistant works through a smart speaker, available to buy on the high street or online. You ask the speaker to carry out a task that it's programmed to do.

For a smart speaker to work, you will need:

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

The smart speaker is always ready to help, whenever you give a command. You do not need to use your phone or tablet when asking the speaker to perform a task.

Common smart speakers 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.

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 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.

Whichever facility or system you want to control through the smart speaker or app needs to be compatible.

For example, if you want to control heating, your heating system will need 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 which devices you've used throughout the day. This lets your chosen contacts know if anything unusual happens, rather than your usual routine. This may feel reassuring that help is on hand, even if you live alone.

3 What else might help?

You usually qualify 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 to maintain your independence around your home, for as long as possible. This might include other pieces of equipment or larger adaptations.



See information sheet: **11C Equipment and wheelchairs.**

It may also be more suitable to receive care support from adult social care services or your main unpaid carer instead.

What other equipment might I need?

With MND, you may need a range of assistive equipment and aids to help you live independently, depending on your symptoms.

If appropriate to your needs, your assessment should look into how EC systems can work together with a wheelchair and communication aid.

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.

AbilityNet

Supports disabled and older people to use digital technology in daily life.

Telephone 0800 048 7642
Email enquiries@abilitynet.org.uk
Website abilitynet.org.uk

Adult social care services

Contact adult social care services for a needs assessment or carer's assessment.

Website search for:
find your local council at gov.uk (England and Wales)
health and social care trusts at nidirect.gov.uk (Northern Ireland)
find my council at careinfoscotland.scot (Scotland)

Age UK

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

Telephone 0800 169 8080
Website ageuk.org.uk

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

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

Telephone 028 7127 6411
Email veronica.mcwilliams@nwrc.ac.uk
Website dial.nwrc.ac.uk

Government information

Online government information about benefits and support. in.

Website gov.uk (England and Wales)
nidirect.gov.uk (Northern Ireland)
gov.scot (Scotland)

Living made easy

Provide impartial advice, information and training on independent living.

Tel: 0300 999 0004
Email: info@dlf.org.uk
Website: livingmadeeasy.org.uk

MND Scotland

Care, information and research funding for people affected by MND in Scotland.

Telephone 0141 332 3903
Email info@mndscotland.org.uk
Website mndscotland.org.uk

National Centre for Electronic Assistive Technology (Wales)

The main contact for EC services in Wales.

Telephone 029 2031 3976

Website cavuhb.nhs.wales/our-services/electronic-assistive-technology

NHS England Specialised AAC and EC Services

Specialised Assistive Technology Services for people of all ages in England.

Website assistivetechology.org.uk

NHS and UK healthcare

Information about NHS services and healthcare across the UK.

Tel: 111 (England, Wales and Scotland)

for Northern Ireland, see individual trust contact page

Website: 111.nhs.uk (For England)

111.wales.nhs.uk (For Wales)

hscni.net (For Northern Ireland)

nhs24.scot (For Scotland)

Northern Ireland Housing Executive (NIHE)

Services for people living in socially and privately rented or owner occupied accommodation.

Telephone 03448 920 900

Website nihe.gov.uk

Research Institute for Disabled Consumers (RIDC)

Research and information to enable independence for disabled and older people.

Tel: 020 7427 2460

Email: mail@ridc.org.uk

Website: ridc.org.uk

The Royal College of Occupational Therapists (RCOT)

Sets occupational therapy standards with a register of qualified therapists.

Tel: 020 3141 4600

Email: hello@rcot.co.uk

Website: rcot.co.uk

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Technology Wales, Rookwood Hospital, Cardiff.

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. You may find the following resources helpful, relating to this sheet.

Information sheets

- 1A 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

Booklets

- Caring and MND - quick guide
- Personal care
- Getting around
- Making the most of life with MND

Large guides

- Living with MND
- What you should expect from your care
- Caring and MND - support for you

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

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