



11A

Clothing


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


If you are living with motor neurone disease (MND) or Kennedy's disease, you may be concerned about how to get dressed and feel comfortable in your clothes as your symptoms progress.

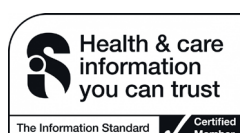
This information sheet will help you to think about clothing and equipment to suit your needs.

The content includes the following sections:

- 1: Where can I find help?**
- 2: What type of clothing do I need?**
- 3: What will help me to feel comfortable?**
- 4: How can 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.



The MND Association has been certified as a producer of reliable health and social care information.

www.england.nhs.uk/tis

1: Where can I find help?

Not everyone with MND or Kennedy's disease experiences the same symptoms or in the same order, so your needs may be different to someone else with the disease. The speed at which the disease progresses can also vary widely and your needs will change over time. Because of this, adapted clothing and assistive equipment may not always be right for you or may only be suitable for a short time.

Prior to making any purchases, seek an independent assessment of your needs with an occupational therapist. The occupational therapist will take into account your likely future needs and let you know which options will be most suitable. This can help you to avoid frustration and costly mistakes.

An occupational therapist can advise on:

- suppliers of adapted clothes, which look good and are easy to handle
- local services that can adapt your own clothes for ease and comfort
- simple ideas you can apply yourself, such as different fastenings
- equipment to help you get dressed (known as dressing aids)
- protective items for use outdoors, eg with wheelchairs and scooters.

Some equipment may be supplied free of charge by adult social care services or the NHS. In Northern Ireland, this may be supplied by your local health and social care trust. However, in most cases, adapted clothing will need to be purchased. See *Useful organisations* in section 4: *How do I find out more?* for a list of suppliers to help you start your search.

Most dry cleaning companies offer a clothing repair service and it may be worth asking how much it would cost to adapt a range of clothes or a favourite outfit.

Top tips

You are likely to develop your own solutions to problems, but sharing ideas with other people affected by MND can be helpful.



"At support meetings, you can exchange ideas that are often inexpensive and creative."

If you wish to meet others living with or affected by MND, you may wish to contact your local MND Association branch or group, Association visitor or local neurological support group. You may also wish to go to our online forum, where others facing similar challenges may make suggestions. See *Further information* in section 4: *How do I find out more?* for details.

To provide you with a starting point, the following top tips have been gathered from the experience of others with the disease.

- fingerless gloves can help keep hands warm, but allow you to grip
- when seeking thermal clothes, ski wear ranges may provide useful items
- some people find silky materials help them to move more easily in bed, but be cautious as these can cause you to slide downwards in a bed or chair (this can also be difficult for the carer if you need assistance for positioning)
- clothes with pockets, eg tops and shirts, are useful for keeping small items close to hand, such as glasses
- poppers are easy to undo, but closing them requires you to position the two halves precisely. Alternative fastenings such as Velcro or large magnetic poppers may be more helpful
- attach a large zipper pull or keyring to a normal zipper to make it easier to grip
- front fastening bras, or sports bras with no fastenings, may be easier to handle
- with nightwear, mid-length is safer than full-length to avoid tripping, particularly if using stairs
- if you use a lot of Velcro fastenings, close them when washing your clothes to avoid clogging them with fluff
- if you have a favourite item of clothing, you may wish to adjust this, eg with larger buttons and button holes
- you may find elasticated waists on trousers skirts easier to handle than zips or buttons.

What can help when getting dressed?

If you have a weak grip or problems using your fingers, fastenings can be difficult and frustrating. Replace existing fastenings, eg change zips and buttons to Velcro, or wear clothing that does not require fastenings at all.

If you prefer clothing with fastenings, when dressing you may find it easier to put these on partly fastened, eg putting a partly buttoned shirt on over your head.

You can buy:

- alternative fastenings, such as elastic shoelaces to get shoes on and off without undoing them
- a variety of aids to assist with dressing, such as zip pulls, button hooks, dressing sticks and shoe/sock devices
- large D rings and Velcro to adapt belts, if buckles are difficult to manage (ask in a sewing supplies store or look for ready-made Velcro belts).

It is important to seek an independent assessment of your needs by a qualified occupational therapist to ensure any items you purchase are suitable.



“With MND and getting dressed, we need to think about how to make life easier for our carers too.”

2: What type of clothing do I need?

How you look in your clothes may be important to you, but a few simple questions can help you think about how each item functions:

- Is this piece of clothing easy for me to handle?
- Is it easy for me to grip, eg not too silky
- Does it have large neck openings and loose fitting sleeves for ease of dressing?
- Are the fastenings simple and can I manage them?
- Can the fastenings be changed, for example by replacing a zip with Velcro?
- Can I find something similar without any fastenings at all?
- Is the material appropriate, for example avoiding itchy fabrics next to the skin?
- Will the style allow for easy access for me to go to the toilet?
- Is the fabric washable and non-shrink, and easy to dry and iron to reduce laundry time for me or my carer?
- Is the style suitable when sitting down, for example will the hemline ride up?
- Will it be comfortable for me if I am sat down in it for a long time?



“My husband wears walking trousers a lot. These are easy to wear, easy to wash and dry quickly.”

Consider any pressure areas on your skin. Zips, buttons, pockets and raised seams can impact on your skin if sat on for a long period of time.

Also consider any clothing that is long or trails if you use a wheelchair, as this could get caught.

Keeping these tips in mind can help to improve comfort and reduce frustration when putting clothes on or taking them off.

If your mobility is affected, you are likely to spend more time sitting and people will focus on the upper part of your body. If you are looking for style and fashion, select clothing to compliment the shoulder line and face.



“We tended to buy larger clothes. Luckily it was warm when my husband had MND and he liked wearing shorts.”

What clothing will help me when going to the toilet?

MND does not usually affect the bladder or bowel, but if your mobility is affected, it can be more difficult to get to the toilet in time.

It can be tempting to drink less to reduce the number of times you need to go, but if you get dehydrated you may get constipated. So it is important to ensure that your clothes do not get in the way when using the toilet.

Clothing that is difficult to handle will make your daily routines more challenging. Wear clothing that is easy to get on or off, or pull up or down. Not only will this be helpful when using the toilet, but when dressing, washing or showering too.

For example, you may find it helpful to wear trousers with Velcro fastenings at both sides, or where the front or back can be lowered as a flap. Some people find braces useful for pulling trousers back up.

You can get detailed advice from your local Continence Advisory Service. These services are based across the UK, so ask your GP for a referral to your regional service if you are experiencing any difficulties.

They can provide guidance on:

- specialist underwear and disposable pads in case you can't get to the toilet in time, to prevent embarrassment or having to change your clothes
- continence equipment and aids, for use at home or when travelling
- adapted clothing for ease of access when going to the toilet.

What footwear should I use?

If you experience 'foot drop' where the foot drags, or you are concerned about the risk of trips and falls, there is specialist footwear to help, such as a 'foot up' device (ask your occupational therapist or physiotherapist for guidance).

In general, shoes should:

- be wide fitting
- support the ankle
- be fully enclosed, eg not slip on or backless
- have good grip
- have low heels
- fasten securely and easily.

Local hospital podiatry departments often have wide fitting supportive footwear for sale and can advise on devices to support the foot and ankle.

You may find your feet swell if you are seated for long periods of time. If this tends to happen, try:

- wide fitting shoes with an elastic lace or Velcro fitting
- shoes in a larger size
- fleece lined boots (which allow for swelling, but also provide extra warmth if your feet get cold quickly)
- wide fit shoes and slippers with additional strap extensions.

Specialist footwear can be very costly and if your needs change, may only be useful for a short period of time. So it is important to get guidance from your health and social care team.

3: What will help me to feel comfortable?

Lightweight and looser fitting clothes may help you to:

- feel more comfortable
- manage more dressing tasks independently
- reduce the time needed for dressing
- feel less tired and frustrated when dressing.

If you need assistance when dressing, looser clothing will also be easier for your carer to handle.

Some clothing may feel better in different situations or temperatures (see heading *How do I manage temperature control?*).

Try not to wear:

- heavy or tight garments, which can restrict movement and may make problems with mobility or arm function feel worse
- tight waistbands, raised seams or clothing that ruckles easily, as these cause discomfort if you are seated for long periods of time.

Ask your occupational therapist for advice about discrete items for personal problems. For example, difficulties with saliva may cause drooling, but this can be managed using neck scarves, adult bibs and tabards, which help prevent dampness to the skin and stains to clothing. Wearing washable and easy-care fabrics will also help.

If you are eating out or with company and are concerned about saliva or spilling food or drink, wearing a dark patterned top may disguise any splashes.



For more information on eating and drinking with MND, including lots of hints and tips, see our guide: *Eating and drinking with MND*

How do I manage temperature control?

If your movement is limited it may be harder to keep warm. Try to:

- wear layers of loose lightweight clothing, as this provides excellent insulation, but layers can be removed if you tend to get hot quickly
- wear additional clothing and protective items outdoors, especially in cold weather
- warm up items of clothing before you put them on, particularly if you are going outside
- use a hat or thick scarf when outdoors, as you may lose body heat through your head
- wear thermal clothes for warmth, or quilted fabrics, wool, cashmere or acrylics (these fabrics create warmth by trapping air and resisting compression)
- look out for absorbent materials such as cotton, viscose and modal as these can help with sweating
- sit in a quilted bag or sleeping bag if you tend to feel cold, whether indoors or outdoors (a blanket can slip and may not protect the back of the legs).

Try not to use nylon and polyester, as they can create static and make you sweat.

Heated products should not be used unless you have checked with your doctor first (especially heated socks and foot warmers if you have swollen feet or circulation problems).

If you use a mobility aid, scooter or wheelchair, you may need specialist items such as capes, bags, covers, gloves or hand muffs. Again, ask your occupational therapist for advice (see *Useful organisations* for a list of suppliers).

4: How do I find out more?

Useful organisations

We do not necessarily endorse the external organisations listed here. These have been provided to help you search for further information if necessary. Details are correct at the time of print, but may change between revisions. If you need help to find an organisation, contact our MND Connect helpline (see *Further information* at the end of this sheet for details about our helpline and how they can support you).

The Able Label

A select clothing site with more designer-led styles of adapted clothing for women.

Address: Iden Farm Cottages, Heath Road, Boughton Monchelsea,
Maidstone, Kent ME17 4JE

Telephone: 01622 744 242

Email: Through the website contact page

Website: **www.theablelabel.com**

Able2 Wear

Adaptive clothing for disabled people and wheelchair users, of all ages.

Address: 53 Donaldson Street, Kirkintilloch, East Dunbartonshire,
Scotland G66 1XG

Telephone: 0141 775 3738

Email: info@able2wear.co.uk

Website: **www.able2wear.co.uk**

Adaptawear

Adaptive clothing created in consultation with health and social care professionals and people with dressing needs.

Address: 14 Undine street, Tooting, London SW17 8PR

Telephone: 0800 051 1931

Email: info@adaptawear.co.uk

Website: **www.adaptawear.com**

Cloutietree

Adaptive clothing for warmth and comfort.

Address: 48 Undine street, Tooting, London SW17 8PR

Telephone: 0800 145 5277

Email: info@cloutietree.com

Website: **www.cloutietree.com**

Complete Care Shop

Disability aids and a variety of male and female incontinence aids, and wheelchair accessories, such as ponchos, capes, aprons and jackets.

Address: Unit 1A, Brook Mill Estate, Station Road, Wrea Green,
Lancashire PR4 2PH

Telephone: 03330 160 000

Email: sales@completecareshop.co.uk

Website: www.completecareshop.co.uk

Designed to Care

Adaptive clothing to make dressing easier.

Telephone: 0800 046 1095

Email: support@designedtocare.co.uk

Website: www.designedtocare.co.uk

Disabled Living Foundation (DLF)

Impartial advice and information on independent living, including fact sheets listing specialist suppliers.

Address: Unit 1, 34 Chatfield Road, Wandsworth, London SW11 3SE

Telephone: 0300 999 0004

Email: info@dlf.org.uk

Website: www.dlf.org.uk

Discretely Different

Underwear and clothing for disabled people.

Address: Titan Clothing Ltd, 33 Main Street, Humberstone, Leicester LE5 1AE

Telephone: 0116 2460231

Email: through the website contact page

Website: www.underwearfordisabled.co.uk

Easy Adaptive Wear

Adaptive clothing for people with mobility difficulties.

Email: through website contact page

Website: www.easyadaptivewear.com

Easybelts

An online shop supplying Velcro belts.

Email: info@easybelts.co.uk

Website: www.easybelts.co.uk

EssentialAids.com

Online shop for daily living aids, including aids for dressing.

Address: 52 The Droveaway, Hove, East Sussex BN3 6PP
Telephone: 01273 719 889
Email: customerservice@essentialaids.com
Website: www.essentialaids.com

Glanmor

Disability aids and wheelchair and scooter products, such as capes and leg cosies.

Address: 208 High Street, Swansea SA1 1PE
Telephone: 01792 642 868
Email: through website contact page
Website: www.glanmor.co.uk

Living made easy

Advice and products to assist with clothing and daily living.

Address: c/o Disabled Living Foundation, Ground Floor, Landmark House,
Hammersmith Bridge Road, London W6 9EJ
Telephone: 0300 999 0004
Website: www.livingmadeeasy.org.uk

NRS Healthcare

Sell a range of daily living aids and disability aids.

Address: Sherwood House, Cartwright Way, Forest Business Park, Bardon Hill,
Coalville, Leicestershire LE67 1UB
Telephone: 0345 121 8111
Email: customerservice@nrshealthcare.co.uk
Website: www.nrshealthcare.co.uk

Parafricta

Low friction garments and bedding to help protect skin with limited mobility.

Address: I-Lab Bedford, Stannard Way, Bedford MK44 3RZ
Telephone: 0800 043 1412
Email: info@parafricta.com
Website: www.parafricta.com

Spring Chicken

Online shop selling a range of dressing aids and easy-fasten clothes.

Address: Sandford Gate, East Point Business Park, Oxford OX4 6LB
Telephone: 01865 339 366
Email: customerservice@springchicken.co.uk
Website: www.springchicken.co.uk

Wheeliechix-Chic

An online shop producing fashion clothing for female wheelchair users.

Address: 135 Mortlake Road, Richmond TW9 4AW

Telephone: 0208 255 0901

Email: enquiries@wheeliechix-chic.com

Website: www.wheeliechix-chic.com

References

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

Email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

Acknowledgements

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Further information

We have related information sheets you may find helpful:

6A – Physiotherapy

6B – Complementary therapies

11C – Equipment and wheelchairs

You can also refer to our main guides:

Living with motor neurone disease – our guide to MND and how to manage its impact, including guidance about eating and drinking, and speech and communication

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

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

Eating and drinking with MND

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 also answer questions about this information, and direct you to our services and to other support:



MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association, PO Box 246, Northampton NN1 2PR

MND Association website and online forum

Website: **www.mndassociation.org**

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

We welcome your views

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them.

If you would like to provide feedback on any of our information sheets, you can access an online form at: **www.surveymonkey.com/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, PO Box 246, Northampton NN1 2PR

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