



Head supports for motor neurone disease

Motor neurone disease (MND) is a progressive and terminal disease that attacks the motor neurones, or nerves, in the brain and spinal cord.¹

Muscle weakness is one of the key features of MND and head drop can result from weakness in the neck, shoulder girdle and long back extensor muscles.² This sheet includes information about head supports that may be used by people with MND.

This information sheet is for health and social care professionals. If you are a person living with MND, we strongly advise you to consult an occupational therapist or physiotherapist. This is essential to ensure the collar or head support meets your needs.

Choosing the right collar or support

A person with MND will be assessed for a head support or collar by an occupational therapist, physiotherapist or an orthotist. Once an assessment has been completed, it may be necessary to try a number of different options to find the right collar, as there is unlikely to be one device that solves all of the problems associated with neck weakness.

Sometimes, a combination of collars is needed that are suitable for different situations. Many people will choose not to wear their collar all the time. Because MND is progressive, the person's needs will change over time, so regular reviews are essential.

Head supports are available at no cost via the NHS, and there should be no need for someone with MND to purchase these privately.

General points

People living with MND retain sensation¹, so can experience discomfort associated with immobility. It is therefore crucial that a collar fits correctly and doesn't create pressure points.

- Neck weakness is only part of the problem and is frequently associated with weakness of the shoulder girdle and long back extensor muscles.
- Many people with MND experience swallowing problems as a result of bulbar weakness.³ A collar with an anterior area cut away may make swallowing easier.
- Forehead bands give freedom around the chin, mouth and throat, making it easier to eat, drink and speak.
- Practical, easy-to-make solutions, such as a roll of foam under the chin with a Velcro fastening, can offer some relief in certain circumstances.

Seated posture in MND

When a person with MDN has neck weakness, the preferred position is tilted, with the back, head and neck supported. A back rest that is shaped to the spine can help with head support. The type of chair chosen can help to achieve the preferred seated posture:

- Riser/recliner chairs with neck rolls or bridge cushions can provide some support.

Referral should be made to social services for the provision of a riser/recliner chair. Where statutory funding or provision has been explored and is not available, our support grant service may be able to help (see page 4).

- Tilt-in-space wheelchairs, which include a mechanism that tilts the whole seat backwards, off-loading the effects of gravity and providing support for the back and neck.

Advice should be sought from NHS wheelchair services on the types of wheelchair available through statutory funding.

Types of head support

There is a range of other head supports and collars available, but there isn't one type that will be suitable for everyone with MND. The MND Association is unable to recommend a particular product.

The following examples are given to assist healthcare professionals carrying out an assessment of need.

- **Simple, soft collar**

A simple, soft collar may be tried as a first step in the early stages of neck weakness, and may be used as an interim measure until a collar providing more support is required.

- **Wheelchair head supports**

A range of supports is available for wheelchairs and these should be considered alongside the wheelchair during assessments.

- **Head Up Collar**

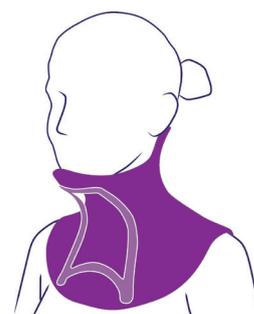
The Head Up Collar has been specifically designed for people with MND. This collar consists of a soft 'snood' which can be customised with medium or firm struts to provide individualised support, allowing the collar to be adjusted as neck weakness progresses. It is available from:

Talarmade

Telephone: 01246 268456

Email: info@talarmade.com

Website: www.talarmade.com



- **The Hereford Collar neck support**

This is a light, mouldable neck support that contains polystyrene beads. The beads can be manipulated, offering easy adjustment and variable degrees of support.

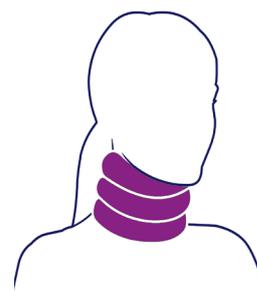
The Hereford collar is available from:

Medi UK Ltd

Telephone: 01432 373500

Email: enquiries@mediuk.co.uk

Website: www.mediuk.co.uk



- **The Headmaster Collar**

This low-profile collar is easily formed to a snug fit under the chin and attached with a comfortable strap.

Each Headmaster Collar is supplied pre-assembled and ready to use. Just bend it to the desired shape by hand. Optional extension pads are also available. The collar can be provided in sizes small, medium and large from:

Matrix Seating

Telephone: 0844 251 2575

Email: sales@matrixseating.com

Website: www.matrixseating.com



- **Hensinger Head Support**

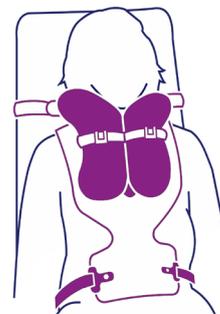
The Hensinger Head Support should be used in conjunction with a chest support. After the chest is secured, the head support can help maintain mid-line head position. It is available in various sizes from:

Trulife UK

Telephone: **0114 2618100** (Orthotics)

E-mail: **info@trulife.co.uk**

Website: **www.trulife.com**



- **Miami J Cervical Collar**

The adjustable sections allow this collar to be fitted to suit the person's anatomy.

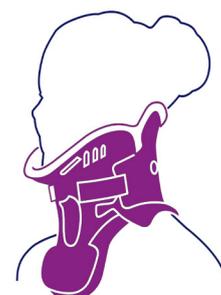
The option of the Miami JTO Thoracic extension allows control of the upper thoracic spine. Using an Occian Back can prevent pressure problems on the back of the head. The wearer can talk, eat and rest without having to loosen the chin-piece and without compromising mobility. This collar and the options mentioned are available from:

Ossur UK Ltd

Telephone: **0845 006 5065**

Email: **ossuruk@ossur.com**

Website: **www.ossur.co.uk**



- **Burnett vacuum head and neck supports**

These collars can be shaped to the person's profile, before air is extracted, leaving a supportive mould. They can be moulded to suit different seating options. After initial instruction, they can be fitted by a carer. They can also accommodate changes as neck weakness progresses.

These supports are available from:

RBF Healthcare

Telephone: **01268 983 842**

Email: **sales@rbfhealthcare.co.uk**

Website: **www.rbfhealthcare.co.uk**



References

- 1 Bäumer D, Talbot K and Turner MR. Advances in motor neurone disease. *Journal of the Royal Society of Medicine*. 2014; 107:14.
- 2 Dharmadasa, T et al. *Motor neurone disease in Handbook of clinical neurology*. 2018. 159:345-357
- 3 Hobson EV et al. *Clinical aspects of motor neurone disease*. Medicine. 2016. 44(9):552-6.

Acknowledgements

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This information sheet has been endorsed by the The British Association of Prosthetists and Orthotists.

How we can support you and your team

MND Connect

Our helpline offers help, information and support, and signposting to people living with MND, carers, family and health and social care professionals.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

Information resources

We produce high quality information resources for people living with MND, carers, family members and health and social care professionals.

www.mndassociation.org/publications

MND Association website

We have a wide range of information to support health and social care professionals working with people affected by MND.

www.mndassociation.org/professionals

Education

Our education programme is designed to improve standards of care and quality of life for people living with and affected by MND. Opportunities include online modules and face-to-face training.

www.mndassociation.org/education

Support grants and equipment loan

Where statutory provision is not available, we may be able to offer a support grant or loan equipment.

www.mndassociation.org/getting-support

Research into MND

We fund and promote research that leads to new understanding and treatment and brings us closer to a cure.

www.mndassociation.org/research

MND register

The MND Register of England, Wales and Northern Ireland aims to collect information about every person living with MND to help plan the care and discover more about the cause of the disease.

www.mndregister.ac.uk

Regional staff

We have a network of regional staff with specialist knowledge of MND. They work closely with local statutory services and community care providers. Contact MND Connect for further information.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

MND care centres and networks

We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist multidisciplinary care for people with MND.

www.mndassociation.org/care-centres

Branches and groups

We have volunteer-led branches and groups nationwide providing local support and practical help to people with MND and their carers.

www.mndassociation.org/branchesandgroups

Association visitors (AVs)

AVs are trained volunteers who provide one-to-one local support to people affected by MND. They can support people affected by MND in person, by telephone or by email or through support groups.

www.mndassociation.org/associationvisitors

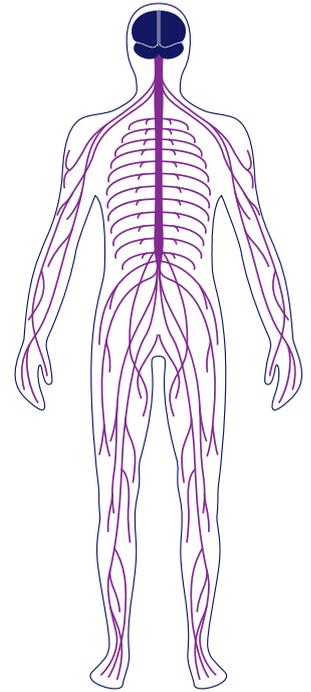
We value your feedback

Your feedback helps improve our information for the benefit of people living with MND and those who care for them. Visit www.smartsurvey.co.uk/s/mndprofessionals or email your comments to infofeedback@mndassociation.org

If you would like to help us by reviewing future versions of our information resources, please email us at infofeedback@mndassociation.org

About MND

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work. MND does not usually affect sight, hearing or sensation.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- It affects people from all communities.
- Some people may experience changes in thinking and behaviour, with some experiencing a rare form of dementia.
- MND kills a third of people within a year and more than half within two years of diagnosis.
- A person's lifetime risk of developing MND is up to 1 in 300.
- Six people per day are diagnosed with MND in the UK.
- MND kills six people per day in the UK.
- It has no cure.



Would you like to find out more?

Contact our helpline if you have any questions about MND or want more information about anything in this publication.

mndconnect
0808 8026262
mndconnect@mndassociation.org

www.mndassociation.org/professionals

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