

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.

Choosing the right collar or support

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 orthotist, occupational therapist or physiotherapist. This is essential to ensure the collar or head support meets your needs.

The NICE Guideline on MND (NG42) states that if a person needs orthoses to help with muscle problems, they should be referred to orthotics services without delay, and the orthoses should be provided without delay. In practice, a person with MND may 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 or functional sets, particularly as MND progresses. People will tolerate wearing a collar for different lengths of time during the day and for specific functions. These individual needs should be considered when prescribing a collar.

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 excessive pressure.

- Neck weakness is frequently associated with weakness of the shoulder girdle and long back extensor muscles. Using a collar may have an impact on posture and function throughout the body.
- Many people with MND experience swallowing problems as a result of bulbar weakness.³ A collar may need to be selected or adjusted based on swallowing needs by a trained professional. Use a collar with an anterior cut out eg. Headmaster collar or a universal two-piece collar, to support swallowing if needed by the person.

- Forehead bands give freedom around the chin, mouth and throat, making it easier to eat, drink and speak, although fastening these to the back of a chair, wheelchair or other supports for anchoring are based on a trial and error process, and need to be closely monitored.
- 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

The type of seating a person uses can enhance posture and comfort with neck weakness.

Depending on the functional level of the person, initial stages of the neck weakness can be managed using a high back chair with/without a neck brace.

The type of chair chosen can help to achieve the preferred seated posture:

- As the weakness progresses using a tilted chair position to support the head, neck and trunk, for example using a riser recliner chair may be useful. However, some people cannot tolerate a tilted position due to respiratory discomfort. If tolerated, a chair can be requested through Social Services. Using a good chair with/without a neck collar can provide comfort and augment function for a person.

Where statutory funding or provision has been explored and is not available, our support grant service may be able to help (see page 5).

- 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 are a range of 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.



Universal two-piece collar

The two-piece collars offer more support than the simple, soft collar. They are height-adjustable and have a large opening around the throat to allow for airway management. They are made up of a solid outer shell, with liners inside for comfort.



Wheelchair head supports

A range of supports is available for wheelchairs and these should be considered alongside the wheelchair during assessments. Your local wheelchair therapist/occupational therapist will be able to advise you on head supports.



Note: The branded collars below listed on the following pages appear in alphabetical order. These are not provided as recommendations, but as links for professionals to explore the options available.

Other stockists may be available, so browse online to compare services and prices.

Adams Collar

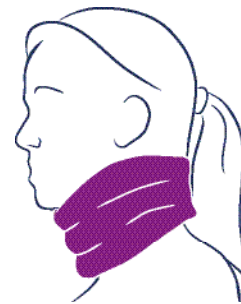
This collar provides semi rigid support and contains mouldable polystyrene beads which can be moved to provide comfort and fit. Loop contact closure allows the collar to be easily adjusted. These supports are available in three sizes from:

DJO Global

Telephone: 01483 459659

Email: ukorders@enovis.com

Website: www.djoglobal.eu/en_UK



Additive Neuro Collar

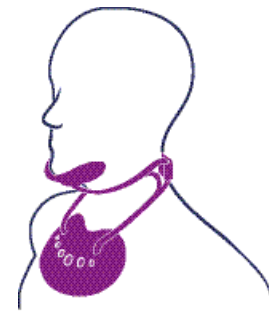
Manufactured as a made to measure device to a scan or cast, with chin and chest sections contoured to the individual's anatomy. It has a spring design allowing for variable resistance options. An adjustable version is also available. These supports are available from:

Crispin Orthotics

Telephone: 0113 252 8866

Email: info@crispinorthotics.com

Website: <https://additiveorthotics.com>



Burnett vacuum head and neck supports

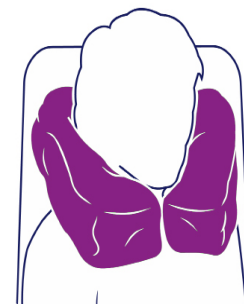
These collars can be shaped to the person's profile, before air is extracted, leaving a supportive mould. They can be moulded to suit different seating options. After initial instruction, they can be fitted by a carer. They can also accommodate changes as neck weakness progresses. These supports are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

RBF Healthcare

Telephone: 01268 983 842

Email: sales@rbfhealthcare.co.uk

Website: www.rbfhealthcare.co.uk



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 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

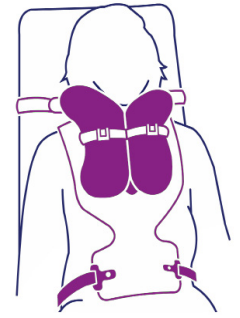
The Hensinger Head Support should be used in conjunction with a chest support. After the chest is secured, the head support can help maintain mid-line head position. It is available in various sizes from:

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.

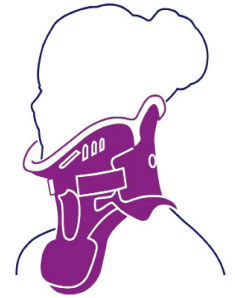
The option of the Miami JTO Thoracic extension allows control of the upper thoracic spine. Using an Occian Back can prevent pressure problems on the back of the head. The wearer can talk, eat and rest without having to loosen the chin-piece and without compromising mobility. This collar and the options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

Ossur UK Ltd

Telephone: 0845 006 5065

Email: ossuruk@ossur.com

Website: www.ossur.co.uk



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.

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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 treatments, and brings us closer to a cure for MND.

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 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