

P1

Head supports for people with motor neurone disease

Information for health and social care professionals

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.

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 orthotics specialist.

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.

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 MND 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 who are 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**

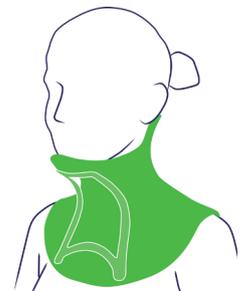
The Head Up Collar has been specifically designed for people with MND. This collar consists of a soft 'snood' which can be customised with medium or firm struts to provide individualised support, allowing the collar to be adjusted as neck weakness progresses. It is available from:

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.

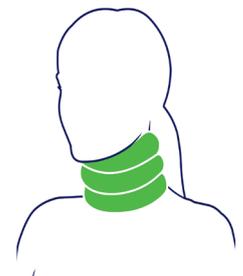
The Hereford collar is available from:

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.

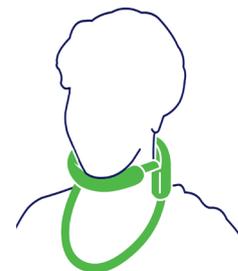
Each Headmaster Collar is supplied pre-assembled and ready to use. Just bend it to the desired shape by hand. Optional extension pads are also available. The collar can be provided in sizes small, medium and large from:

Matrix Seating

Telephone: 0844 251 2575

Email: sales@matrixseating.com

Website: www.matrixseating.com



• Hensinger Head Support

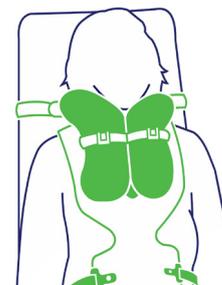
The Hensinger Head Support should be used in conjunction with a chest support. After the chest is secured, the head support can help maintain mid-line head position. It is available in various sizes from:

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.

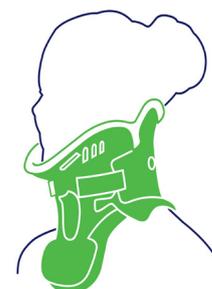
The option of the Miami JTO Thoracic extension allows control of the upper thoracic spine. Using an Occian Back can prevent pressure problems on the back of the head. The wearer can talk, eat and rest without having to loosen the chin-piece and without compromising mobility. This collar and the options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

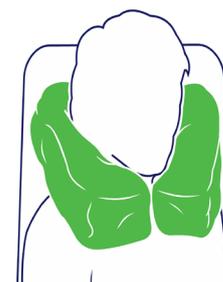
These supports are available from:

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.

Support from the MND Association

We support health and social care professionals to provide the best possible care for people living with MND, their carers and families. We do this in a number of ways:

MND Connect

Our helpline offers help, information and support, and signposting to other services and agencies. The service is for people living with MND, carers, family members, health and social care professionals and Association staff and volunteers who directly support people with MND.

Call the team on 0808 802 6262 or email mndconnect@mndassociation.org

Information resources

We produce high quality information resources for health and social care professionals who work with people with MND. We also have a wide range of resources for people living with and affected by MND. Downloads of all our information sheets and most of our publications are available from our website at www.mndassociation.org/publications or order directly from the MND Connect team.

MND Association website

Access information for health and social care professionals on our website at: 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, such as conferences and masterclasses.

Find out more at www.mndassociation.org/education

MND support grants and equipment loan

Where statutory funding or provision has been explored and is not available, we may be able to provide a support grant or equipment loan.

Referrals for support grants or equipment loan need to be made by a relevant health or social care professional. For further information, visit www.mndassociation.org/getting-support

For enquiries about MND support grants or equipment loan, MND Connect on 0808 802 6262 or email mndconnect@mndassociation.org

Research into MND

We fund and promote research that leads to new understanding and treatment and brings us closer to a cure. Contact the Research Development team on 01604 611880 or email research@mndassociation.org

Alternatively, visit www.mndassociation.org/research for more information. For the latest research news, visit our research blog at www.mndresearch.wordpress.com

MND register

The MND Register of England, Wales and Northern Ireland is a research study funded by the MND Association which aims to collect information about every person living with MND. The information will help plan the care for people living with MND and tell researchers more about what might be causing the disease.

People with MND who do not live near an MND Register recruitment site can take part in the study directly via self-registration on the project website.

Visit www.mndregister.ac.uk or email mndregister@kcl.ac.uk for further information.

Local support

Regional care development advisers

We have a network of regional care development advisers (RCDAs) covering England, Wales and Northern Ireland. RCDAs have specialist knowledge of the care and management of MND. They work closely with local statutory services and community care providers to ensure effective support for people affected by MND. RCDAs provide education for health and social care professionals in MND, and are champions at influencing care services in their respective areas.

MND care centres and networks

Care centres and networks are teams of professionals who are specialists in MND. We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist clinical expertise from diagnosis onwards.

Branches and groups

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

Association visitors (AVs)

Association visitors provide one-to-one local support to people affected by MND. Managed by regional care development advisers, they are volunteers with experience of MND who can visit people affected by MND within their homes or contact them by telephone, email or through local support groups. They can also provide a link with health and social care professionals. You may be in contact with Association visitors following up on queries from the families they support.

We value your feedback

Your feedback is important to us and 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 publications, you can access an online form at <https://www.smartsurvey.co.uk/s/MNDProfessionals> or email us at infofeedback@mndassociation.org

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

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James Wells**

About us

The MND Association was founded in 1979 by a group of volunteers with experience of living with or caring for someone with MND.

Since then, we have grown significantly, with an ever-increasing community of volunteers, supporters and staff, all sharing the same goal – to support people with MND and everyone who cares for them, both now and in the future.

We are the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.

Our mission

We improve care and support for people with MND, their families and carers.

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND.

We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

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 the senses such as sight, sound and feeling.
- 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 a proportion 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.

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