

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 motor neurone disease.

If you are a person living with MND reading this sheet, we strongly advise you to consult an occupational therapist or physiotherapist. This is essential to ensure the collar or head support meets your individual 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 a member of the orthotics team. Once an assessment has been undertaken, it is often a case of trial and error to find the right collar, as there is unlikely to be one collar that solves all of the problems with an individual's head support. 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. This will make reassessment 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.



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Catherine Knights, Care Centre Coordinator, King's MND Care and Research Centre

Seated posture in MND

The preferred position for someone with MND and neck weakness 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 equipment loan service may be able to help (see page 5).

- Tilt-in-space wheelchairs, which include a mechanism that will tilt the whole seat backwards, off-load the effects of gravity and provide support for the back and neck.

Advice should be sought from NHS wheelchair services on the types of wheelchair available through statutory funding. Our wheelchair service (see page 5) may be able to help if enquiries to statutory services for the timely provision of an appropriate wheelchair have failed.

Types of head support

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

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:

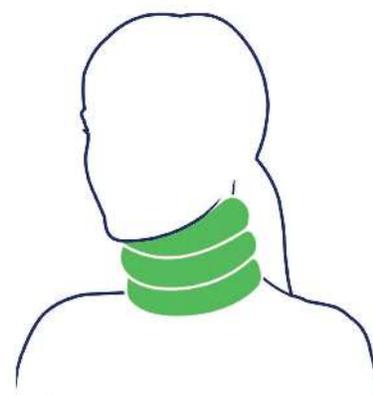
Medi UK Ltd

Plough Lane, Hereford, HR4 0EL

Telephone: 01432 373500

Email: enquiries@mediuk.co.uk

Website: www.mediuk.co.uk



Oxford Lees Head Support

This requires accurate measurement and/or a template. It is available from:

Oxford Centre for Enablement (OCE)

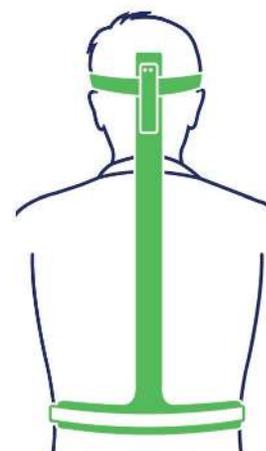
Nuffield Orthopaedic Centre

Windmill Road, Headington, Oxford OX37LD

Telephone: 01865 227 600

Email: OCE@ouh.nhs.uk

Website: www.ouh.nhs.uk/oce



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:

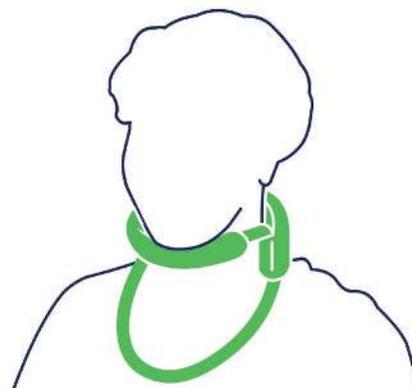
Matrix Seating

35 Breach Lane, Shaftesbury, Dorset SP7 8LD

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

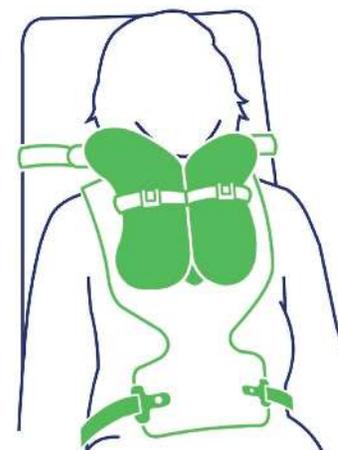
Customer Service

41 Amos Road, Meadowhall, Sheffield, S9 1BX

Telephone: **0114 2618100** (Orthotics)

E-mail: info@trulife.co.uk

Website: www.trulife.com



The MND Oxford Collar

This head support is designed to help people who retain some control over the position of their head but whose neck muscles are weakening and tire during the day. The weight of the head is counter-balanced, enabling some degree of flexion which is particularly helpful when swallowing. This support is available from:

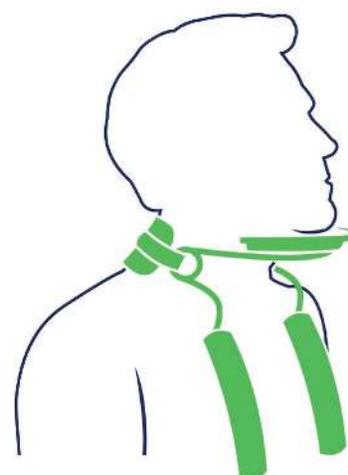
Salt Techstep

Lord Street, Aston, Birmingham B7 4DS

Telephone: **0121 333 2099**

Email: techsteporders@salts.co.uk

Website: www.saltstechstep.co.uk



Marlin Cervical Collar

A rigid, moulded collar with trachea opening and washable foam liners. It is available in five sizes: x-small, small, medium, large and x-large from:

Trulife UK

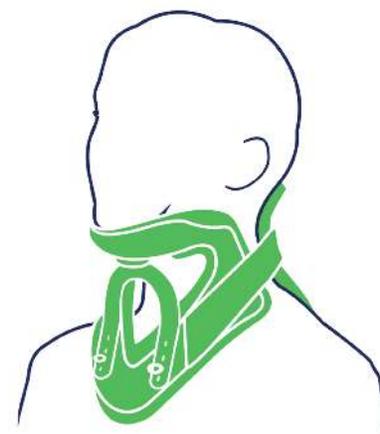
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41 Amos Road, Meadowhall, Sheffield, S9 1BX

Telephone: **0114 2618100** (Orthotics)

E-mail: info@trulife.co.uk

Website: www.trulife.com



Miami J Cervical Collar

The adjustable chin and occipital (back of the head) sections allow this collar to be fitted to suit the patient'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:

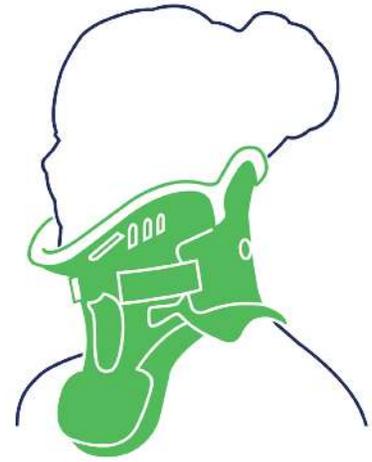
Ossur UK Ltd

Unit 1 S:Park, Hamilton Road, Stockport SK1 2AE

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.

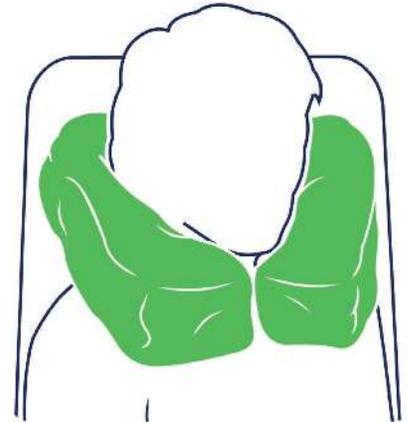
As with most collars, they are helpful for periods of time or for certain activities, such as travelling or transferring, but may cause restriction for other activities, such as eating and drinking. These supports are available from:

RBF Healthcare

Telephone: **01702 527401**

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

Website: **www.rbfindustries.co.uk**



Sheffield Support Snood

A new head support is currently being developed as part of the Head-up research project, funded by the National Institute for Health Research, supported by the MND Association and being carried out at the Sheffield Institute for Translational Neuroscience (SITraN).

The Sheffield Support Snood has been designed specifically for people with MND, and further testing is currently taking place. We will update this information sheet as soon as this collar is available. Read the latest news on MND research at www.mndassociation.org/research

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 Nakamura R et al. Neck weakness is a potent prognostic factor in sporadic amyotrophic lateral sclerosis patients. *J Neurol Neurosurg Psychiatry*. 2013; 84(12):1365-1371.
- 3 Hardiman O et al. Clinical diagnosis and management of amyotrophic lateral sclerosis. *Nat. Rev. Neurol*. 2011; 7(11):639-649.

How the MND Association can support you and your team

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.

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Please contact MND Connect if you have any questions about the information in this publication.

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**. You can also order our publications 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.

Our support grant service consists of providing care grants and quality of life grants for people with MND. This service is supported by MND Association branch and group funds, and by the Association's central fund.

Our equipment loan service is focused on three core items of equipment to help people with day-to-day tasks and communication:

- riser-recliner chairs
- specialist communication aids
- portable suction units.

For suction units, a small charge is made to statutory services for carriage, maintenance and cleaning.

Referrals for support grants or equipment loan need to be made by an occupational therapist, speech and language therapist or other relevant health or social care professional. For enquiries about MND support grants or equipment loan, call the MND Support Services team on **01604 611802**, email **support.services@mndassociation.org** or visit **www.mndassociation.org/getting-support**

Wheelchair service

If you are seeking information on wheelchairs, or if there are delays in assessment or provision of an appropriate wheelchair for someone with MND, our wheelchair service may be able to help, through training, joint assessments, advice or support. For our wheelchair service, call MND Connect on **0808 802 6262** or email wheelchairs@mndassociation.org

Communication aids service

This service helps people affected by MND and health and social care professionals with queries about communication aids. The service provides limited financial support for communication aids or some items on loan, if unavailable or delayed through health and social care services. Our aim is to improve provision and information on a local and national level, through collaboration with professionals. Call **01604 611767** or email communicationaids@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 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

Our peer-to-peer research and care community blog (RECCOB) has a number of reporters who write updates on MND-related workshops and events around the world. Subscribe for email alerts at www.reccob.wordpress.com

International Symposium on ALS/MND

Each year we organise the world's largest clinical and biomedical research conference on MND. It is the premier event in the MND research calendar for discussion on the latest advances in research and clinical management, attracting more than 800 delegates from at least 30 countries. Find out more at www.mndassociation.org/symposium

MND Association membership

Join us now and help fight MND. Membership costs £12 for individuals. It is free for people with MND and for carers, spouses or partners of people living with MND. Call **01604 611855** or email membership@mndassociation.org

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

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.

Please send us your feedback on
Head supports for people with motor neurone disease.

Thank you for taking the time to provide your feedback on one of our information resources.

This questionnaire can be accessed online if preferred, using the following link:
www.surveymonkey.com/s/professionalinformation

What is your profession or specialism?

Did you find this resource useful?

Yes Somewhat Not really No Please explain your answer

Will this information resource help you to provide people affected by MND with any of the following? (tick all that apply)

- | | |
|---|--|
| <input type="checkbox"/> an increased understanding of their symptoms | <input type="checkbox"/> more confidence |
| <input type="checkbox"/> an increased understanding of their condition | <input type="checkbox"/> improved quality of life |
| <input type="checkbox"/> more independence | <input type="checkbox"/> a greater ability to maintain dignity |
| <input type="checkbox"/> an increased ability to raise awareness of their needs | |

Were there any particular topics that were useful to you?

Was there any information that you didn't find useful or relevant?

Are there any other MND-related topics that you'd like more information about?

Do you have any other feedback about this resource or our other information for professionals?

Would you be happy to help us improve our information by becoming an expert reviewer?

Yes (please include your email address below) No

Do you have any experiences of working with people with MND you could share as an anonymous quote or case study for future resources?

Yes (please include your email address below) No

Please return your completed form to:

Education and information team
MND Association
PO Box 246
Northampton NN1 2PR

Name: _____

Email: _____

Acknowledgements

Thank you to the following people for their valuable contributions to this information sheet:

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**Jenny Rolfe, Senior
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Oxford MND Centre**

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Andrew Grindle**

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MND Association

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www.mndassociation.org

 @mndassoc

 /mndassociation

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.



mndconnect
0808 802 6262
mndconnect@mndassociation.org