

P1

Head supports for Motor Neurone Disease

Motor neurone disease (MND) results from the progressive loss of motor neurones in the brain and spinal cord. These are the nerve cells that control movement. It leads to muscle weakness and can cause difficulties with movement, breathing, swallowing and speaking.¹

Muscle weakness in the neck can cause the head to drop forward or to the side, making it difficult for the person to lift and maintain their head in an upright position.² This can lead to pain, poor posture and challenges with social interactions and daily activities. It also affects breathing, swallowing and communication.^{1,3,4}

This sheet provides information about head supports for people with MND, which may help manage neck weakness, improving comfort, safety and participation in everyday activities.⁴

It's intended for use by health and social care professionals. If you are a person with MND, we strongly advise consulting an orthotist, occupational therapist, or physiotherapist to ensure the collar or head support meets your needs. It covers:

- 1. Assessing the need for head supports**
- 2. Managing posture**
- 3. Types of head support**



Information for professionals:

Information sheet P2 – Wheelchairs for motor neurone disease
Booklet – Occupational therapy for motor neurone disease

See page 10 to order publications.

1. Assessing the need for head supports

Head supports are available at no cost through the NHS, so people with MND should not need to purchase them privately.

A multidisciplinary team approach is essential when assessing the need for head supports. Any healthcare professional, including the GP, can make a referral. According to the NICE Guideline on MND (NG42), if a person requires orthoses to assist with muscle problems, they should be referred to orthotics services without delay, and the orthoses should be provided promptly.⁵

The orthotist can help when:

- the person has difficulties maintaining head position, or there's evidence of progressive head drop
- there are concerns regarding swallowing, breathing or posture that may be affected by neck position
- there's a need for advice on appropriate collars or other types of supports
- the person already wears a collar, but it is no longer adequate or causing discomfort or other issues
- they experience fatigue or discomfort during daily activities or communication.

Access to orthotics services varies depending on local arrangements. Other professionals with relevant expertise, such as occupational therapists and physiotherapists, can also assist when the person experiences the issues listed above or needs an assessment for head supports.

When prescribing head supports, professionals should collaborate to ensure the person's needs are met. This includes considering the person's comfort and preferences on a collar's appearance and use. As MND progresses, the individual's needs will change over time, so regular reviews are essential.⁶

During assessments, it is advised to use collars with caution in the presence of:

- fixed cervical deformity that the collar cannot accommodate
- significant dysphagia or elevated aspiration risk
- existing pressure areas at collar contact points
- cognitive or behavioural factors that may affect the person's ability to comply with treatments.

In these cases, it may take some additional trial and error to find a suitable head support. Learn more below about what to consider during assessments.

Choosing the right collar or support

There is no single head support suitable for everyone with MND. One device is unlikely to address all the problems associated with neck weakness, so it may be necessary to trial different options.

A combination of supports may be needed for different situations.

When choosing a collar or head support, consider the factors listed below.

Comfort and ease of use: Different people will tolerate wearing a collar for different lengths of time during the day and during specific activities. Prioritising comfort and ease of use during daily activities can help with long-term use.⁶ For example, lightweight devices can reduce strain and fatigue.

Consider also how easy the collar is to put on and take off, and whether the person can do this independently or needs assistance.⁶ Carers and care workers should be instructed on how to safely fit the collar.

Skin integrity: Skin issues like pressure sores and irritation may occur, especially around the chin, shoulders, back and sides of the neck.⁶

Carefully monitor any pressure areas and make sure the collar fits correctly, without being too loose. Improper fit may lead to rubbing or discomfort. Choosing breathable materials can also help reduce the risk of skin damage.

Swallowing/breathing impact: Collars can restrict swallowing, which in some people with MND is already affected.^{1,7} It's important to select or adjust the collar to make sure the person can safely swallow.^{6,7}

For example, collars with a front cut-out, such as the Headsfirst collar, may be more comfortable for those with swallowing issues. A speech and language therapist can help assess any swallowing needs.

Also consider that certain collar types may not be suitable for individuals who use assisted ventilation to help breathing, either non-invasively (NIV) or via a tracheostomy.⁸

Safety: It's important to ensure the person can safely move while wearing a head support. Collars may limit some compensatory head movements that could help a person with MND maintain balance. A physiotherapist can help assess this.

Additionally, collars are not crash-tested, so the person with MND should be informed of any potential risks of wearing them while travelling in vehicles.

Using a collar

Prolonged use of collars may cause pressure sores so it's important to gradually increase wear time as tolerated and monitor the skin.⁶ Clinicians suggest to stop using and reviewing the collar if redness on the skin persists beyond 30 minutes, or if there are any pain, rubbing, blistering or signs of skin breakdown.

The person should be referred for reassessment if any of the following occur:

- new or worsening swallowing difficulties when using the collar
- increased breathlessness or reduced ability to manage breathing³
- new or persistent pain, pressure or discomfort related to collar use (including skin issues, such as redness beyond 30 minutes and pressure sores)
- noticeable decline in head control or changes in head position
- the collar obstructing vision or causing dizziness
- any signs that the collar no longer fits appropriately due to the progression of MND symptoms or weight loss.

2. Managing posture in MND

Neck weakness can lead to incorrect alignment of the head, neck, shoulder and back, resulting in posture problems.⁸ Additionally, weakness in the trunk may cause a person to lean sideways or slide forward in a chair, further affecting posture and comfort.

Posture can be improved with a properly fitted collar that maintains head position, and with appropriate seating support that helps achieve the preferred seated posture. This can also relieve strain caused by neck weakness.⁸ For example, a high-back chair, with or without a neck brace, may be helpful in the early stages of neck weakness.

As weakness progresses, a tilted position may offer better support for the head, neck and trunk. A riser recliner chair can be effective in improving comfort and function, and may be used with or without a collar.⁸ However, some people may not tolerate a tilted position due to respiratory problems. Riser recliner chairs can be requested through Adult Social Care Services. If statutory funding is unavailable, our support grant service may be able to assist (see page 9).

Tilt-in-space wheelchairs are also available. These chairs tilt the entire seat backwards, reducing the effects of gravity and providing support for the back and neck.⁹ The NHS wheelchair services can advise on available wheelchairs through statutory funding.

3. Types of head support

There are various head supports that can be used alone or in combination with a chair or wheelchair. These include soft, rigid and semi-rigid collars, which offer different levels of support and customisation depending on the person's needs.

The MND Association does not recommend specific products. The examples listed below are provided in alphabetical order to assist healthcare professionals in assessing individual needs. Availability may vary depending on local orthotics services.

In some cases, clinicians find that simple, practical solutions, such as a roll of foam under the chin secured with Velcro, can offer relief. A simple inflatable or memory foam travel collar may also be helpful as a temporary measure while people wait for other collars.

Forehead bands

Forehead bands allow freedom around the chin, mouth and throat, making it easier to eat, drink and speak. However, anchoring them to the back of a chair or wheelchair requires careful trial and monitoring.



Head Up collar

The Head Up Collar consists of a soft 'snood' with a flexible frame that can be reshaped and adjusted to suit the person's anatomy and comfort preferences.² It can also be adjusted as neck weakness progresses.



Its semi-rigid structure supports the chin, without restricting the head's natural movement. The collar is made from lightweight, breathable material. However, the closed-neck design may lead to sweating, which could affect comfort, and it may interfere with swallowing and eating.¹⁰

Headsfirst or Headmaster collar

This low-profile collar consists of a chin rest mounted on a semi-rigid frame, secured with a comfortable strap around the neck. It is available in three sizes and can be manually shaped to suit the individual. Extension and chest pads are also available.¹¹

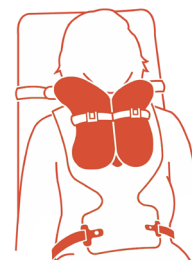


It may not be suitable for individuals with severe muscle weakness or lateral head drop, as it provides limited support in these cases. However, it can be used in combination with wheelchair adaptations that offer lateral support.¹⁰ The open-neck design may be more comfortable when swallowing and eating compared to other devices.

Hensinger head support

This is a foam wrap-around collar which supports the person's head. Made from waterproof foam covered in a vinyl coating, it is also available with soft covers.

It must be used with a chest support. Once the chest is secured, the head support helps maintain a mid-line head position.¹²



Inflatable head and neck supports

These collars can be shaped to the individual's profile. The desired shape is set by removing air. Once this is done, they become firm and supportive.¹³

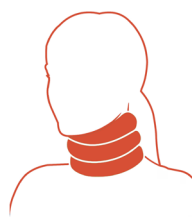
They can be adjusted to be used with different types of seating and modified as neck weakness progresses. Carers can fit these collars with professional guidance.



Mouldable polystyrene beaded collar

This collar provides semi-rigid support and contains mouldable polystyrene beads that can be moved to improve comfort and adjust the fit.¹⁴

A loop contact closure allows the collar to be easily adjusted. It may also include a central plastic insert that can be attached to increase rigidity. These supports are available in three sizes.



Rigid collar

Rigid collars offer firm, stable immobilisation, restricting neck movement. For this reason, people with MND may find them too rigid or uncomfortable. Prolonged use may also accelerate muscle atrophy and weakness, cause pressure areas and interfere with swallowing and daily activities.^{6,15} Therefore some clinicians recommend using them on a part-time basis.



Examples include the Aspen Vista Collar, which helps maintain eye level and swallowing positioning.¹⁶

Another example is the Miami J Cervical Collar, which features adjustable sections to suit the person's anatomy. This can be used with the Miami JTO Thoracic extension, which provides control of the upper thoracic spine, and the Occian Back which can prevent pressure problems on the back of the head.¹⁷

These collars allow the wearer to talk, eat and rest without having to loosen the chin-piece or compromising mobility.

Torticollis collar

This collar can be effective when the person's head drops to the side.¹⁸ However, the off-the-shelf version might be bulky and difficult to fit to the individual's anatomy.



A custom 3D-printed model is also available, offering tailored support. These are typically made from lightweight, breathable materials and have a discreet design, which may improve long-term comfort and compliance.

Soft collar

A simple, soft collar may be used in the early stages of neck weakness or when comfort and fatigue are the main concerns.⁶ It is flexible, lightweight and does not restrict movement. It can also serve as an interim measure until a more supportive collar is needed.



However, it may not be suitable for individuals with more severe muscle weakness and may require frequent replacement as the material is not durable.

Universal two-piece collar

These two-piece collars offer more support than a soft collar. They are height-adjustable and have a large opening around the throat to allow for airway management.



They are also easy to fit with hook-and-loop fastenings. They feature a solid outer shell, with liners inside for comfort.¹⁴

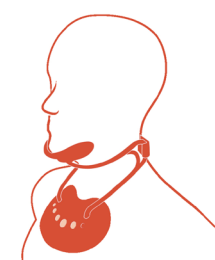
Wheelchair head supports

A range of head supports is available for use with wheelchairs. These should be considered alongside the wheelchair during assessments. A wheelchair therapist or occupational therapist can provide guidance on suitable options.



3D-printed neuro collar

This collar is custom-made using a scan, allowing for a personalised fit tailored to the individual's anatomy and the direction of head drop. It includes sections under the chin and over the chest, along with a spring system that provides adjustable resistance.¹⁸



This can be modified to provide more or less support, depending on the person's needs on the day. It's lightweight, breathable, and can offer a discreet appearance.

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How we can support you and your team

Our MND Connect helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. They can also provide further information about our services mentioned below.

Email: mndconnect@mndassociation.org

Tel: **0808 8026262**

MND Association website

Our website offers supporting information on MND, our work, services, and how to get involved.

mndassociation.org/professionals

Stay updated on events, publications and opportunities for professionals.

mndassociation.org/educationupdate

X: [mndeducation](https://twitter.com/mndeducation)

Bluesky: [mndeducation.bsky.social](https://bsky.app/profile/mndeducation.bsky.social)

Information resources

We produce high quality information for people with MND, carers, families and professionals, available in multiple formats and languages.

mndassociation.org/pro-info-finder

mndassociation.org/careinfinder

Education

Our education programme aims to improve standards of care and quality of life. Opportunities include webinars and face to face equipment training.

mndassociation.org/education

MND Professionals' Community of Practice

A peer led group supporting cross disciplinary learning in MND care. Membership can contribute to CPD and offers access to networking and learning events.

mndassociation.org/cop

Local support

We offer online and local peer support, plus trained volunteers who provide practical help by phone, email or visits.

mndassociation.org/local-support

We fund and develop specialist care centres and networks across England, Wales and Northern Ireland, offering multidisciplinary care.

mndassociation.org/care-centres

Financial support

We offer a range of grants to support people living with MND, their families and unpaid carers. These are not in place of any statutory funding that should be available.

mndassociation.org/getting-support

MND register

The Register aims to collect information about everyone with MND in England, Wales and Northern Ireland to support care planning and research.

mndregister.ac.uk

Research into MND

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND. We also produce information sheets on MND research for people with or affected by MND.

mndassociation.org/research

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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 smartsurvey.co.uk/s/mndprofessionals or email your comments to education@mndassociation.org.

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

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Motor Neurone Disease Association
Francis Crick House
6 Summerhouse Road
Moulton Park
Northampton NN3 6BJ

Tel: 01604 250505

Email: enquiries@mndassociation.org

Website: mndassociation.org

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**Every day we support people affected
by Motor Neurone Disease.
Because with MND, every day matters.**