

## Postural Care

**Posture is the position of your body when you are lying, sitting, standing, or moving around.**

There are two types of posture. The position of your body when you are moving around (dynamic posture) and the position when you are not moving (static posture).

Your everyday activities can affect your posture, and your posture can impact on the shape of your body.

If you have a muscle-wasting condition and you have difficulty moving around or need support to maintain your position when upright or with repositioning, you may be at a greater risk of developing problems with your posture. This means you could need postural care to protect your body shape. With a muscle-wasting condition, it is important to understand posture at all stages of your life, and to access specialist care and the right information to take care of your posture and protect your body shape.

Muscle-wasting conditions and related neuromuscular conditions are progressive conditions that cause muscles to weaken and waste over time. Muscle-wasting and weakness can impact postural stability, function, balance, and muscle length, and can result in pain or

discomfort. As a condition progresses, it can be harder to maintain a symmetric (evenly balanced) position against the forces of gravity, which can cause unwanted changes to your posture and body shape – and can mean that complications are more likely to occur without postural care and management.

If you have a muscle-wasting condition, changes to your posture may be gradual and not noticeable at first. You may experience more muscle weakness on one side of your body, which might cause you to move or sit in a way that is asymmetrical (unevenly balanced) and could cause further instability. Some individuals may compensate by using muscles which are not as weak; this can lead to further tightness and asymmetrical movement patterns.

Asymmetrical movement can result in uneven changes to your posture and body shape. Maintaining body symmetry as much as possible is essential to protecting your posture and body shape. Having 24-hour postural care can help to encourage body symmetry and symmetrical movement patterns.

In some muscle-wasting conditions, core muscles may become weaker. This can mean that, without the correct postural care in place, you may fatigue quicker than usual.

Fatigue is a common symptom that most people with muscle-wasting conditions experience. If you need any further advice or information about fatigue, here are some additional links to help you understand and manage your symptoms, identify potential triggers, and provide fatigue management techniques. Having 24-hour postural care can reduce fatigue and improve functional ability.

- [Fatigue Management](#) – Muscular Dystrophy UK
- [MDUK Muscles Matter 2022: Fatigue](#) – YouTube

Without correct postural care, unwanted changes to your posture and your body shape could result in:

- Pain and discomfort
- Joint stiffness
- Contractures
- Scoliosis
- Hospital admissions
- Increased equipment and care needs
- Decreased function and independence
- Social isolation
- Reduced quality of life

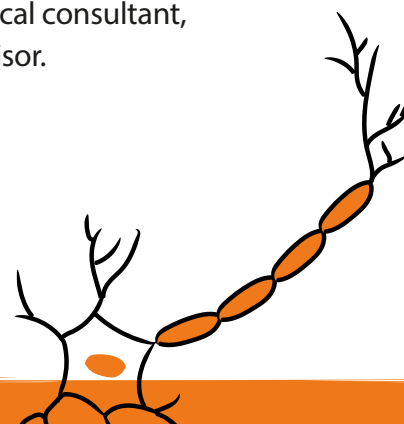
In some circumstances, changes in posture and body shape may lead to difficulties with breathing, swallowing, and digestion. By taking care of your posture during the day and night, you may be able to reduce the risks associated with these difficulties. There are many other possible benefits associated with 24-hour postural care, such as maintaining good general health, promoting independence and well-being, and preserving energy.

You can start taking care of your posture and thinking about 24-hour postural care at any stage in life.

If you notice that your posture or the shape of your body is beginning to change or has changed, you should speak to a physiotherapist or an OT for advice about postural care. They can help you understand your needs by assessing your body shape, posture, and positioning. This will help them advise on equipment and good positioning 24-hours a day.

**“Postural care is important and relevant from early years to ensure that body shape and function , especially for the upper limbs – is preserved. Good postural care can slow the progress of a neuromuscular scoliosis and for our child this allowed them to sit more comfortably and enjoy the activities that made them happy.” – Sheonad**

Physiotherapists are health professionals who help people manage their condition through various exercises. They usually work in a hospital or a community setting. Many of the neuromuscular clinics across the UK will have a specialist neuromuscular physiotherapist working within their team. It is also possible to access support from a specialist physiotherapist through organisations such as the Neuromuscular Centre (NMC) in Cheshire and Muscular Dystrophy Support Centre (MDSC) in the Midlands. You can get a referral through your GP, neurological consultant, or neuromuscular care advisor.



Occupational therapists (OTs) are health professionals who focus on helping people to do all the things they need and want to do in their daily lives. They are employed by the NHS or social services. Some neuromuscular clinics have specialist OTs. Your GP, neurological consultant, or neuromuscular care advisors can make referrals to an OT service for advice about postural care. It is also sometimes possible to self-refer for an occupational therapy assessment through your local council.

OTs and physiotherapists can work with you to create a 24-hour postural care plan to support you with maintaining body shape. It can be helpful to involve your carers or family members in your 24-hour postural care plan.

24-hour postural care is an important aspect of managing and living well with a muscle-wasting condition. The aim of 24-hour postural care is for your body to be symmetrical, where possible, and for you to be well supported throughout the day and night, in a way that is safe and comfortable. Along with good positioning, 24-hour postural care may

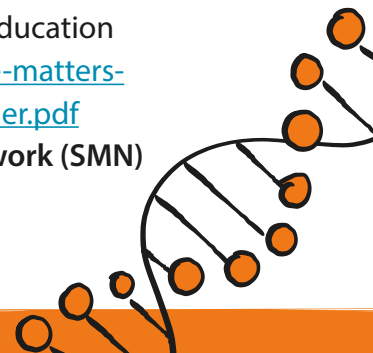
**“Getting an early awareness of how the correct postural care can positively impact on long term health and quality of life was completely enlightening. Knowing how and when to have informed discussions with medical professionals around equipment and support available will put us on the front foot in respect of positioning and sleep as we care for our son in the coming years.”** – Gerry

also include specialist seating, positional equipment such as sleep systems and wedges, side lying equipment, stretching and mobility equipment.

**Remember** – every person is different and requires individual advice, support, and equipment. This factsheet is a source of information but should not replace direct advice or information from a specialist consultant or health care professional. If you have any concerns, you should speak to your neuromuscular clinical team.

**If you need any further advice or information, here are some helpful links to resources which may also help with understanding posture and postural care:**

- **PAMIS**  
(Promoting a More Inclusive Society)  
PAMIS is a Scottish charity who support people with profound and multiple learning disabilities and their carers. PAMIS are members of the Scottish Postural Care Forum and the Scottish Postural Care Education Forum, supporting families to have their voices heard in the development and delivery of the Scottish postural care strategy, [Your Posture Matters](#). They have a range of resources available on their website about postural care.
- **Postural Care | PAMIS**
- **Postural Care: A guide to 24 hour postural management for family carers** by [PAMIS & NHS Lanarkshire.a5-booklet-final.pdf](#)
- **Your Posture Matters: Let's take care of it together.** NHS Education for Scotland. [your-posture-matters-lets-take-care-of-it-together.pdf](#)
- **The Scottish Muscle Network (SMN)**



SMN are a national managed clinical network for children and adults with neuromuscular disorders. The Network has produced several information leaflets and videos about posture and physiotherapy that you may find useful.

- **Information about Postural Management.** Scottish Muscle Network. [Postural-management.pdf](#)
- **Simply Emma**  
Simply Emma is a leading travel and disability blog focused on accessible travel and life experiences from a wheelchair user's perspective. Simply Emma has written a blog on Postural Management: Ways to Manage Posture with Muscular Dystrophy. [Postural Management: Ways to Manage Posture with Muscular Dystrophy - Simply Emma](#)
- **Muscular Dystrophy UK Care Plan** [Care plan | Muscular Dystrophy UK](#)  
Muscular Dystrophy UK has worked alongside a range of specialist health professionals to develop a care plan that can be filled in by you and your neuromuscular clinicians. This care plan can be shown to any health professional and helps them to give a tailored approach to your healthcare. The care plan can also be used to provide information about your posture and your 24-hour postural care plan.
- **NHS Greater Glasgow & Clyde –** [Neurological Conditions Postural Care](#)

## Glossary

- **Postural care** – protecting a body shape 24 hours a day.
- **Scoliosis** – a sideways or twisting curvature of the spine.
- **Contractures** – when the muscles and tendons around a joint become shorter and tighter.
- **Asymmetrical Movement** – when the body is not moving identically on the left and right side.
- **Fatigue** – an overwhelming sense of exhaustion and lack of energy. Fatigue is often related to a combination of factors.
- **Postural Stability** – having a strong and stable base to hold our body in a straight or upright posture.
- **Specialist seating** – seating which is adjusted to the individual to promote postural stability.
- **Sleep systems** – a system used on a bed to support a person's posture and body shape during sleep and rest.

[www.muscular dystrophyuk.org](http://www.muscular dystrophyuk.org)

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