

Postural care

Protecting and restoring
body shape



Do you support someone with multiple disabilities or
are you responsible for commissioning services for them?

If the answer is yes, you need to know about postural care.

Supported by



Introduction

People often assume that body shape distortion is inevitable for people with multiple disabilities¹, but that is not the case.

With correct positioning, body shape distortion is preventable and can even be corrected later in life.

Failure to protect body shape can have serious consequences for a person's health and quality of life. It can even cause premature death.



¹ For example, people with profound and multiple learning disabilities (PMLD)

What is postural care?

Postural care is about protecting someone's body shape.

People who find it hard to move – for example, those with multiple disabilities – are most at risk of developing body shape distortions. This is because they often sit and lie in limited positions.

If we understand why certain postures are distorting the body, we can correct them. Postural care is about using the right equipment and positioning techniques to help protect and restore body shape.

The earlier the intervention, the better – but it is never too late to start protecting and restoring someone's body shape.



The current situation

Many people do not understand the importance of protecting body shape (postural care) for people with multiple disabilities. As a result, provision of postural care services is patchy, and although some areas are doing postural care well, others are not doing it at all.

Some people are having their body shape protected in the day – for example, with a wheelchair that supports their posture – but getting no protection for their body shape at night.



What do we want?

The members of the Postural Care Action Group want:

- to challenge the assumption that distortion of body shape is inevitable for people with multiple disabilities
- all people with multiple disabilities to get the support they need to protect their body shape, 24 hours a day.

“Many people, like us, are unaware of how important posture is for those we are caring for. We are allowing problems to arise through ignorance.”

Parent



Craig's story

“Throughout Craig’s life, not enough importance was given to postural care. We had standing frames and good wheelchairs but nothing was done to protect his body shape at night. The attitude from the professionals was that deterioration was inevitable.



“When, at 14, Craig went in for major surgery, the surgeon said: ‘You do know that his body shape will shorten his life – it’s inevitable because of the pressure on his lungs and heart’. Despite telling us this, nothing was done to improve it.

“Over time we found out about sleep systems and did some training. Once you have all the information, training and a simple understanding of the body, it all suddenly makes sense.

“When we got the training, we didn’t realise how little time we had left with Craig. There’s no doubt in my mind that his life was shortened because of his body shape. That is why it is so important that other families find out about postural care.”

Craig’s mum

Why is postural care important?

Failure to protect body shape can result in lots of health complications. For example:

- contractures – where the muscles tighten up and the person can’t straighten their limbs
- scoliosis – curvature of the spine
- difficulty breathing
- poor digestion
- constipation
- pressure on internal organs.

These complications can cause suffering, pain and even death.

There is growing awareness about the importance of postural care services:

Healthcare for All (Michael, 2008) recognised that there is a gap in services for children with profound disabilities and complex needs who have postural care needs.

Recommendation 12 in *Raising our sights: services for adults with profound intellectual and multiple disabilities* (Mansell, 2010) says that NHS bodies should ensure they provide health services to adults with profound intellectual and multiple disabilities which focus on the protection of body shape.

Tommy's story

"Tommy has multiple disabilities. He was 40 years old when he began using night-time positioning.



"Tommy had always slept in a limited position, which translated into his seated position too, and caused him lots of problems.

"His internal organs were compromised, and this meant he could not digest food easily and his capacity to breathe was affected. Tommy was in a great deal of pain and he would often bite his fingers or make himself sick. He was very unhappy at this stage.

"His deteriorating body shape also meant that it was possible that he would need surgery for scoliosis, which would be expensive and likely to cause emotional trauma.

"Over two years, Tommy's chest was gently de-rotated. His body was gradually realigned and he was made much more comfortable. At 42, he is no longer in pain after eating and he is doing very well."

Tommy's support worker

Benefits of postural care

Investing in postural care services has clear benefits to the health and well-being of individuals.

It also reduces the need for invasive and expensive interventions, including surgical procedures. So it can save commissioners money.

"Postural care has improved his health and well-being. The cost savings are also clear as it has meant a reduction of recurrent pressure sores, better reflux management, reduced chest infections and reduced pain, meaning there is less need for medication and hospital admissions. He has also needed less staff input for his behaviour, which had become challenging due to the pain he was in. The need for spinal surgery, which can be very expensive, has been reduced too."

Health professional



Rebecca's story

Rebecca is 42. She lives in her own bungalow with one-to-one support. She has profound and multiple learning disabilities and seizures which affect her life. A few years ago her family noticed her body shape was distorting.



“Rebecca used to lie in a twisted position with her legs over to one side. By using night-positioning equipment (a sleep system) we have been able to counteract this and she can now lie on her back and put her legs straight. We introduced the sleep system very gradually, just for a few minutes during the day, so she got used to it, then introduced it at night.

“It started off as just a sleep system but has now evolved into a whole package of 24-hour postural care with a team effort behind it – Rebecca works with her physiotherapist, takes part in a moving to music class, swims, and does physiotherapy exercises. Simple things like stroking the dog and just generally keeping her arms moving also help.

“We've seen huge improvements in Rebecca's body shape and health which we never thought we would achieve.”

Rebecca's parents

Milly's story

Milly is 10 and has cerebral palsy. She lives at home with one-to-one support.



“I knew her life was being affected by her posture as she could no longer use her standing frame and she was very uncomfortable because of her rotating hip. But I didn't really know anything about postural care or why it was important.

“Then, about a year ago, I attended a postural care awareness course which was a complete eye-opener for me. I saw for myself how badly a person's body can become distorted and realised that it could be prevented.

“I had already been given a sleep system and even been told how to use it, but I was afraid to do so.

“Now, having done the course, I understand what I'm doing and feel motivated to carry on.

“Milly is progressing very quickly with her range of movement. She enjoys going on roller coaster rides and horse riding, and is free from pain.”

Milly's mum

What postural care services are needed?

The commissioning of postural care services should be a key part of the local strategy to meet health needs. The following should be provided:

Information

There needs to be good information available for families about local postural care and training services.

Training

Postural care is a simple, practical approach but it is not intuitive, so professionals and families must get the information and training they need to do it properly and safely.

Postural care pathway

There needs to be a clear postural care pathway in place, which involves professionals and families working together to support someone's posture.

A postural care pathway will involve:

- early identification of people who have, or are likely to develop, postural care needs
- assessment using measurements of body symmetry
- training for all involved
- developing a postural care plan for the individual and getting the right equipment
- ongoing monitoring and reviewing of the support needed.

Funding for equipment

There must be funding available to enable people to get the equipment they need – for example, a sleep system.



Make postural care a priority!

Postural care should be an integral part of the healthcare that a person with multiple disabilities receives. It is something all health professionals working with people with multiple disabilities should be thinking about.

Annual health checks should include checks for postural care needs, and the support a person needs to protect their body shape should also be outlined in their health action plan.



How it can be done: the Wakefield case study

“My manager went on a postural care awareness course and realised this is what we needed in our area. Previously we didn’t have the money for basic equipment and staff felt they weren’t able to provide the level of postural care needed.

“The business case was put forward for equipment, training and more staff and we got the funding.

“We started measuring with basic equipment and we did hip audits to identify the children at risk. We also started awareness training for parents. We have good working relationships with, and support from, our orthopaedic consultants and started running joint paediatric orthopaedic clinics in special schools.

“We have now established a postural care pathway that starts with the early identification of children at risk. It’s a robust way of ensuring families have everything they need to look after their child’s posture. Annual measurements show us how things are going, but if people are worried we can take them more often. Families know they can come to us if they think things aren’t right so we can work together to solve problems.”

Physiotherapist, Wakefield

“It’s a joint approach between physiotherapy and occupational therapy and means both teams can do a postural care assessment. We also talk to schools and whoever else is seeing the child – so it’s a holistic approach.

“We really wanted a service that focused on early intervention and prevention to maintain a person’s health for as long as possible. The evidence suggests that everything we have put in place is working, as we have had no new hip dislocations in our area this year.



“Therapy services are an easy ‘soft target’ to cut, but the more expensive services might not be needed as much if you get the prevention side right.

“The most important thing we’ve learnt is that families, agencies and professionals need access to training and knowledge and to work together to enable consistent, good-quality 24-hour postural care.”

Commissioner, Wakefield

For more information

Watch our film about postural care and download this booklet and a PowerPoint presentation at www.mencap.org.uk/posturalcare

Order free copies of this booklet and the film at publications@mencap.org.uk
Call: 020 7696 6900

Contact Postural Care Skills, part of the Postural Care Action Group. Postural Care Skills gives advice about postural care and runs awareness courses and accredited training for families and professionals throughout the UK.

Go to www.posturalcareskills.com
Email info@posturalcareskills.com

Contact PAMIS, part of the Postural Care Action Group. PAMIS gives advice about postural care in Scotland.

Go to www.pamis.org.uk
Email pamis@dundee.ac.uk

Take action!

If you are concerned that not enough is being done to develop appropriate postural care services in your area, there are things you can do to help:

- Work with your learning disability partnership board to make sure your local health strategy includes plans for postural care services.
- Show this booklet and the film to health professionals and commissioners and ask them what they are doing to address the issue.
- Visit or write to your local MP and show them this booklet and our film. Ask them to write to the person responsible for commissioning health services.
- Tell us, and we will also write to your local health commissioner, explaining why postural care services need to be a priority.

Email campaigns@mencap.org.uk
Call 020 7696 5613

Postural Care Action Group

The Postural Care Action Group is a group of organisations and individuals working to raise awareness about the importance of protecting body shape. It includes:

Organisations:



Individuals:

Janet Cobb, independent consultant

Elspeth Dixon, parent, and learning disability specialist physiotherapist

John and Liz Goldsmith

Bas Jansen, physiotherapist

Mike and Julie Ormian, family carers

Rebecca Ormian, PMLD champion