



FOUNDATION Making the Difference for Local Sick Children



# A Guide to 24 Hour Postural Management

For families and carers of children with complex physical needs

### Contact details for your Child Development Team

affix contact details label

#### Introduction

Children with motor disorders, for example Cerebral Palsy (CP), who are limited in their activity are at risk of developing postural problems which could include hip dislocation and/or spinal deformities. These in turn can lead to pain and discomfort as well as difficulties with breathing, digestion, eating, drinking and swallowing.

By using 24 hour postural management you will be helping to prevent or reduce the impact of these difficulties.

Postural management when introduced at an early age can help to protect and maintain body shape by the use of careful positioning and by encouraging physical activity.





### What is 24 Hour Postural Management?

Postural management (PM) is a programme of activity and controlled positioning which manages a child's posture. It enables a child to be comfortable in a sitting, lying, standing or moving position. Children who are comfortable are more able to learn and carry out normal daily activities<sup>1</sup>.

Programmes are specifically tailored to meet each child's individual needs and may include special seating, wheelchairs, night-time support, standing supports, functional activities, active exercise, orthotics, surgical interventions and individual therapy sessions.

To be effective postural management is applied throughout the day and night. Your therapists will provide support and guidance to help you incorporate this into your daily routine.

#### Why is 24 Hour Postural Management needed?

Children who have difficulty moving and who are unable to sit, stand or walk by themselves are at risk of developing complications of the muscles and joints in the body.

If left unchecked this can lead to reduced activity due to pain, structural changes, breathing and digestive difficulties and the possible need for surgery.

There is also the additional risk of pressure sores, tissue damage and poor circulation.



#### **Factors Affecting Posture**

Low tone - this is when the muscles are "floppy" and more effort is required by the child to support their head and body in an upright position.

High tone (spasticity) - this is when there is increased tension in the muscles. Over time this can cause shortening in muscles and ligaments with a resulting loss in joint range, movement and functional ability.



# When to Introduce 24 Hour Postural Management

Ideally, at a developmentally appropriate age:

- Lying support, including nighttime positioning - if the child is not able to lie symmetrically by the age of 3 months.
- Supportive seating if the child has not developed a degree of postural control in sitting by the age of 6 months.
- Standing support if the child is unable to stand symmetrically by the age of 12 months.
- Early intervention is key to establishing more normal patterns of active movement in order to prevent deformities.





# Possible Benefits of 24 Hour Postural Management

- Improves functional ability.
- Facilitates safe eating and drinking.
- Aids communication / social interaction.
- Enables access to environments and learning opportunities.
- Reduces fatigue.
- Improves attention and concentration.
- Promotes the development of normal movement patterns.
- Encourages active movement to maintain muscle length.
- Maintains bone and joint alignment to reduce the progression of deformity / body distortion.
- Helps maintain bone strength.
- Manages pressure.
- Enormous health benefits occur due to the positive impact on the autonomic nervous system functions such as breathing, swallowing, digestion, cardiac function and circulation.

### Hip Displacement / Scoliosis

Children with postural difficulties are at increased risk of hip displacement. This can lead to pain, loss of movement and function especially if the hip dislocates.

Normal Hip

In this X-ray, the child's right hip is dislocating.

Children may also develop curvature of the spine (scoliosis). The curvature will increase as the child grows and may lead to a significant scoliosis especially during puberty. Keeping children well supported in a comfortable position can then become increasingly difficult.

#### Dislocated Hip

Spinal Scoliosis

CPIPS

#### **Use of equipment**

Postural equipment complements therapy programmes by supporting children in a symmetrical posture where a passive stretch is applied to the muscles over a period of time.

When well positioned, children are more able to participate in activities.

They may be more able to communicate and make choices thus improving their overall quality of life.

Good positioning also promotes safe swallowing to reduce aspiration and resulting chest infections.

By incorporating your child's equipment into your daily activities it will be easier to establish a routine. For example, seating may be used at mealtimes or for fine motor play. Your child may enjoy being in their stander for messy play, to watch their favourite TV programme or to help in the kitchen with mixing or washing the dishes.



#### What parents have said about their child's equipment



"Equipment seems daunting to begin with however in the long term it is a huge benefit to us as a family as well as our child."

> "It is 'prescribed' - like medication would be."

# Parent Stories...



#### **Matthew**

'We were first introduced to posture management for Matthew when he was around 7 months old. Until then we had been trying to sit him on our knee or sit him slouched in a high chair to feed him which was neither easy for us, or comfortable or safe for him. The first piece of equipment Matthew was given was his chair.

It instantly changed our daily life. Matthew was now fully supported and comfortable which immediately improved his mood. He clearly felt more secure and content and it gave him more energy to focus on eating or playing. We now have various pieces of equipment for Matthew, which have grown and changed as he has.

The different pieces allow us to make sure he is properly supported and in a good and safe position for 24 hours a day. Since having his posture management in place, we have found moving and handling a lot easier, interacting with him a lot easier and also feeding and trying to play with Matthew is much easier when he is standing up, or sitting in his chair because we can look right at him and both hands free to help and guide him with his hands or with his looking.

As his parents, we want to see Matthew in a good position and we know how important it is to try and avoid future health problems as much as possible. It also allows Matthew to experience his surroundings and be included and involved with what's going on in a room. It gives us a bit of normality!'

Mel & Luke, Parents of Matthew

# Parent Stories...



### Shaun

'When Shaun was little it took a while until we were given a diagnosis. He had a buggy and a tumbleforms seat but no information was given about postural management or the risks of hip dislocation and scoliosis. The physiotherapist would see Shaun at school and would work on activities to help him sit and stand.

Over the years, Shaun had several operations on his hips though it was never explained what these were for. Shaun continued to use a stander and walker at school with a comfy seat to relax in at home.

We had to stop using his stander when his hip became painful. He needed more surgery to remove the top of his thigh bone as his hip had dislocated. It would have been good to know at an earlier age about the increased risk of hip dislocation and the pain this could cause.

Shaun is 25 now and attends a day centre where there are limited opportunities to change his position. We still have to be aware of his posture. He is not able to tell us when he is sore but he starts to push up off his hip when he is uncomfortable. Then we know to lie him down on bed to give him a stretch. When he has had periods when he is in pain his mood changes and eating and drinking become more difficult.

We are very lucky that Shaun has such a laid back temperament; this made it easier to look after him. Now he is a much happier person and is mostly free from pain in his hips.

Shaun grew up at the wrong time when there was little information shared about postural management.

Lobraine, Shaun's mum

# Parent / Carer Responsibilities

As postural management is a 24 hour approach some parents can find this overwhelming especially in the early years.

Your Physiotherapist, Occupational Therapist and Speech and Language Therapist will work with you to explain and identify the appropriate equipment to meet your child's postural needs and give you guidance to enable your child's programme to be specifically tailored for you and your family.

You will be provided with a postural management plan with pictures of your child explaining how to use their equipment. This will include the best positions for day to day activities like eating and drinking, play, sleeping, bathing, showering and hoisting (if applicable).

You will be responsible for the day to day maintenance of equipment - ensuring equipment is clean and safe, e.g. screws / bolts checked regularly. You should report any damage or repairs to your local therapist or the occupational therapy store.

Correct moving and handling techniques are important when using postural management equipment to help position your child safely and reduce the risk of injury to yourself.



# 24 Hour Postural Management Training

Families and the team around the child need to be given the right information, support and training to ensure that they are able to apply effective postural management to the person that they are caring for.

Training for parents and carers is essential to allow 24 hour postural management to be effective.

Parents who have previously attended the 24 Hour Postural Management Course have said:



The earlier the intervention, the better – but it is **NEVER TOO LATE** to start protecting and restoring someone's body shape. (MENCAP 2011)<sup>2</sup>

## References

- 1. Gericke, T (2006) Postural management for children with cerebral palsy: Consensus statement. Development medicine and child neurology. Vol 48 (4), p244.
- 2. MENCAP Postural Care Action Group (2011), Postural Care: Protecting and Restoring Body Shape, London, MENCAP.

## **Bibliography**

- 1. Northwest Group of Paediatric Physiotherapists and Children's Occupational Therapists (2007) Good practice Guidelines to 24-Hour Postural Management (draft). Manchester: NHS Manchester.
- 2. Greater Glasgow and Clyde group of Allied health Professionals (2009) Guidance on "Good Practice" for the provision of 24 Hour Postural Management. Glasgow: NHS Greater Glasgow and Clyde.
- 3. Postural Care: A Guide to 24 Hour Postural Management for Family Carers (2014) NHS Lanarkshire & PAMIS.



Parent/carer workshops are available, please contact your local Child Development Team therapists.

# For moving and handling advice:

A Carers guide to safer moving and handling of people

Produced and available from Back Care The Charity for Healthier Backs or www.backcare.org.uk





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