

NEW WRITING

Postural Care Provision – Current policies and objectives

Anna Goldsmith



Anna joined PCSP (UK) Ltd in 2006 to co-ordinate the company's bid to become a Nationally Approved Centre for the Open College Network. Having successfully gained this status for the company Anna began training as a

Postural Care tutor. Anna has spoken at national and international events promoting the importance of Postural Care. She has acted as a consultant to the Department of Health's Valuing People Support Team to advocate for the adoption of person-centred approaches such as Postural Care provision.

Summary

Postural Care, otherwise known as Protection of Body Shape is a fundamental unmet health need for people with a movement difficulty. This article will discuss current service provision and how it can be seen to be failing many individuals and their families. It will also discuss the moral and legal reasons why investment in self-advocates, families, Personal Assistants and those within an individual's first circle of support, is the only way to ensure that we protect body shape, muscle tone, and most importantly, quality of life for individuals with a movement difficulty.

Introduction

If we do not give families and Personal Assistants (PAs) the skills they need to self-manage Postural Care we expose individuals to risks which can be guarded against. Distortion of body shape can cause pain, suffering, and ultimately, premature death for individuals with a movement difficulty and we have a legal and moral duty to ensure that this does not happen. With the full consent and approval of both the individual who may need Postural Care and their family, simple steps can be taken to address body shape distortion.

The effects of leaving the body unprotected are known to be predictable and avoidable.¹ Under such circumstances we must anxiously examine whether the services we are currently offering are effective in protecting body shape, and if not, we need to address this.² It must also be noted that acknowledging some services may require development is in no way a reflection on current hard-working staff.

Currently, a service-centred approach dominates provision which has meant that investment in families and PAs has been limited. When a person begins to show signs of body shape distortion the most common treatments offered are invasive interventions such as stretching, splinting, serial casting, surgery and medication.³ These are very expensive, often

dangerous and upsetting for everyone who is involved with a person's care and, if not offered within the context of a robust Postural Care Pathway, are highly unlikely to be effective.⁴ A Postural Care Pathway must be family-led and take into account the whole 24 hours of the day in order to be effective.

The Audit Commission 2003 Review of Services for Disabled Children⁵ found:

... a lottery of provision, dependent on where people live, and how hard they can push for the services they need; too little being provided, too late, with long waits for information, equipment and treatment; a maze of services, that frustrates and confuses families; and pockets of good and innovative practice, and service champions.

Coleen Annette's story below reveals some of the most common interventions which are offered for body shape distortion along with some costs. Coleen's family used night-time positioning and they are very proud of how they improved Coleen's body shape, muscle tone and quality of life.

Coleen Annette's Story

Coleen was 6 years old when she first began using night-time positioning. At this age she had already developed severe asymmetry of body shape. Coleen was hospitalised regularly due to severe chest infections, she had very high muscle tone and her hips were at risk of dislocation. She was offered surgery and expensive medication to control her muscle tone. Her family were very worried about the future.



Coleen's unsupported lying position

Coleen was at risk of needing all of the interventions listed below. Many had already been offered to her family. On average the costs are as follows:

- Hip surgery: £5000 - £8000
- Spinal surgery: £16,000 - £24,000
- Dysphagia (choking difficulties) along with surgery to insert a tube into the stomach to feed people: £2000
- Intrathecal Baclofen pump (a device which releases medication into the spine to reduce muscle tone): £3000
- Ongoing medications: £5000 per year
- Hospital admissions: £300 per night
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As the photograph below shows, complex equipment is not always necessary to make a huge difference to someone's life. Coleen's family had the right information and they used their imagination to achieve incredible results for Coleen. Coleen's muscle tone reduced, she was admitted to hospital fewer times for chest infections and she was much more comfortable. She did not need surgery on her hips or spine, she did not need medication for her muscle tone and she spent much more time at home with her family than in hospital. Very sadly Coleen passed away in 2005 but her family are very proud that they were able to reduce Coleen's muscle tone and improve her quality of life with Postural Care.



Coleen's family used household items to support her

Postural Care

Some of the common interventions, listed above, which were offered to Coleen may not be

offered in some areas of the country and, obviously, not every person may need all of these interventions. However, the costs given illustrate just how expensive body shape distortion is to correct. The current practice of investing in invasive interventions without first investing in families to enable them to carry out gentle, respectful, conservative measures is logically and morally indefensible. By investing in families to self-manage Postural Care we will reduce body shape distortion and reduce costs by making acceptance of this condition a thing of the past. Most importantly, we will reduce the negative impact on a person's quality of life by reducing the need for these interventions.

Families are the key to Postural Care but effective Postural Care has been hindered because investment has been made mainly in buildings, services and invasive practices rather than in families. Families must be in control, and have the choice to make their own decisions. Because the most skilled and motivated people involved are usually the parents and/or siblings, an investment in families is economically sensible and liberates a massive untapped resource. The principles of Postural Care are not intuitive so effective training must include a structured approach to qualifying families in the following topics:

1. Why the body distorts and how to measure and protect it.
2. Analysing pain-related behaviours.
3. Saying 'no' to such abusive practice as restraint and respecting consent of all the individuals involved with night-time positioning.
4. Analysing risk and benefit so that families can make their own decisions.
5. How, because spasticity is a spinal reflex, symmetry around the spine reduces tone.
6. Behavioural complexities, physical dangers and disturbances of sleep in those with movement impairment.
7. Monitoring core temperature of individuals when they may not have the ability to regulate their own temperature.
8. Acquiring, improvising and using equipment. This includes specialist equipment such as wheelchairs and household equipment – such as teddy bears!

Acquiring the right equipment

Alongside current treatment plans we must also consider the effects of equipment acquisition on individuals and their families. Effective Postural Care will often require a specialist wheelchair, alternative seating, and sometimes specialist night-time positioning equipment.

The 'UN Convention on the rights of the child' (1989) is designed to protect both children and adults from inappropriate equipment provision yet recent reports, such as the BDF Newlife report, '*It's not too much to ask*'⁶ highlight that many people are being failed with ill-fitting equipment, long waiting lists and inappropriate training. It reported:

Most people would assume that disabled and terminally ill children are protected and provided for under established laws, using the taxes we pay into our welfare state system. But we believe this is far from reality for the majority of children in the UK.

A report from Barnardos and Whizz-Kids⁷ reported on wheelchair provision as follows:

Despite a policy and legislative framework that supports better mobility provision, and evidence of the importance of mobility in a child's development, the experience of many disabled children is that the NHS does not provide them with a wheelchair that meets their needs.

The correct, fitted equipment will benefit all children and adults with movement difficulties to protect body shape but these reports highlight the difficulties that families and individuals face to get the right equipment.

Conclusion

Postural care reduces the need for hospitalisation and the cost, risk, pain and distress involved in surgery and invasive interventions. By enabling families to self-manage this approach we will be upholding current government agendas, such as the 2006 Department of Health report on Self-Care and demonstrating adherence to the Disability Equality Duty. The 2006 report on Self-Care claimed that '*There is a need for wholesale change in the way services think, train and design/deliver services*'.⁸ If we can acknowledge that current medical models are not effective at protecting

body shape we can begin to think about alternative models of practice which involve expert families. Quality assured, nationally approved training such as that offered by PCSP (UK) needs to be available to families if we want to protect body shape, muscle tone, and quality of life for those individuals with a movement difficulty.

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