



Public Health
England

Protecting and improving the nation's health

Making reasonable adjustments to postural care services

Making reasonable adjustments to postural care services

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

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Easy-read summary



Posture is about how people sit, lie, stand and move.

Your posture will affect your body shape.

Postural care is important when people can't move their bodies very well.

It is about looking after someone's body shape.



People need postural care during the day and during the night.

People may need help to sit well or stand well during the day.



Night positioning systems can be used to help look after someone's body shape at night.

They can also be used to support someone when they are lying down during the day.

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The law says public services should put 'reasonable adjustments' in place to help people with learning disabilities use services.

This means they need to change their services so they are easier to use.



This report has examples of easy-read information and films about postural care.

These can be used to help improve postural care for people with learning disabilities.



This report has good practice examples of how local areas have set up postural care services.

There are also case studies about how individuals have been helped to have better postural care.

Most of the pictures in this report are from Photosymbols (www.photosymbols.co.uk)

The other photos have been shared with us by family carers.

Introduction

This guidance is to help health and social care professionals and family carers and supporters learn more about how to support the postural care needs of people with learning disabilities who are at risk of body distortion.

Under the Equalities Act 2010,¹ public sector organisations have to make changes in their approach or provision to ensure that services are accessible to disabled people as well as everybody else. This report is the 16th in a series of reports looking at reasonable adjustments in a specific service area (see Appendix A). The aim of these reports is to share information, ideas and good practice in relation to the provision of reasonable adjustments.

We searched for policy, guidelines and research that relate to postural care for people with learning disabilities. A summary of this information is below. We put a request out through a range of networks for people interested in services and care for people with learning disabilities. We asked people to send us information about what they have done to support people with learning disabilities who have postural care needs.

This report sets out what we found and describes the online resources we found and where you can access them. This is followed by a selection of case studies about how postural care services have been developed and how individuals have been supported to get good postural care.

We would like to thank everyone who shared expertise, resources and contributed examples from practice to this report.

Postural care and people with learning disabilities

What is postural care?

Postural care refers to an approach that aims to preserve and restore body shape and muscle tone for people with movement difficulties. People with profound and multiple learning disabilities often sit and lie in limited positions, leading to a high risk of body shape distortion. This is not inevitable. The right equipment and positioning techniques can help to protect body shape in people with movement difficulties.

Postural care addresses all body positions that an individual adopts over the day and it usually involves a personalised 24 hour programme that includes:²

- provision of adaptive seating
- positioning equipment to support the person in lying, including at night time
- moving and handling techniques
- advice and training for family carers and professionals across all settings

A recent systematic literature review did not find any studies looking at the numbers of people with learning disabilities likely to need postural care.³ This would be useful information for those commissioning services for this group. However, the number of people with profound and multiple learning disabilities can be used as an approximation. In 2009 this was estimated to be just over 16,000 adults and this figure is expected to rise until 2026. There is more recent data available relating to children and in 2014/15 it was estimated there were over 10,000 children with profound and multiple learning disabilities in England.

National guidance and reports

Two national reports have highlighted the gap in services to protect body shape for people with profound and multiple learning disabilities.^{4,5} It was noted that early intervention can prevent the need for surgery and it was recommended that NHS bodies should provide a service that recognises postural care issues and addresses them effectively.

In 2012 NICE recognised the clinical efficacy of body shape protection in their guidance about managing spasticity in children and young people.⁶ They stated the need for a 24-hour postural care management programme that includes assessment of the postural needs of a child or young person when they are asleep or resting. The guidance also

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recognised the importance of training and support of family members or carers as part of effective postural care.

The Confidential Inquiry into Premature Deaths of people with learning disabilities (CIPOLD) established the link between a failure to protect body shape and resultant premature death.⁷ It recommended that Clinical Commissioning Groups (CCGs) should ensure they commission expert, preventative services including proactive postural care support.

Why is this an important issue?

There are physical, psychological and emotional effects of body shape distortion and poor postural care can have severe and life-threatening consequences. In someone with movement difficulties, failure to provide postural care will lead to the person regularly adopting their preferred sitting and sleeping positions. Over time, due to a lack of movement and the effects of gravity, highly predictable body shape changes develop which eventually mean they cannot move out of their preferred position.⁸ Their body shape will continue to deteriorate, resulting in health problems, pain, increased equipment needs and greater dependence.

Respiratory problems are the main reason people with profound and multiple learning disabilities need primary or secondary medical care and pneumonia is the most common cause of death in this group.⁷ Some of the risk factors for respiratory problems that can be reduced by good postural management are:

- airway clearance dysfunction
- saliva management difficulties
- immobility
- reflux
- sleep disordered breathing
- thoracic deformity

Other physical health problems associated with body shape distortion include:⁸

- problems with the musculoskeletal system, such as hip dislocation, contractures, curvature of the spine and reduced movement
- difficulties in swallowing and risk of choking
- constipation
- pressure on internal organs
- recurrent pressure sores

Such complications will cause discomfort and possibly severe pain. They will certainly have a negative impact on someone's quality of life and can lead to emotional and psychological problems including:

- fatigue

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- depression
- isolation
- feelings of helplessness

The Mencap booklet *Postural care: protecting and restoring body shape* and accompanying videos (see resource tables for links) share family stories about the range of problems faced by people with body distortion.

What are the benefits of postural care?

Provision of 24-hour postural care reduces health risks and improves quality of life for individuals. It can also benefit those caring for the person. Evaluation after the first year of an occupational therapy postural management service showed a positive impact for both patients and carers.² For people receiving the postural care these included:

- improvement in quality of life
- improved daily functioning and participation
- increased comfort
- reduced agitation and less disruptive behaviour
- reduced muscle tone
- improved overall positioning

The benefits reported by family carers and paid support staff were:

- greater understanding of postural issues and positioning
- reduced stress
- easier to assist with basic activities of daily living
- more consistent approach for staff

Person centred outcomes such as reduction in pain, increased dignity and better sleep are important. However, body symmetry measurements are fundamental to assessing the outcomes of postural care interventions. The Goldsmith Indices of Body Symmetry⁹ can be used to measure:

- degree of rotation of chest
- chest depth width ratio
- wind sweeping index of hips
- right and left hip abduction/external rotation

The Goldsmith Indices of Body Symmetry provide a systematic, objective approach that give clarity as to what is actually happening in terms of the body shape. The measurements are taken when the person is lying down, meaning they are not affected by someone being poorly positioned in a chair or seating system. It is generally expected that children with postural problems will deteriorate over time. Interventions may only slow this deterioration down, rather than stop or reverse it. Therefore maintenance of body symmetry should be viewed as a positive outcome.

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Other objective outcomes that can be used to assess the impact of postural care interventions include the number of hip dislocations.

Although postural care can be an expensive service it does reduce the need for invasive and costly interventions including:⁸

- surgical procedures
- complex equipment for mobility
- adaptation to the home
- enteral feeding
- pain management
- increased need for medications such as Botox or Baclofen

So, in addition to the tangible benefits for individuals and their carers, a postural care service could also be cost effective in the long term.

What are the barriers to good postural care?

Lack of awareness

Research has shown that health and social care practitioners, teachers and short-break/respite carers are often unaware of both the consequences of body shape distortion and the fact that it is avoidable.³ Physiotherapists have an essential role in the implementation of a postural care programme for an individual, but they are reliant on referrals from other professionals. There is a need for greater awareness of postural care needs in members of multidisciplinary teams and better knowledge about why and when they should refer someone for 24-hours postural care.¹⁰

Dysphagia and constipation are some of the health problems that can be caused by or made worse by body shape distortion, yet this link is not always made. Therefore, if someone has constipation/dysphagia and also movement difficulties this should lead to a more holistic approach and a consideration of postural needs, or an appropriate referral for this. Too often the acute needs are addressed rather than the underlying issue of body shape distortion.

A study exploring postural care knowledge in nursing students concluded that the information the students are given is too complex and recommended a broader introduction to postural care needs. The authors proposed that this would help students transfer their university learning to practice in a range of settings.¹¹

Family members caring for someone with profound and multiple learning disabilities will usually have multiple other health needs to address. They may not always recognise postural care as an important issue.¹² There is a need to raise awareness of the

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significance of postural care, especially in view of the fact that body distortion is likely to be contributing to other health problems.

Lack of resources

Even if the problem is recognised, postural care services do not exist in all areas. People with more severe body shape distortion are liable to need specialist services which may not be available locally.¹³

Where services do exist there may still be difficulties in funding the equipment that is needed. Specialist equipment such as wheelchairs, seats and postural support systems is an important aspect of protecting the health of disabled children and the people caring for them.¹⁴ Evaluation of an occupational therapy postural management service found that most of the reasons for dissatisfaction related to waiting times for equipment.² Lack of funding is one of the most common reasons given for lack of night time postural management equipment.³

Challenges in implementing postural care programmes

A survey of physiotherapists reported that family carers often rejected night time positioning systems. Studies have identified a number of reasons why family carers and teaching staff may not participate in postural care management programmes. These include:^{3,12,15}

- negative perceptions about the appearance of specialist seating and standing supports
- lack of understanding of the benefits of postural care
- lack of knowledge and confidence in carrying out the programme
- lack of time and competing priorities
- parents feeling unsupported in the implementation of programmes
- difficulties with practical aspects of using equipment
- lack of relevant ongoing training

There is evidence that when families manage to use night time positioning for a consistent period of time they see benefits, such as their children lying straighter, sleeping better and showing less pain. However parents may need a lot of support when beginning to use night time positioning as a number of difficulties in adopting these have been found:¹⁶

- equipment can be difficult to use and transport
- difficulty in sleeping
- increased repositioning at night
- concerns about discomfort and temperature regulation

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Hospital admissions

Many people with profound and multiple learning disabilities have regular, and sometimes lengthy, stays in hospital. The problems this can cause in terms of body distortion are only anecdotally reported (see case studies).

Generally in hospitals there is no recorded information about positioning and therefore it is not addressed. Hospital passports should include details about how a person needs to be positioned at different times, for example for eating and drinking or at night-time, and all staff need to be aware of these needs.

It can be difficult for people to take their own equipment, such as night positioning systems, into hospital due to problems with space and laundry. The special sheets that some people use are not able to cope with high temperature washes and may not be returned to the correct person. If someone with a postural care programme is admitted to hospital and likely to stay for more than a few days then ideally their physiotherapist should write some temporary guidelines for their stay which may include advice on recreating a positioning system using available materials such as pillows.

This case (provided by a senior physiotherapist) illustrates some of the problems that can occur when an individual with postural care needs is admitted to hospital:

When Simon was admitted to hospital his family took his positioning system in. They were told by hospital staff that it could not be used as it was an infection control risk. However, it later transpired that this information was incorrect. When equipment belongs to one person there should not be any issues around infection control.

Simon's hospital passport flagged his positioning needs but it was not read and he was not being positioned correctly during his admission and spent the majority of his time lying on a flat mattress. Simon ended up in hospital for over three months and in this time his posture deteriorated to the extent that he no longer fitted properly in his moulded wheelchair. It also meant it became more difficult to wash and dress him. He had to start taking painkillers due to the muscle pain and a referral had to be made to the special seating service for adjustments to be made to his moulded wheelchair.

Thus hospital staff need better education regarding positioning. Hospital risk assessments should also address issues of positioning and equipment. If necessary an individual should be referred to the physiotherapy department. If a hospital has a learning disability liaison nurse they could play a role in consideration of positioning for people with postural care needs and ensuring that hospital passports are read and followed.

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If hospitals are going to provide positioning systems then they need to consider issues such as:

- versatility
- noise
- cross infection risks
- impact on temperature regulation of the person using it

There can also be issues for people coming in for out-patient appointments. There is a need for simple, adaptable seating to accommodate body-shape changes in X-ray rooms. If someone is wrongly positioned while an X-ray is taken, this means further discussions will be based on images that do not accurately reflect usual posture. It should be possible for there to be a selection of seat inserts in the X-ray room that radiologists can put into place to support someone correctly during the X-ray.

Lack of consideration of postural care as a safeguarding issue

Despite the fact that a failure to support body shape can lead to serious consequences and even be life-threatening, it is not always viewed as a safeguarding issue. Families have reported respite and short-break settings not using recommended night time positioning systems, and some family carers and supporters view positioning and the use of night time positioning as restrictive. There is a need for more education around the concept of positioning as a method for keeping people safe and comfortable, rather than as something restricting them. Failure to implement someone's positioning routine should be considered a safeguarding issue rather than a treat.

Clayton (2013) makes a series of recommendations about postural care in relation to safeguarding.¹³ These include:

- empowerment - protection of body shape must be viewed as part of a holistic approach to supporting individuals to live fulfilled, pain free lives within their local community close to the people that love them
- prevention - protecting body shape reduces the need for complex care provision enabling people to be supported closer to home

Lack of research

A systematic review of the relevant research literature identified a number of gaps in the evidence base.³ There is an urgent need for evidence about the effectiveness of 24-hour postural care programmes and night-time positioning equipment. This could support the calls for improved specialist services and better funding for equipment, such as night time positioning systems. The existing research does not provide the evidence required by commissioners.

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It would be useful to have studies looking at the potential cost effectiveness of postural care services. This type of specialist service could be cost effective in the long-term but there is no research into this.² A report by Centre for Economics and Business Research proposed that if better provision of equipment resulted in even a modest reduction in the need for surgery and other interventions such as Botox, the costs of the equipment could be recuperated.¹⁴

Commissioning considerations

In order for people to have good postural care there is a requirement for people to have access to services, equipment and training to support the long term management of their body shape.¹⁷ CIPOLD recommended that commissioners acknowledge the need for expert and proactive postural care support.⁷ CCGs should consider investing in postural care interventions to improve quality of life and save money.

There are lots of barriers around the provision of good postural care services, including:

- strict eligibility criteria for wheelchair services, excluding people who need these services
- delays in the provision of equipment meaning that sometimes people are measured for a moulded wheelchair but by time it arrives they have grown or their body shape has changed and it is no longer suitable and may not even be safe
- the range of equipment an individual needs are likely to be provided by different departments or statutory bodies, who may have different commissioning and assessment arrangements
- lack of integration between services and organisations
- lack of knowledge around the demand for services and equipment
- funding not matching demand
- lack of evidence of the outcomes of a good postural care service
- overall lack of accountability for protection of body shape and an acceptance that body shape distortion is inevitable for people with complex disability

What do we know about what works?

There are some published studies about what works in postural care services. A systematic review described the evidence around interventions and reported:³

- research around surgical interventions showed mixed results, as there can be complications from surgery
- case studies into behavioural approaches suggest that using a reward stimulus for holding a posture can lead to people maintaining a therapeutic posture for longer
- appropriate and personalised equipment can result in positive outcomes, for example people show physical and functional benefits from moulded seat inserts in wheelchairs
- positioning can have an impact on communication and oxygen saturation

Night-time positioning

There is some research around the benefits of night-time positioning and the use of sleep-systems. This was reviewed in the NHS Buyer's Guide to *Night-time postural management equipment for children* produced by the Centre for evidence-based purchasing.¹⁸ The guidance concluded that there is a need for more robust and long-term research evidence about 24-hour postural management programmes but cites several studies that are indicative of improvements such as better sleep, reduced pain and benefits for hips. As discussed above, it can be difficult to introduce changes to night-time positioning but with a high level of support and gradual changes it can be done successfully.¹⁶

Training

There is some evidence of the importance, and effectiveness, of training. Evaluation of a postural training programme across seven Primary Care Trusts for health professionals and family members showed positive feedback with participants reporting increased confidence in their skills in relation to postural care.¹⁹

Another study evaluated a training programme developed for parents and school staff.¹⁵ This used a questionnaire to assess knowledge and understanding, concerns and confidence in providing postural care before and after the training as well as focus groups and interviews. One of the positive outcomes of this was parents reporting a greater understanding of the importance of postural care for their child. Additionally school staff reported improved knowledge and understanding about the impact of posture on learning and the child's learning.

There are examples of how training can be effective in the case studies later in this report.

Commissioning

Commissioning postural care services should be a key part of the local strategy to meet the health needs of people with profound and multiple learning disabilities, but as noted above there are challenges. CECOPS CIC (<http://www.cecops.org.uk/>) is the independent standards and certification body for all assistive technology services. They have produced a code of practice for disability equipment, wheelchair and seating services. This covers the commissioning, provision, and clinical and technical aspects of services. It consists of 47 measureable outcomes and some of the benefits of using it are:

- it provides a benchmark for all related services

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- it provides a template for commissioners and providers and a tool for managing contracts
- it addresses problems, such as rigid eligibility criteria
- it promotes integration of services and shows how this can be done
- it promotes a holistic and person-centred approach

This code of practice is a tool that can support commissioners to ensure that people using services get positive outcomes. Commissioners can include requirements in a contract stipulating that suppliers must be accredited to CECOPS or a similar organisation.

Partnership working

Many people will have a role to play in ensuring good postural care for an individual; this could be the escort on the bus, the teaching assistant at school, family carers and supporters as well as health and social care professionals. Partnership working between professionals and those who provide hands on care and support is vital.^{12,13} There are case studies that illustrate this later in the report.

Across the country there are examples of innovative services and practice and some evidence suggesting benefits, although there is a need for more robust evaluation.

These include:

- a postural care pathway in Wakefield (see case study section for further details) – children in this area have equipment provided if needed and their postural symmetry is measured objectively. Since the development of this service there is evidence of a reduced need for surgical interventions, such as hip surgery²⁰
- training for supported living staff which led to an increase in referral rates²¹
- a 24-hour postural care service led by occupational therapists – evaluation after the first year reported very positive feedback from professionals and family carers as well as maintenance or improvement in objective body measurements²

Resources

The two tables that follow list all the information and resources we have found in relation to supporting the postural care needs of people with learning disabilities .

- Table 1 lists websites and resources that may be of use to professionals/family members and carers who want more information and resources
- Table 2 lists the easy-read resources and films we have found. This is where you can find information to use with people with learning disabilities

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Some resources may be available from more than one site, but we have only given one link. We have only included resources that are free to download, although some of the websites may also include resources you can buy.

Table 1: Resources about postural care for professionals/family members and carers

Theme	Description	Provider	Link
Postural care: protecting and restoring body shape	A booklet about what postural care is and why it is important.	Postural care action group and Mencap	https://www.mencap.org.uk/sites/default/files/2016-11/Postural%20Care%20booklet.pdf
Postural care: protecting and restoring body shape	A PowerPoint presentation about what postural care is and why it is important.	Postural care action group and Mencap	https://www.mencap.org.uk/sites/default/files/2016-11/Postural%20care%20presentation.pdf
Postural care - protection of body shape	This 'Learning Byte' provides a brief guide to postural care. It includes stories to illustrate the points and also activities to aid learning.	NHS Education for Scotland and Simple Stuff Works	http://www.nes.scot.nhs.uk/media/3560277/NES%20learning%20byte%20postural%20care.pdf
Postural care: A guide to 24 hour postural management for family carers	Information with case studies about the importance of postural care. It describes how Lanarkshire provides 24 hour postural management plans for those who need this.	PAMIS and NHS Lanarkshire	http://pamis.org.uk/site/uploads/postural-care.pdf
It's My Life! Postural care pathway	This care pathway has been developed to put families and personal assistants in control to self-manage effective postural support for people with impaired movement. The pathway is divided into 5 steps	Simple Stuff Works	https://www.nationalelfservice.net/cms/wp-content/uploads/2014/10/postural-care-pathway.pdf
The economic benefits of better provision of equipment for disabled and terminally ill children	A report on the potential benefits of an improvement in the availability of equipment for disabled and terminally ill children	British Healthcare Trades Association and Centre for Economics and Business Research	http://www.bhta.net/sites/default/files/document-upload/BHTA%20paper%20-%20benefits%20of%20better%20provision%20of%20childrens%27%20equipment.pdf
An A to Z of	A guide for Teaching	Canterbury Christ	https://www.kent.ac.uk/chss/d

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Theme	Description	Provider	Link
postural care	Assistants, Educationalists, Children, Young People, Parents and Everyone. This A to Z booklet aims to give basic information and may act as a starting point for discussions with the therapy team, the child's family and others in the school.	Church University	ocs/A-Z_Posture_Booklet-v5c-pages-web.pdf
Postural Care factsheet	A brief factsheet about the principles of postural care and why it is important.	Learning Disabilities Mortality Review (LeDeR) programme	http://www.bristol.ac.uk/media-library/sites/sps/leder/21.%20Postural%20Care.pdf
Got my back!	A booklet that accompanied a conference about postural care called 'Got my back!'. This provides background information as well as desired outcomes from the day	Changing Our Lives	http://www.changingourlives.org/wp-content/uploads/2016/09/Got-My-Back.pdf
Got my back! conference slides	A series of slides from presentations at the Got my back! conference	Changing Our Lives	http://www.changingourlives.org/got-my-back/
Top tips for supporting and meeting the needs of people with profound and multiple learning disabilities	This includes 10 top tips for supporting the postural and mobility needs of people with profound and multiple learning disabilities	NHS Midlands and East	https://www3.northamptonshire.gov.uk/learning-disability-partnership-board/easy-read-info/Documents/PMLD%20ToP%20Tips.pdf
Postural Care Profile	This is a template for a two page postural care profile. It is designed to provide a pictorial overview of postural care recommendations for an individual.	Care Management Group	https://www.ndti.org.uk/uploads/files/Postural_Care_Profile_Template.docx

Table 2: Videos and easy-read information about postural care

Theme	Description	Provider	Link
What is postural care?	A short easy-read leaflet about postural care	PCSP (UK) Ltd	http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/healthy-lifestyles/other/What_Is_Postural_Care1.pdf
Connor's story	A 4 minute film about good postural care	Simple Stuff Works	https://www.youtube.com/watch?v=U-_SlwJ_vgc
Postural care family stories	A 14 minute film where families share their experiences of postural care	Simple Stuff Works	https://www.youtube.com/watch?v=DE78VmZE8a8&t=76s
Postural Care Training Video for Parents & Carers	An 11 minute film (aimed at parents and carers) explaining the need for postural care	Lincolnshire Community Health Services NHS Trust	https://www.youtube.com/watch?v=Z4diyG9QQHY&t=21s
Sarah Clayton talks about postural care	A 13 minute film about the need for postural care, the importance of a personalised approach and the need for objective outcomes	University of Derby	https://www.youtube.com/watch?v=BO_DwjqrEVI
Myth Buster Animation	A 4 minute film addressing some of the myths about postural care	Simple Stuff Works	https://www.youtube.com/watch?v=r2B7qcQkpwE
A simple story: therapy for children with complex needs	A 3 minute film about the need for night-time positioning	Simple Stuff Works	https://www.youtube.com/watch?v=CeWMIltvzgOg
Never too old	A 4 minute film about how postural care issues can be addressed for older adults	Simple Stuff Works	https://www.youtube.com/watch?v=1V0ODuPkrTs
Postural Care	A series of 6 short films covering: What is postural care? Wakefield story Craig's story Millie's story Rebecca's story What needs to happen 22 minutes in total	Mencap	https://www.youtube.com/watch?v=qXZjm1tbs-0&t=3s https://www.youtube.com/watch?v=-4h-xLqO1yg https://www.youtube.com/watch?v=UxJclKH3j0U&t=24s https://www.youtube.com/watch?v=CyhrczpzQ2g&t=1s https://www.youtube.com/watch?v=W4sDRllc_FY&t=4s https://www.youtube.com/watch?v=8PF9zbkDHxg

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Theme	Description	Provider	Link
Postural Care	Series of 7 film segments Introduction What is posture? What causes body shape to change? What is postural care? Sharing knowledge Benefits of 24-hr postural care Credits 34 minutes in total	PAMIS Scotland	https://www.youtube.com/watch?v=Y6_7bNe5ZhU https://www.youtube.com/watch?v=XiVgmzcSrK0 https://www.youtube.com/watch?v=IOoA66qVgQs https://www.youtube.com/watch?v=zAbtSYR302g https://www.youtube.com/watch?v=xF-L8kbPTV4 https://www.youtube.com/watch?v=uFF2iZKhh_Q https://www.youtube.com/watch?v=Ni3bT8a2-sg
Got My Back!	A series of 4 short films covering: General information A poem by Charlie and Kara A lack of postural care after a stroke A vlog about sports 7 minutes in total	Changing Our Lives	https://www.youtube.com/watch?v=W4rvaKpZ1LM https://www.youtube.com/watch?v=ydRQqo5AmyA https://www.youtube.com/watch?v=wskJ3yJqz2s https://www.youtube.com/watch?v=JvsRkR1hIWw
Tommy's Story - 24-hour postural care	A 5 minute film about Tommy's experiences of body distortion and the difference his postural care plan has made	Bas Jansen Disability Services Commission Western Australia	https://www.youtube.com/watch?v=fbmNt4uNeGw
Birmingham's 24 Hour Postural Care Pathway	A 13 minute film about Birmingham Community Healthcare NHS Trust's 24 hour Postural Care Pathway. Their approach is family centred, with input from physiotherapists, sleep system providers and parent carers	Birmingham Community Healthcare NHS Trust	https://www.youtube.com/watch?v=UH5M0_PQfH4
Sensory stories	These three sensory stories have been designed to support the delivery of good postural care. As you move through the story there are cues for your postural	Simple Stuff Works and The Sensory Story Project	https://www.simplestuffworks.com/wp-content/uploads/2016/10/Space-sleepy-sensory-story.pdf https://www.simplestuffworks.com/wp-content/uploads/2016/10/The-Beach-House-a-sleepy-

Theme	Description	Provider	Link
	care night-time routine. There is advice on how to gather or create the sensory stimuli required for the stories.		sensory-story.pdf https://www.simplestuffworks.com/wp-content/uploads/2016/10/Beauty-sleeps-A-sleepy-sensory-story.pdf

Examples of reasonable adjustments and case studies

Below are some examples of where services have worked to make changes to their systems and pathways or to develop resources with the aim of improving outcomes for people with learning disabilities and postural care needs. These include case studies about:

- developing a multidisciplinary postural care service (pages 22-24)
- seeking funding for a postural care service (page 24-25)
- the value of working with families (page 25-27)
- postural management – provider perspectives (pages 27-29)
- using objective outcomes to assess effectiveness of interventions (pages 29-30)
- the importance of training as part of a postural care service (pages 30-32)
- enabling the use of sleep systems in acute hospitals (page 33)
- using sensory stories to aid positioning (page 34)
- working with an individual and her family to introduce a postural care programme (pages 34-35)
- overcoming the challenges of getting the right equipment (pages 35-37)
- enabling successful use of a sleep system in combination with a continuous positive airway pressure (CPAP) machine (pages 37-38)
- the importance of equipment being right for an individual (pages 38-39)
- managing without personalised equipment (page 39-40)
- managing hospital admissions (pages 40-41)
- the impact of a pressure ulcer and how it was successfully treated (pages 41-43)

Developing a multidisciplinary postural care service

The development of a postural care service in Wakefield began in 2004. A business case was put forward for equipment, training and additional staff and the funding for this was provided. The team started measuring body shape with basic equipment and they did hip audits to identify children who were in need of postural care. Since then they

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have established a postural care pathway which provides a robust way of ensuring that children's postural needs are met. One of the key factors to the success of this work is collaborative multidisciplinary team working that is inclusive of families:

- family carers are viewed as crucial to the delivery of good postural care. Training and education is provided and there are also parent support groups. Efficient communication between home and school is vital
- The orthopaedic consultant set up joint paediatric/orthopaedic monthly clinics initially, and these are now run weekly where they are needed, for example in special schools. If surgery is necessary then dates are set together to ensure rehabilitation is available. The present Orthopaedic Consultant is developing a business case for an in-house Botox clinic
- physiotherapists are trained to make non-medical referrals for hip X-rays. They oversee hip surveillance and complete hip audits every two years
- the wheelchair service is set up differently in Wakefield to other areas. Therapists employed by the Acute Trust staff the clinical side of the children's wheelchair service as they know the children, their families and their needs best. Early use of moulded seating systems is available when necessary (for children under a year) and specialist equipment is provided in a timely manner. The wait for an appointment with the specialist seating clinic is less than a month. The therapists work collaboratively with the experienced engineers
- paediatric commissioners have developed strong relationships with commissioners who are very supportive of the postural care work. Commissioners understand the benefits of an early intervention service which focuses on prevention rather than treatment or rehabilitation. The cost benefits of prevention of dislocations and scoliosis are seen through reduced surgical intervention and medication for pain management. This has resulted in increased equipment budgets. The commissioning team have shown their willingness to share their work and experience to support other areas to develop their services
- the Integrated Community Equipment Store have a dedicated paediatric equipment budget and generally children get the equipment they need in a timely manner, including night-time positioning equipment
- special schools have staff who are well trained and their own postural care lead. All children on the postural care pathway have a photographic postural care plan which is followed daily. These plans include the use of standing frames, and frequent changes of position using specialist seating, wedges for lying face down and side lying supports as required
- respite care services receive on-going training and each respite care facility has a qualified, accredited postural care lead who ensures continuity of postural care programmes for children in their setting. They also support parents to use sleep systems with their children

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- the Postural Care Interest Group is a small working group of occupational therapists and physiotherapists from across the Trust. They meet every few months to ensure the sustainability of the postural care service and to explore what else is needed
- the measuring clinics take place in school or at the hospital. All children at risk of body distortion are measured at least yearly using the Goldsmiths Indices. It is critical to protect normal chest dimensions as reduced internal capacity of the abdomen and thorax increase the risk of respiratory disease, constipation and reflux

The success of the work in Wakefield is evidenced by improved physical results seen in the children on the postural care pathway. Additionally, the results from their last audit in 2012 showed that in Wakefield they had no children or young people with complex needs with a dislocated hip (other than one person who moved into the area with existing bilateral hip dislocations). This was in contrast to 24 children with hip dislocations in a nearby comparable area, which does not have the same postural care pathway.

Key to the success of the work has been the holistic approach, with families, agencies and professionals working together to provide good quality 24-hour postural care for those who need it. Many of the team members have been in post for a significant length of time and this has been a crucial factor in enabling the establishment of close working relationships.

For further information please contact Suzanne Carter,
Suzanne.Carter@midyorks.nhs.uk

Seeking funding for a postural care service

In Newcastle Upon Tyne Hospitals Trust the community paediatric team wanted to set up a postural care service. There was not the capacity to provide this service within existing resources, so a band 7 physiotherapist sought funding for this from a Quality and Improvement Fund. She applied for additional support to give dedicated time to set up a postural management service for children with disabilities in Newcastle. More specifically, they requested a band 7 physiotherapist and a band 4 technical instructor for half a day per week for 12 months.

The funding application was extensive and included:

- a summary of the project with a justification for the request
- the aims of the project
- information about the work that had led up to the project
- an outline plan of how the time would be used
- why they had chosen to work with this particular group of children
- how they would evaluate its success

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- how the learning from it would be shared

This application was successful, and the expectations are that following this period this work will be absorbed into business as usual. Newcastle Upon Tyne Hospital's Trust have also requested that the team provide a written report and present the work at the foundation's committee and other relevant conferences to ensure the project is publicised.

For further information, please contact Frances Slowie, f.slowie@nhs.net

The value of working with families

PAMIS is an organisation in Scotland that works solely with people with profound and multiple learning disabilities and their families for a better life. Due to the level of physical disabilities that a number of their families face, body shape distortion is something which is prevalent. One family member attended a training session on postural care for her son's care team and shared her experience with PAMIS and requested that, as an organisation, they support families in a similar situation by offering them the same training opportunity. (Craig's experience and the postural care campaign 2011 <http://pamis.org.uk/site/uploads/pamis-resources-postural-care.pdf>)

Through their Family Support Service, they have supported over 80 families and professionals to attend postural care training run by Postural Care Skills UK/Simple Stuff Works since 2009. Feedback has always been exceptionally positive, with families in particular feeling a range of emotions. One question consistently raised is "why didn't I know about this earlier?"

In 2013, within the NHS Lanarkshire area, PAMIS secured funding to host another workshop for carers to undergo the accreditation aspect of the course and create an information resource for families. To oversee the work a Postural Management Planning Group (PMPG) was created with membership from family carers, PAMIS and physiotherapists (representing Children and Young People and Learning Disability teams). Several families who had completed the 2 day accredited postural care training and felt knowledgeable and confident in supporting their own child's body shape were supported to identify themselves as postural care champions. These carers were, and are, invaluable in sharing their story and experience of postural care.

Due to the success of the initial year funding, they were able to secure a further year, which gave them time to train more families to an accredited level and develop a film/DVD https://www.youtube.com/watch?v=_YC8U9YR92k. Together with the PMPG they oversaw this work but brought on board occupational therapists representing Children & Young People and Learning Disability. They also developed the postural

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care champion's role, helping these particular carers to develop their presentation skills, create presentations and have materials to help them share their story. (Morrison et al, 2016)

Within the NHS Grampian area, the initial family carer had gone on to become a trainer herself, had secured funding through Carers Information Strategy and was working in partnership with a physiotherapist to deliver postural care accredited training to more families and professionals in the area.

Within the NHS Greater Glasgow and Clyde area, they were again successful in applying for funding over two consecutive years to host two postural care training sessions being delivered by Simple Stuff Works.

Despite the success of these local area developments, they recognised there was a need for a co-ordinated consistent Scotland-wide approach with strategic support giving guidance to practitioners on what type of information should be available, when and how it should be shared. PAMIS sought support from the Keys to Life strategy team (Scottish government Learning Disability strategy <https://keystolife.info/>) gaining a small funding grant for 1 year to:

- identify stakeholders
- create partnerships
- develop our postural care champion role
- provide opportunity to create more postural care trainers within Scotland
- create a National Postural Care reference group
- begin to develop a Scottish Postural Care Strategy

Through this, 27 people attended postural care “train the trainer” training from a variety of backgrounds including Allied Health Professionals, early years’ workers, personal assistants and family carers. Having family carers as trainers is incredibly important for several reasons. A co-produced approach to learning and sharing of information is essential for clear messages about body shape protection to be heard. The family carer is empowered in being able to share quality information and their experiences are valued by being recognised as an equal partner.

A good practice example is described below:

A strong commitment from NHS Greater Glasgow and Clyde physiotherapists, both Children and Young People and Community Learning Disability Team, has enabled the area to develop a model of sharing information with families and professionals by seeing postural care champions (family carers) as a key component to their training team.

The Children and Young People team have visited school parent’s evenings to engage directly with families on postural care. Having postural care champions there has had a positive impact on these events as photographs and films of individuals experiences

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can be shared with new families. This has been particularly successful in getting families along to more informative awareness raising sessions

The Community Learning Disability Team has hosted postural care awareness raising sessions within several day centre environments with a postural care champion sharing their experience at each event. On evaluation, the family story always has a positive response demonstrating the impact and benefit in learning directly from family carers.

PAMIS has created a learning hub which is accessible through their website at <http://hub.pamis.org.uk/enrol/index.php?id=9>. This initially developed as a means to support those who completed the postural care trainer training but has been of interest to a wider group of people and will continue to develop.

A range of stakeholders have been interested in joining their National Reference Group. Due to geographical spread and the number of people interested, it has been difficult for this group to create momentum and they are now looking at how best to progress; potentially with a smaller core group and feedback to the larger interested group for comment.

In August 2017, they launched postural care film as a national resource and used this as an opportunity to begin the process of creating a strategy. With support from Scottish Government, a range of NHS Boards and family carers, they have begun the conversation of what a strategy should like, who needs to be involved and what the vision for the future is. The outcome of their discussions has confirmed that a strategy is welcomed and that everyone involved is committed to achieving their aim of stopping body shape distortion.

For further information please contact Michelle Morrison, m.w.morrison@dundee.ac.uk

Postural management – provider perspectives

Hollybank Trust provides residential accommodation in a range of settings for people aged five and over. Most of the people they support have profound and multiple learning disabilities. The physiotherapy department is made up of 3 Physiotherapists and 4 physiotherapy assistants and they take a 24 hour postural management approach.

All new staff working at Hollybank complete a mandatory 4 day induction before they begin work which includes an introduction to postural management delivered by a physiotherapist that covers:

- understanding destructive postures and the effect on the body
- Introduction to the 24 hour postural management approach
- Introduction to the equipment used in 24 hour postural management

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Within each home physiotherapists deliver more specific group training as needed. This can be on broad range of topics but usually the training focuses on postural management or equipment training. Physiotherapists and assistants can deliver one to one training as required.

Each individual at Hollybank has a Care Plan document which holds detailed information on their general care and more detailed information on their postural care needs. Each need has a risk assessment, care plan and information sheet. The information sheet holds instructions on how to use specific equipment and who to contact for repairs. Equipment includes sleep systems, wheelchairs, orthotics and other mobility equipment, standers and walkers.

When new residents come for assessment at Hollybank the equipment they require is included in the costings for the placement. However it can be more difficult to fund new equipment for current residents. Potential routes are the funding authority, self-funding, the exceptional case committee or charitable funding.

Hollybank have found it hard to identify an outcome measure that is suitable for the people they support. Postural assessments are the tool that they find most useful in demonstrating effectiveness, as maintenance of posture is a good outcome. However there is a drive towards demonstrating improvements and so they are currently exploring the use of the Goal Attainment Scale to identify personalised outcome measures.

For further information please contact Megan Gascoigne,
m.gascoigne@hollybanktrust.com

Care Management Group (CMG) is a learning disability provider that specialises in care for people with complex needs. They currently support almost 100 people with profound and multiple learning disabilities across a number of their services. In order to meet their postural needs the organisation has employed an independent physiotherapist to deliver regional training on postural care. They have also provided additional bespoke education which focuses on individual needs.

Other initiatives to help meet the postural care needs of the people they support include:

- detailed Postural Care Protocols/Pictorial Guidelines that sit alongside Moving and Handling Plans
- training for support staff to undertake passive movement exercises (in accordance with robust guidelines)
- commissioning an independent physiotherapist to provide passive movement when it is not appropriate for this to be carried out by support staff

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- hydrotherapy pool sessions (with and without physiotherapist present, but all with a Health Screening and Risk Management Plan in place)
- ongoing support and advice regarding postural care, pressure area care and moving and handling

As training is a vital part of their postural care approach they aim to start offering support staff the OCN accredited Level 2 'Postural Care' module in collaboration with Simple Stuff Works. A number of their staff have completed the Train the Trainer course in order to enable this to be ongoing within the organisation.

Nurses within CMG are currently piloting a postural care profile. This is a quick reference guide to an individual's postural positioning. It will sit alongside the person's hospital passport and give an overview of:

- how to position the person in their wheelchair
- how to position the person in their sleep system
- any signs to look out for that would raise concerns

Table 1 has a copy of the template for this and you can see an anonymised example of a completed profile at https://www.ndti.org.uk/uploads/files/Postural_Care_Profile_-_Example_Anon.pdf

At a strategic level CMG host a quarterly people with profound and multiple learning disabilities forum which has a focus on health care needs, postural care, communication, community participation, social inclusion and engaging in meaningful activities. The forum provides a place to share good practice, develop new initiatives and advocate for people.

CMG are an active part of the working group which is developing a National Postural Care Strategy. The organisation plans to implement a companywide postural care strategy in line with this.

For further information please contact Michael Fullerton, michael.fullerton@cmg.co.uk

Using objective outcomes to assess effectiveness of interventions

The Liverpool Postural Care Pathway (LPCP) is a collaborative multi agency model for children with 24-hour postural care needs. The Goldsmith Indices of Body Symmetry (GloBS) is one of the annual outcome measures that they use to look at how the 24 hour postural care plans are working. This is a set of validated, non-invasive objective measurements of body symmetry (Goldsmith et al, 1992). These measurements are entered into a database along with other data including information about hip x-rays and

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hip migration. Comparison with previous years is used to guide the level and area of postural care intervention provided for individuals.

The effectiveness of the pathway was evaluated by looking at the data on their primary outcome measure, the GloBS. At the time of the evaluation there were 203 children on the Postural Care Pathway. Of these, 127 had at least 2 GloBS measurements and so were included in the evaluation.

For some individuals the changes in their body shape are irreversible and therefore the goal of postural care will be to prevent further distortion, rather than working towards restoration of body shape (Hill and Goldsmith, 2010). Therefore interventions should be viewed as a success if postural problems are slowed down or stopped. The data showed that 84% of people who had night-time positioning equipment showed maintenance or improvement in their body symmetry as measured using the GloBS. For those without equipment, 79% showed maintenance or improvement.

These outcomes demonstrate the effectiveness of the LPCP. Longitudinal analysis of outcomes from people on LPCP is underway; these outcomes include quality of life, hip radiography and hip clinical examinations.

More detailed analysis was undertaken on the data of five children who have complex postural needs and who receive regular support from the Community Respiratory Physiotherapy Service (CRPS). Measurements of their respiratory function and quality of life were compared against GloBS and this was suggestive of a possible trend between significant postural care and respiratory needs. Those whose chest shape symmetry deteriorated had higher reported respiratory symptom scores and/or increased respiratory hospital admissions.

This has led to the introduction of risk screening tools into the pathway in order that they can identify and monitor respiratory needs. They now also work collaboratively with respiratory colleagues.

For further information please contact Joshua Birch, joshua.birch@alderhey.nhs.uk

The importance of training as part of a postural care service

Following participation in a 'Skills for Health Project', along with Postural Care CIC (now part of Simple Stuff Works) the therapy team at Pennine Care NHS Foundation Trust worked to set up a 24 hour postural service, particularly looking at provision of night time equipment. One of the main barriers was to secure funding for night time equipment. Eventually a funding stream through integrated health and social care was established by:

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- raising awareness
- presenting at heads of service sessions
- using outcomes measures such as the Goldsmith indices of body symmetry (AMI)
- introducing informal systems to demonstrate effectiveness

There is now a postural care pathway for night time equipment and all children and young people who need to be on this pathway are (over 40 children). They continue on the postural pathway until they are 19 and this means:

- they are measured annually using the Goldsmith Indices of Body Symmetry
- therapists respond to any noted changes in body shape
- the therapist liaises with the parents and carers and reviews/ updates any night time equipment needs

They have now combined body shape measurements with the new Cerebral Palsy Integrated Pathway Scotland (CPIPS) assessment - a nationwide initiative that is a hip surveillance assessment. The outcomes provide much needed evidence for commissioners that can support the need for continued funding of equipment.

Training has been a vital part of this work in order to ensure that parents, carers, therapists, nurses, education and support staff are equipped with the knowledge and skills necessary to not only to identify any concerns about asymmetrical body shape but also to know how to address it successfully. Training has been provided at different levels:

- accredited courses - since completion of training the postural care tutor has delivered the training promoted in the initial Skills for health project. She has run 2-3 courses a year for the last 6 years, mainly the 2 day Postural Awareness course and also a course in using the Goldsmith Indices of body symmetry assessment tool. Both of these courses are accredited by the Open College Network through an organisation called Simple Stuff Works. All of the Therapy staff within the Trafford Children's department have completed the 2 day course. These courses are open to anyone who wishes to attend and over the last few years they have been funded through the Trust's Learning and Development department, which means anyone who works for Pennine Care can access them at no cost to themselves or their department. The feedback from these has been very encouraging
- other training takes place in an informal way at home visits with families. This has involved using skeletons, balloons and practical examples alongside YouTube videos and PowerPoint presentations. The approach helps ensure parents understand the importance of 24 hour postural care as an integral part of therapy intervention for their child. Involving and training parents and carers in postural care improves the transition process as it equips them with the knowledge they need to raise any future issues and concerns about an individual's posture and body shape
- short information sessions have been delivered for nursing teams and educational staff. Further sessions are planned for the Early Intervention Team and community paediatric consultants

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- peer support has also been an integral part of this programme. A local Postural Care Network group was set up for Physiotherapists and Occupational therapists working in both adult and children's services. This has allowed the sharing of best practice, such as postural pathways, assessments and outcome measures. This culminated in the Network group presenting at the Association of Paediatric Physiotherapists Specialists Interest group, again promoting how to set up and move forwards with postural care
- often therapists will come for an informal visit to the department to see the set-up of the service with a view to implementing a similar service

For further information please contact Ingrid Stanfield, ingridstanfield@nhs.net

Leeds and York Partnership NHS Foundation Trust identified that following restructuring of the physiotherapy service there were problems with postural care for people with learning disabilities living in their supported living services. The change in the referral system meant that supporters had to notice the issue and make an appropriate referral. Subsequently the referral rate dropped and there was an increase in critical incidents that were linked to poor postural care.

The trust seconded a senior physiotherapist to work for six months across its learning disability homes. She was tasked with increasing the postural management skills of the staff teams. As her workload was dedicated to this work she was able to spend time in the homes in order to learn more about them which enabled her to tailor the training package she developed. This was delivered to all staff in the supported living service (133 in total).

Following the training the staff members showed increased awareness of the postural needs of the people they supported and this was evident in the threefold increase in referrals to the specialist service. They also set up a system of postural care champions within each home to ensure a continued emphasis on the importance of good postural care.

Support staff are vital to the delivery of good postural care and so there is a need for relevant training for this group. However, there is a high turnover of support staff so this needs to be funded on an ongoing basis.

For further information please contact Rebecca Vickers, r.vickers@nhs.net

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Enabling the use of sleep systems in acute hospitals

In Derbyshire Healthcare Foundation Trust, the physiotherapists in the Community Learning Disability Team were concerned that when people they supported were admitted to hospital they either had no access to postural care or that equipment often went missing if they took their own sleep systems in. This was particularly unacceptable when the person or their family had paid for the equipment. People who spent lengthy periods in hospital without using their sleep systems had altered shape on discharge often requiring re-moulding for their chairs at a cost. They were sometimes in severe discomfort from not having been supported correctly in bed.

One of the physiotherapists worked with the Learning Disability liaison nurse at the Royal Derby Hospital to put forward a case of need for the hospital to have its own systems available for anyone to use. The hospital agreed to fund 2 full systems. They selected a system which covers most postural needs as you can position someone lying on their back or on their side. The systems consist of:

- a full mattress
- a horse-shoe shaped roll (to go under knees)
- a basic roll (to go between knees)
- 4 medium brackets and 2 large brackets

They then worked with a company that manufacture and supply postural care equipment to re-design their systems so that they would meet the stringent Infection Control regulations. These regulations require all equipment to have sealed seams so fluids cannot penetrate and anything that has to go for laundry has to be able to cope with exceptionally high temperatures. For this reason the hospital decided to use normal hospital cotton sheets, rather than the stretchy sheets provided. They acknowledge this is not ideal but feel it is a good compromise. These systems are now available for sale to people needing to meet this standard of Infection Control.

The physiotherapist and liaison nurse devised a form for people to describe how a patient should be positioned and request the equipment needed. They also ran training sessions for the physiotherapists and occupational therapists working on the wards as they over-see postural care and can pass on information to the nursing staff.

The systems have been a success, as people now have access to postural support while they are in hospital. These systems were originally requested for adults with a learning disability but they have been used in Paediatrics, neurology, head injury and on the elderly care wards. They are reported as being particularly useful for older people who may have some confusion, as the feeling of being “held” seems to help some people sleep better.

For further information please contact Debbi Cook, Debbi.Cook@derbyshcft.nhs.uk

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Using sensory stories to aid positioning

Sensory stories are a wonderful resource, fun for people of all ages and abilities to share together. A sensory story partners concise text, typically less than ten sentences with rich and relevant sensory experiences that engage the story experiencer. They can be particularly beneficial to individuals with profound and multiple learning disabilities. The narrative aspect of the story can be accessed through the words alone, the stimuli alone, or a combination of both.

Night time positioning is an important aspect of good postural care. Getting used to a new night time position can take time, practice and patience. Supporting someone to learn to lie comfortably on their back can be challenging but there are recognised benefits. Sensory stories can be used to form part of a bed time routine that incorporates good postural care.

Table 2 contains links to three sensory stories designed to support the delivery of good postural care. The stories are designed to be used in conjunction with the postural advice from a therapist. As the narrator moves through the story there are cues for the postural care night-time routine. There is advice on how to gather or create the sensory stimuli needed for the stories. The stories can also be used during the day to help the person practice a new position before this is introduced at night.

For further information please contact Joanna Grace through the website

<http://www.thesensoryprojects.co.uk/home>

The case studies below are examples we have been sent by professionals and family carers. They describe how support was provided to an individual and the types of reasonable adjustments that were made. For reasons of anonymity we have changed some details, such as gender and age of the individuals, and we are not linking these case studies to the services, but we would like to thank the following teams for their contributions:

- Bolton Community Learning Disability Team
- Care Management Group
- Lincolnshire Partnership NHS Foundation Trust
- Merton Team for People with Learning Disabilities and Complex Needs

Working with an individual and her family to introduce a postural care programme

Isobel, a young woman with learning disabilities, dystonic athetoid cerebral palsy and sensory peripheral neuropathy, was referred to her local postural clinic. Isobel had a series of issues with dystonia in her legs. After her right hip dislocated four years previously she had surgical intervention to improve the position of her hip joint. Two

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years after that she also had surgery on her left Achilles tendon to improve her foot position and passive ankle movement. Isobel lives at home with parents and some additional support. She had not been using a postural sleep system and she preferred to sleep on her left side.

Following assessment at the postural clinic it was clear that her current sleeping position was putting a lot of stress on her right hip which had previously dislocated and was at a high risk of doing so again if the side lying position was maintained. A daily home stretching programme was provided for Isobel's arms and legs to improve range of movement and prevent joint stiffness. Although the exercises had to be completed by her family and carers the exercises were adapted to allow Isobel to be as active and involved in them as possible.

Isobel needed to get used to lying on her back in a better postural alignment and to having postural support to prevent her right hip from dislocating and spinal deformity developing. This was a challenge, but she slowly became used to lying on her back. This was achieved with the encouragement of her family and by giving her accessible information about the health risks of her current position. They used animated videos and photographs showing her alignment with and without support to help her understand this. Isobel was followed up and reviewed over the next two years, with the exercise programme and support adjusted as required. This included the introduction of a T roll to help her right hip relax further, allowing the head of the femur to drop into the socket more comfortably. During this time, she was referred for Botox injections into her right hip adductors and hamstrings to reduce muscle tightness, especially at night.

Since having the injections (every 6 months) alongside twice daily stretching exercises she has been able to comfortably sleep through the night and the range of movement in her legs has improved and has continued to improve on each yearly review. Spinal symmetry has slightly improved and chest shape remains conventional.

Isobel continues to be reviewed, as following an Orthopaedic consultation it was agreed that a tendon release procedure for her right inner hip may alleviate her discomfort. Following this procedure there is potential for her sleep system to be adjusted further to help spinal symmetry improve even more.

Isobel's case illustrates the lengthy nature of this sort of intervention. Therapists are often under pressure to discharge a person from a service following treatment and this may not be appropriate when someone needs a long-term intervention.

Overcoming the challenges of getting the right equipment

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The team worked to support a young man in his 20s who had cerebral palsy, dystonia, significant and severe lumbar lordosis and a mild learning disability who lived with his parents and siblings. He had sudden onset of severe hip and back pain. This was causing him significant distress and physical problems. He became fearful of eating and drinking after two episodes of choking and lost a lot of weight and areas of pressure were beginning to become apparent. Due to the pain he was in, he became unable to participate in meaningful activity and his mental health was deteriorating. Being moved was very painful for him and so he wanted to stay in his wheelchair all day which limited personal care and toileting. He was retaining his urine which put him at risk of infection.

He already had a wheelchair and sleep system in place but had not accepted a posturally supportive armchair. It was noted that his family struggle to accept new equipment and he felt more mobile in his wheelchair. However, an assessment showed that the cause of his pain was the amount of time he was spending in his wheelchair, which was negatively impacting on his spinal position.

A holistic approach was taken which included:

- the learning disability nurse and the physio helped him to access GP services for pain management and he was prescribed fentanyl patches
- he was referred to Orthopaedics, the wheelchair clinic, mainstream dietician service and to the learning disability team for nursing and speech and language therapy (SaLT) input
- education and advice was given to him and his family around the importance of positional change and an alternative to his wheelchair
- the OT and the physio arranged a specialist seating assessment and the trial of an appropriate specialist armchair
- the OT and the physio worked with wheelchair services to explain and rectify issues with the chair. This improved his position and therefore decreased his pain
- the OT provided equipment to support him with eating and drinking while in his wheelchair and armchair
- the SaLT carried out a dysphagia assessment to ensure safe eating and drinking (on the same day as the referral). They then gave advice and provided thickener for fluids
- the dietician gave advice and support around appropriate nutritional supplements and fortification of food. This is supported via the learning disability weight clinic

The benefits from the specialist armchair were immediately apparent, as his pain decreased once he was correctly positioned. However, this had been provided on a short-term loan and there was a struggle to get funding. An application to the local CCG via the Effective use of resources team was refused. It was then taken to the Independent Living/Equipment Service and, after a lengthy process, was agreed as a special order based on urgent need. Without this armchair there could potentially have

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been further deterioration of posture, which would have resulted in significantly increased health and social care costs.

The outcomes from this approach are:

- the individual is now pain free
- he can access the community with the support of his personal assistant and participate in meaningful activity
- he is enjoying his food again and slowly gaining weight
- there have been no further choking episodes
- pressure concerns are resolving
- the individual and his family now know more about his condition and are more willing to accept input and equipment that is needed
- they can follow treatment advice which will reduce the risk of this type of episode reoccurring
- the changes in postural management have reduced his pain and currently he does not need orthopaedic intervention – this is expensive and potentially risky
- his level of analgesia is being reduced

The input for this individual has highlighted both the instant and long-term benefits of 24-hour postural management. To achieve this, it was necessary to work collaboratively with the individual, his family and supporters. The greatest barrier to this type of work is the challenge of securing funding – postural management equipment is not considered essential equipment within the Adult service despite the potential financial benefits which can be realised through reduced hospital admissions and pressure ulcer prevention.

Enabling successful use of a sleep system in combination with a continuous positive airway pressure (CPAP) machine

A consultant from the Sleep Clinic requested input from the Physiotherapist and Occupational Therapist from the Community Learning Disabilities Team around optimal positioning for use of a continuous positive airway pressure (CPAP) machine. The referral was for an individual who had severe learning and physical disabilities with complex health needs. When support workers had used the CPAP machine overnight the mask had slipped, resulting in an eye injury. Consequently, the CPAP machine was not now being used overnight.

The therapists reviewed the sleep system and ordered a new component to improve positioning, as well as replacement of some worn parts. This equipment was paid for by Continuing Healthcare (CHC) funding and once it was in place the therapy team set up the new sleep system and provided guidelines for its use and training for support staff. The new system was reviewed prior to CPAP being reintroduced and it was established

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that there were significant improvements for the individual in terms of position and posture.

The Consultant and physiotherapist devised a plan to introduce the use of the CPAP machine gradually, working towards overnight use of it within three months. This involved:

- initially trialling the use of the CPAP with the sleep system at times of day when support staff could closely monitor
- use of a monitoring sheet to record observations and any safety concerns
- regular visits from the therapists to review progress and adjust the sleep system and guidelines as needed

The trial went well and the individual could use the CPAP machine for several hours at a time with minimal intervention from support staff. Waking night support was requested via CHC funding and a joint decision (between therapists, CHC and provider organisation) was made to start using the CPAP machine overnight. This was monitored and the therapists provided further training for support staff as needed. The situation will continue to be reviewed by the therapists as adjustments to the sleep system will be needed due to postural changes over time.

The joint working with therapists, Sleep Clinic Consultant, provider services and CHC Team has resulted in the safe and effective use of the CPAP machine overnight with the sleep system, as the required positioning has been achieved. The nightly use of the sleep system has contributed to maintaining the individual's health and wellbeing.

The importance of equipment being right for an individual

Matthew has a profound and multiple learning disability, cerebral palsy and epilepsy, which is well controlled. Matthew moved into a residential home two years ago and he settled well. Matthew is wheelchair dependent and reliant on others for all his daily care and needs. He is PEG fed and communicates through eye pointing, facial expressions and body language.

Matthew spends most of the day in his wheelchair, apart from time out on his bed with postural support. Prior to his move, Matthew had a moulded seating system mounted on a tilt-in-space wheelchair base. However, this system did not support him well; he was sitting "on" rather than "in" the seat, his legs were scissoring and without the ankle straps secured he migrated down the chair until he was almost out of it. Matthew was then placed on the Postural Care Pathway and following his first clinic assessment a copy of their report was sent to the local wheelchair services in support of a review of his seating.

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Just over six months later Matthew received his new mould, which was an improvement but was still not totally right for him. He was reviewed by the postural care service and they found that Matthew was not weight bearing through either buttock, the seat was too long and did not accommodate his limited right hip flexion. This meant he was not able to sit fully back and was not sitting comfortably. The outcome of the review was an overall deterioration in body symmetry which it was felt was due to the new moulded seat. A copy of the review report was sent to wheelchair services, who reviewed Matthew again and said he should alternate use of his old and new chairs until he got used to the new system. Eventually Matthew attended the wheelchair clinic with the postural care team to try to ensure a better outcome, as by this time he was refusing to go into the new mould and had developed a sore over his right hip. The outcome of this visit was a general agreement that the mould shape was good (length shaved back to allow him to sit into the seat) but it was not soft enough for him. A Foam Carve was then supplied which has memory foam lining to offer extra comfort and protection. The pommel that came with the Foam Carve had to be sent back as it was too wide and hard, causing sores on the inside of his knees, but after being shaved back and covered in a gel, it was gradually reintroduced.

Prior to this intervention Matthew would only tolerate his previous moulded wheelchair for very short periods and became anxious as soon as carers tried to hoist him in. Since the modifications to the pommel his carers have gradually introduced it and he now tolerates it most of the day. His posture is much improved with it in place. Together with the implementation of an exercise programme and the use of bed positioning supports this has led to an all-round improvement in body symmetry and ranges of joint movement.

At his first annual postural care review it was found that Matthew was much more comfortable, able to tolerate being seated for lengths of time with the pommel in place and there was an overall improvement in his body symmetry. He is weight bearing through his bottom, ranges of joint movement have improved and he is sitting fully back in the seat with no pressure problems. His general health has also improved; he has only had one chest infection in recent months and he has gained weight.

This case study demonstrates not only the importance of 24-hour postural care, but highlights how lengthy the whole process can be when working with, and being reliant on, other agencies. In Matthew's case this led to a long delay in him being able to sit comfortably in his wheelchair. This case also shows maintaining someone's posture is a group effort involving the individual, family, carers, equipment providers, therapists and other agencies.

Managing without personalised equipment

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Emma had a full postural control specialised seating system which needed adjusting and this work takes a full day. Emma cannot eat and drink safely without proper support and her mother was concerned about how she would manage without the system. So a Burnett vacuum system was used as a temporary solution. This is pumped up and moulds to the individual's body shape. This provided adequate support for Emma while the adjustments to her full seating system were done.

If there is no access to a Burnett vacuum system then in this type of situation beanbags could be used as an alternative.

Managing hospital admissions

In our experience, even a short stay in hospital can cause Anna major issues for many weeks afterward. During one admission she spent a lot of time on the bed and rubbed her ankles on the sheet. Consequently she got a pressure sore that took some months to heal. This also meant she was not able to use her Ankle Foot Orthoses (AFOs) as these rubbed the pressure sore. This was a nightmare.

Many hospitals do not want wheelchairs in hospital, but Anna now has a hospital admission plan that says she has a physiotherapy plan in place and should be nursed in her postural support wheelchair if possible.

The plan says that Anna needs 24-hour postural management and lists what she has at home:

- standing frame
- wheelchair supportive seating
- comfy chair supportive seating
- orthotics - day and night foot orthoses
- daily exercise programme
- standing transfers with support of 2 support workers and handling belt

During a hospital admission, it is important that as many interventions as possible continue, to prevent her present condition deteriorating or any loss of skills. This is obviously influenced by the medical condition necessitating her admission.

The hospital admission plan notes that it may not be possible for the standing frame or comfy chair to go into hospital but that Anna should sit out in her wheelchair as soon as she is medically able and as much as possible. When she is in the wheelchair she should be wearing her day AFOs. These are solid plastic and keep her ankles to right angles.

If her condition allows then her current exercise programme should be carried out daily. For standing transfers, Anna should be wearing AFOs and the handling belt should be used. This requires two support workers, one on either side with Anna stepping to her left using her strong leg.

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Overnight she should wear her wrist splint and her night-time AFOs, which are lighter than the ones she wears in the day. It is particularly important she wears these at night if she has not been able to stand much in the day as she needs to keep the angle of ankles or she will not be able to stand. In the past a variety of night-time positions have been tried, but with her severe epilepsy Anna has hurt herself during a seizure. Therefore, for Anna it has been decided that if her programme is followed during the day and she wears her splints at night, then she does not need a night positioning system. When she is in hospital she has staff with her at all times and they ensure she is repositioned in the night.

The impact of a pressure ulcer and how it was successfully treated

Oscar has lived in a specialist residential service which supports adults with profound and multiple learning disabilities for 12 years. Oscar has a diagnosis of profound and multiple learning disabilities and has associated complex health needs. He has a scoliosis, a gastrostomy due to a severe dysphagia, gastro-oesophageal reflux disease, ulcerative colitis and obstructive airway disease requiring BiPaP therapy overnight to support breathing and stabilise the airway to prevent the soft tissue from obstructing Oscar's airway.

Almost one year ago, Oscar had a hospital admission for initially a lower respiratory tract infection, which then developed into an inpatient referral for a Gastroenterology Team review for his gastrostomy stoma site that was sore and leaking. Oscar was kept in so they could explore further treatments and during this prolonged hospital stay he developed a grade 4 pressure ulcer on his right hip (see below)



Once home, Oscar had to stay in bed in a left side lying position to promote healing of the pressure ulcer. He was unable to access his chair due to pain and discomfort, but also due to a risk of further pressure damage to his right hip. Recommendations and subsequent guidelines for staff were produced by Oscar's physiotherapist.

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The pressure ulcer caused pain and discomfort so he was prescribed regular analgesia and staff utilised the DisDAT tool to support recognition of the sometimes subtle signs of pain and discomfort.

Being very social but restricted in his bedroom by a physical issue that was beyond his control had huge effects on Oscar; he became very low in mood and withdrawn. A temporary activity plan was designed to facilitate Oscar's engagement from the comfort of his own bedroom.

Oscar had a Community Nurse visit him alternate days to change his dressings. Due to his ulcerative colitis requiring immunosuppressants and recent physical ill-health, the pressure sore was slow to heal. Numerous wound dressings were tried including hydrofibre, seaweed, iodine and honey. As there was slow progress, a dressing technology that provides suction which draws out excess fluid from a wound was used. The dressing helps to prevent bacteria from entering the wound. It also improves blood flow to the wound which helps it to heal. In addition to this, the dietitian prescribed a protein supplement (protein aids the body in repairing damaged tissues). To help improve his nutritional status generally, Oscar had a higher concentrate of feed prescribed, but this was administered at a slower rate to minimise risk of reflux/aspiration.

This combination finally proved successful, and Oscar's pressure ulcer started to show signs of healing. Oscar was able to spend a small fraction of time in his wheelchair; he could come downstairs and socialise more. He even was able to go into the hydrotherapy pool as they had arranged a visit from the Community Nurses just as he came out of the pool to redress his wound.

As Oscar spent so long in bed he had experienced postural changes and so his physiotherapist, alongside the local wheelchair services, reviewed his posture and wheelchair. A pressure map was completed with his old wheelchair cushion, which evidenced pressure loading on his right hip. A new multi-celled air cushion was molded (star cushion) to his new body shape and a repeat pressure map completed evidencing well distributed pressure offering optimal comfort and minimising risk of pressure damage.

Additionally, the physiotherapist completed a measurement of Oscar's body symmetry using the Goldsmith Indices to get a baseline. It is hoped that with increasing periods in his wheelchair and him getting back to sleeping supine with his sleep system, his body posture will improve. Future measurements using the Goldsmith Indices will provide objective evidence of any improvement.

Almost a year after the formation of the grade 4 pressure ulcer, Oscar is now able to spend the majority of the day in his wheelchair (with regular position changes out of his

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chair). He no longer requires a pressure relieving mattress and is back in his sleep system and is able to enjoy being out and about.

Appendix A

Blood tests for people with learning disabilities: making reasonable adjustments.

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