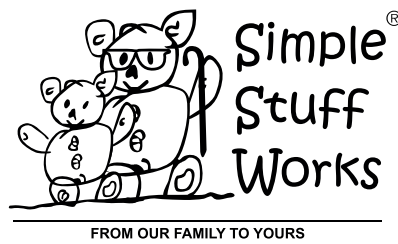


It's My Life!



This Care Pathway puts
families in control to self-manage
Postural Care

Sarah Clayton
John and Liz Goldsmith

Name.....Date of Birth.....

Recorded byDate.....

Where does this pathway of care fit?

The Confidential Inquiry into Premature Death of People with Learning Disabilitiesⁱ was published in March 2013 and is a harrowing read. The team recommended that adults with learning disabilities are “to be considered a high-risk group for deaths from respiratory problems”. They went on to recommend that alongside access to seasonal flu and pneumonia vaccinations “...CCGs must ensure they are commissioning sufficient, and sufficiently expert, preventative services for people with learning disabilities regarding their high risk of respiratory illness. This would include expert, proactive postural care support, aggressive treatment of gastro-oesophageal reflux, the ready availability of speech and language therapists or other suitably qualified nurses able to undertake swallowing assessments, the development of clear clinical pathways for gastrostomy insertion, and the frequent review of patients waiting for a gastrostomy procedure to protect them from risk of aspirating.”

Sir Jonathon Michael’s Enquiry ‘Healthcare for All’ written in response to Mencap’s ‘Death by Indifference’ found:-

“There also appears to be a gap in services for children with profound disabilities and complex needs who have musculoskeletal problems. Early interventions are not undertaken to prevent postural deformities from developing. Many families receive no support or advice about how to manage the sleeping position of their child and the Inquiry heard examples of cases where later wheelchair use and/or back surgery could have been avoided if effective early intervention had been provided.”

It was acknowledged as far back as Valuing People (2001) that “people with learning disabilities may need specialist equipment because they also have a physical disability or sensory impairment”. Inherent in this Care Pathway are the means by which those who are to use the equipment on a daily basis are empowered to make appropriate, meaningful choices.

Transforming Care, with the inclusion of Care and Treatment Reviews are part of NHS England’s commitment to transforming services for people with learning disabilities, autism or both. Services for children and their families have undergone radical reform with the introduction of single Education, Health and Care Plans including personal budgets for the provision of identified need.

Reasonable Adjustment guidance for the provision of postural care is to be published by the Improving Health and Lives Team and can be found here: <https://www.gov.uk/government/publications/postural-care-services-making-reasonable-adjustments/postural-care-and-people-with-learning-disabilities>

New Care Standards have been developed for those supporting individuals with profound and multiple learning disabilities and can be found here <http://www.pmlmlink.org.uk/wp-content/uploads/2017/11/Standards-PMLD-h-web.pdf>

This Pathway recognises that “carers make a vital contribution to the lives of people with learning disabilities, often providing most of the support they need.

Introduction

This care pathway has been developed to put families and personal assistants in control to self-manage effective postural support, pain monitoring / relief and thermal comfort, safely and humanely for people with impaired movement.

Postural Care is gentle, respectful, consistent and effective to protect and restore body shape, muscle tone and quality of life.

Past evidence shows that without postural care people (of any age) who find it hard to move (for any reason) are often left in easily avoidable damaging positions which distort their body.

In terms of safety, failure to provide postural care means exposing people to an obvious risk which could be guarded against

Postural care needs to be reasonably constant day and night (Tardieu 1988) so families and personal assistants are the people who make it happen.

“Given enough information and the chance to talk things over with peers, ordinary people (in this context non-medical people) are more than capable of understanding complex issues and making meaningful choices about them”

The Wisdom of Crowds (2004) James Surowiecki

Body shape distortion seen in previous generations of people with impaired movement shows that the principles of postural care are not intuitive so families and PAs need training, support and equipment to self-manage effective postural care safely and humanely.

The Social Model

In 1976 a seminal article was published (Fulford and Brown) which identified position as a cause of what was then termed “deformity” and called for therapeutic intervention and yet in 2006 many families do not receive either structured training and support or a reliable source of equipment.

Success relies on families’ own daily effort and may entail behavioural change within intimate and emotive aspects of their own private lives, (Goldsmith, S. 2000) therefore this strategy reflects a social rather than a medical model and offers a structure in which families and PAs are supported to control the approach.

Family Led Variance Reporting

Variance reporting is keeping a record of any reasons why the strategy was not able to follow its expected course. It can be useful to code the reasons so it is easier to analyse issues in order to improve care in the future. This process will be led by the person, family

and personal assistants. This is a major factor in putting people in charge of their own solutions.

Inherent in this system is the possibility of variance from the expected course; however the process of families leading risk / benefit analysis and variance reporting forms the foundation of partnership working.

Structure of the Pathway

The Care Pathway Process Map is divided into 5 Steps:-

Step 1

- a) Identifying that a person needs Postural Care
- b) Working out who is involved and how to build relationships

Step 2

- a) Where are we now? Measurement of the person's Body Symmetry using The Goldsmith Indices®
- b) What do we do next? Co-producing a plan with all those involved

Step 3

Is everyone confident and competent to deliver effective Postural Care?
Delivery of the accredited and quality assured Postural Care Award

Step 4

Does the person have access to the equipment they need?
How can access be ensured? PHBs, local services, charitable or private funding

Step 5

Provision of ongoing support including regular Measurement of Body Symmetry using The Goldsmith Indices®

Variance Reporting

Throughout this process the person, their family and those supporting them need to record their successes and difficulties at each step. This will help them to identify potential sources of support and difficulty in the future

The Mansfield Checklist of Need for Postural Care

Any person who finds it difficult to vary and control their position during the day or at night may be in need of postural care,

☒ the box which best describes their situation:-

- | | |
|---|--|
| Is the person limited to a restricted number of positions? | Yes ☐ No ☐ |
| Does the head seem to turn mainly to one side? | Yes ☐ No ☐ |
| Does the body seem to fall sideways? | Yes ☐ No ☐ |
| Do the arms tend to be held in a position in which it is difficult to use them? | Yes ☐ No ☐ |
| Does the body seem to fall forwards or backwards? | Yes ☐ No ☐ |
| Do the knees seem to fall mainly to one side? | Yes ☐ No ☐ |
| Do the knees seem to fall inwards or outwards? | Yes ☐ No ☐ |
| Is the body shape already asymmetric? | Yes ☐ No ☐ |

If there are ticks in the "yes" boxes think carefully about whether _____. needs physical support to protect and restore their body shape, muscle tone and quality of life. Confer with all those involved to decide if being on the Postural Care Pathway would be helpful to them.

Does _____ and those who care for him/her want to be on the Postural Care Pathway?

Yes ☐ No ☐

Signature of Care Coordinator.....

Date.....

The Care Coordinator will be qualified in postural care, they may be the person concerned, a family member, a personal assistant or a professional.

b) Working out who is involved and how to build relationships

If it is agreed that being on the postural care pathway would be helpful, make a list of all the people who will need to help, either directly or indirectly.

Consider all the professionals who can help or who need to be informed that

_____ is on the Postural Care Pathway

Build a trusting, helpful relationship with everyone concerned

Name / Role	Help needed Describe how this person needs to help to make postural care successful	Action Describe what action could be taken to develop a trusting, helpful relationship with this person

Person led Variance Reporting

Describe any factors which have prevented the Postural Care Pathway from taking it's expected course during Step 1

a) Identifying that a person needs Postural Care

b) Working out who is involved and how to build relationships

Step 2

a) Where are we now? Measurement of the person's Body Symmetry using The Goldsmith Indices®

What is it? Who needs it?

Observing symmetry of the margin of the ribs (the costal margin) will be helpful and taking measurements of body symmetry when protecting and restoring body shape is like weighing yourself, when you are on a diet. It tells you where you are starting from so you can work out what you need to do to succeed.

To take the measurements gently, carefully and accurately takes time but it does not hurt.

There are three procedures, called The Goldsmith Indices® of Body Symmetry which have been tested for reliability and validity. (Goldsmith et al 1992, Goldsmith and Hill 2001)

Some or all of the measures can be done, or a bit at a time.

If the individual can communicate they can decide if they wish to have the measurements taken, if they cannot those who care for them and know them best would decide.

An advocate for the person takes part in the Procedures so that person would be in charge.

Would you like to have the measurements taken?

Yes ☐ No ☐ Signature _____

Date _____

Simple Stuff Works offer a nationally recognised, QCF Regulated qualification in Measurement of Body Symmetry. The Qualification Guide can be found here: <http://www.ocnwmr.org.uk/documents/Guides/MOBSGuide.pdf>

The Goldsmith Indices® results sheets can be found here with other relevant information about how the measures are used in different parts of the country: <https://www.simplestuffworks.com/resources/>

b) What do we do next? Co-producing a plan with all those involved

As a result of measuring body symmetry plans can be made as to how the body can be protected and restored by providing postural care. A report about what the measurements mean and what to do on a daily basis is completed. Illustrations are useful to help everyone understand what is needed.

Date of measurements	Date planning report completed

Person led Variance Reporting

Describe any factors which have prevented the Postural Care Pathway from taking it's expected course during Step 2

a) Where are we now? Measurement of the person's Body Symmetry using The Goldsmith Indices®

b) What do we do next? Co-producing a plan with all those involved



Step 3

Is everyone confident and competent to deliver effective Postural Care?

Delivery of the accredited and quality assured Postural Care Award

The Expert Family

In this context the word “Family” is taken to mean the person and those who care for them (adapted from Benner 2001)

“This family has an intuitive grasp of each situation.... Like the chess master they cannot always articulate why they have done something - they might say it just felt right – and this results from plentiful and rich experience in a range of similar situations. Here the family is “unconsciously competent” – care is fluid and seamless and highly effective, and it is delivered seemingly without undue conscious effort.

Benner says that to understand such expertise you have to first look at the knowledge that is embedded in practice. This knowledge was often hidden in the past, because families were poor at articulating it or describing it systematically. This meant that their skill often became invisible: if families are unable to say what it is they do, then others will not recognise their unique contribution”.

Simple Stuff Works offer a nationally recognised, QCF Regulated qualification in Postural Care for families and personal assistants so that their skill can be formalised and their knowledge, competence and confidence to self-manage postural care can be recognised. The Qualification Guide can be found here:

<http://www.ocnwmr.org.uk/documents/Guides/PosturalGuide.pdf>

The Postural Care Award comprises six elements:

- ❶ Identification of Need
How and why the body distorts with identification of destructive postures and conversely the supportive symmetrical postures which protect body shape, muscle tone and quality of life.
- ❷ Pain and Consent
Analysis of pain and non-pain related behaviours, with development of a baseline score so that pain can be monitored / managed and the individual's consent identified and respected.
- ❸ Physical Assessment
Assessment of body shape and muscle tone to analyse risk / benefit of activities and strategies.
- ❹ Therapeutic Positioning at Night
Understanding of behavioural complexities, physical dangers and disturbances of sleep behaviour in those with movement impairment.
Application of therapeutic positioning at night in a safe, humane manner.
- ❺ Achieving thermal comfort
The complexity of achieving thermal comfort when both reflex and behavioural components of thermal regulation may be compromised. Routine monitoring of core temperature and application of appropriate thermal care.
- ❻ Co-producing a Postural Care Plan
Consideration of the challenges faced by families and personal assistants and how support might be offered, including the use of postural care equipment effectively, safely and humanely.

Person led Variance Reporting

Describe any factors which have prevented the Postural Care Pathway from taking it's expected course during Step 3

Delivery of the accredited and quality assured Postural Care Award

Please note that a person's Postural Care Plan may change as individuals have access to information and experience, please ensure that the plan is up to date!

Step 4

Does the person have access to the equipment they need? How can access be ensured? PHBs, local services, charitable or private funding

As a result of completing the previous training and developing helping relationships with professionals, families and personal assistants have the opportunity to combine specialist knowledge with an encyclopaedic understanding of the individual as their condition changes from day to day. They will understand the individual's pain related behaviours and ensure that interventions are gentle and respectful. They will know about the individual's particular vulnerability, what equipment is needed and why they need it. They will also know what best suits their own personal environment and situation.

☒ the box to indicate equipment needed, possibly including:-

- 1 Wheelchair ☐
- 2 Alternative seating ☐
- 3 Standing frame ☐
- 4 Walking aid ☐
- 5 Support for the lying posture during the day ☐
- 6 Support for the lying posture during the night ☐
- 7 Moving and handling equipment ☐
- 8 Equipment to assist personal care ☐
- 9 Orthotics ☐
- 10 Any other equipment needed to protect body shape ☐

Families and professionals must collaborate to develop a reasoned statement of equipment needs, costs and sources of funding with a record of dates acquired.

Equipment	Why it is needed	Cost / Funding Source	Date acquired

“Independence through user led services... is about defining our own needs...being responsible for our own lives”
Incurably Human (2005) Micheline Mason

Well informed families know what equipment best suits their needs, services are required to establish funding direct to families to provide vital equipment when it is needed to enable them to provide postural care.

Person led Variance Reporting

Describe any factors which have prevented the Postural Care Pathway from taking it's expected course during Step 4

**Does the person have access to the equipment they need?
How can access be ensured? PHBs, local services, charitable
or private funding**

[illegible]

Step 5

Provision of ongoing support including regular Measurement of Body Symmetry using The Goldsmith Indices®

Use the following checklist to structure reviews:-

Has postural care been made difficult by any of the following issues ?

- With established distortion of body shape?
- With difficulties regarding tone and movement?
- With any other health issues?
- With lack of equipment?
- With the family's / PA's difficulties?

How might postural care be improved?

- How can time spent in destructive postures be reduced?
- How can time spent in supported postures be increased?
- How can the lying posture be made less destructive?
- How can the lying posture be made more comfortable?
- How can all the sitting postures be improved?
- How can the standing posture be improved if appropriate?
- How can transfers be made safer and easier?
- How can problems with body shape be worked around?
- How can problems with tone and movement be reduced?
- How can problems with health be alleviated?
- What medical information would be helpful?
- How can problems with lack of equipment be overcome?
- Are there any ways in which the family/PA can be helped?

Complete a measurement of body symmetry at appropriate intervals depending on progress.

Date of Measurement	Illustrated Planning Report Attached?	Comments

Keeping in touch

This Pathway operates an open door policy with regards to contact between families, personal assistants and professionals. Everyone should feel that their queries and requests for help are part of a dialogue within a trusting and helpful relationship.

As the need for postural care is ongoing it is not appropriate for individuals to be discharged from sources of support although it has been found that levels of contact naturally reduce as appropriate equipment is acquired and empowerment to self-manage is established.

Describe any factors which have prevented the Postural Care Pathway from taking it's expected course during Step 5

[illegible]

Postural Care Pathway: A Self-Management Approach

1. Benner, P. (ed) (2001) "From novice to expert: excellence and power in clinical nursing" 2nd edition. California: Pearson Education
2. Care Quality Commission: "Health care for disabled children and young people. A review of how the health care needs of disabled children and young people are met by the commissioners and providers of health care in England." March 2012
3. Carnaby, S. Pawlyn, J. *Profound Intellectual and Multiple Disabilities: Nursing Complex Needs*. Hill, S. Goldsmith, L. "Posture, Mobility and Comfort" Wiley Blackwell Publishing 2008
4. Goldsmith, L. "Posture, Mobility and Comfort" Wiley Blackwell Publishing 2008
5. Clayton, S. (2015) Postural Care. In Gates, B. Fearn, D & Welch, J. (eds.). *Learning Disability Nursing at a Glance*. Pgs 100 – 101. Wiley-Blackwell Publishing.
6. Clayton, S. (2013) "Postural Care; We've a mountain to climb and we've only just got our boots on!" PMLD Link: Wellbeing, Vol 25 No 3 Issue 76, pgs 18 – 21. Available at <http://tinyurl.com/o4j8on8> [Accessed 20th April 2015]
7. Clayton, S, Netbuddy April 2013: Postural Care: "Protecting and Restoring Body Shape." [Online] (updated 2nd April 2013) Available at <http://bit.ly/GlqMoH> [Accessed 17th April 2013]
8. Clayton, S. "Nationally Recognised and Accredited Training Provision in Postural Care." *Posture and Mobility: Training, E-Learning and Tele-Rehab*, Vol 30:2 pgs. 18 – 21. Winter 2013
9. Clayton, S. "Postural Care; We've a mountain to climb and we've only just got our boots on!" PMLD Link: Wellbeing, Vol 25 No 3 Issue 76, pgs 18 – 21. Winter 2013
10. Claytons, S: "Supporting Families to Better Access Postural Care." *Learning Disability Today*, March/April 2013
11. Cobb, J. and Giraud-Saunders, A., Commentary on 'Biomechanics and Prevention of Body Shape Distortion', *The Tizard Learning Disability Review*, Vol. 15, Issue 2, pgs. 30 - 32 , 2010
12. Department of Health: "Understanding Personal Health Budgets." Spring 2012
13. Fulford, G.E. Brown, J. K. (1976) "Position as a cause of Deformity in Children with Cerebral Palsy" *Developmental Medicine and Child Neurology* 18. 305-314
14. Golding, RM. Goldsmith, L. Gray, M. 'Physical assessment of individuals with multiple disability', *RNIB Certificate in Multiple Disability*, Royal National Institute for the Blind, 1991
15. Golding, RM. Goldsmith, L. "The Caring Person's Guide." Macmillan Education Ltd, 1986
16. Goldsmith (Clayton), S. "The Mansfield Project : Postural care at night within a community setting" *Physiotherapy* 86, 10, 528-534, 2000
17. Goldsmith, J. Goldsmith, L. 2009. "Goldsmith Indices of Body Symmetry: Protecting Body Shape". In: *European Seating Symposium Incorporating Assistive Technology*. Dublin Ireland, 14-17 September 2009, European Seating Symposium: Dublin

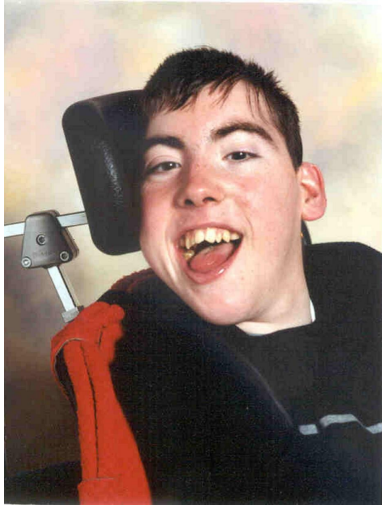
18. Goldsmith, J. Goldsmith, L. Hill (Clayton), S. "Working Together to Protect Body Shape" *Posture and Mobility*, Volume 26:2, ISSN 1752-1629, December 2009
19. Goldsmith, J. Goldsmith, L. Hill, S. "Working Together to Protect Body Shape" *Posture and Mobility*, Volume 26:2, ISSN 1752-1629, December 2009
20. Goldsmith, J. Hill, D. (2001) "Biomechanics of Distortion of the immobile chest" and "Biomechanics of regaining equilibrium of the immobile chest" Proceedings Manual, Canadian Seating and Mobility Conference P 89-92 and P102-105
21. Goldsmith, L. Golding, RM. Garstang, RA. Macrae, AW. "A technique to measure windswept deformity" *Physiotherapy*, 78, 4, 235-242, 1992
22. Goldsmith, S. (2000) "The Mansfield Project: Postural care at night within a community setting" *Physiotherapy* 86, 10, 528-534
23. Goldsmith. J, Goldsmith. L, Hill (Clayton). S, Waugh. A: "Postural Care Textbook" Supporting material for accredited courses at Level 2 and 3. Originally published September 2004
24. Gyles Glover, G. Ayub, M: "How people with learning disabilities die." Improving Health and Lives: Learning Disabilities Observatory. Supported by Department of Health. http://www.improvinghealthandlives.org.uk/uploads/doc/vid_9033_IHAL2010-06%20Mortality.pdf June 2010
25. Health Action Planning and Health Facilitation for People with Learning Disabilities: Good Practice Guidance, Department of Health, 2009. Page 53
26. Heslop et al: "Confidential Inquiry into the Premature Death of People with Learning Disabilities: Final Report." Norah Fry Research Centre, March 2013
27. Hill (Clayton), S. "Therapeutic Positioning: working in partnership towards tangible outcomes for children" *Interconnections Quarterly Journal*, Issue 6 July 2009
28. Hill (Clayton), S. and Goldsmith, J., 'Biomechanics and Prevention of Body Shape Distortion', *The Tizard Learning Disability Review*, Vol. 15, Issue 2, pgs. 15 – 29, 2010
29. Hill (Clayton), S. Waugh, A. "Body Shape Distortion: Promoting Postural Care At Night" *Learning Disability Practice*, 12, 7, 25-29, 2009
30. Hill (Clayton), S: "A One Year Postural Care Training Programme for the Workforce Supporting the Needs of those with Complex and Continuing Healthcare Needs: Project Evaluation" March 2011
31. Hill, S. "Therapeutic Positioning: working in partnership towards tangible outcomes for children" *Interconnections Quarterly Journal*, Issue 6 July 2009
32. Houghton, M. and Royal College of General Practitioners Learning Disabilities Group., A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability. Page 28. 2010

33. Improving Health and Lives: Learning Disabilities Observatory: "Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGs)" October 2012
34. It doesn't happen to disabled children - child protection and disabled children. Report of the National Working Group on Child Protection and Disability. NSPCC 2003
35. Jenny Whinnett and Anna Waugh: "Craig's Experience and the Postural Care Campaign." PMLD Link: Therapies, Vol 23 No 3 Issue 70, pgs. 15-16. Winter 2011
36. Jill Davies: "An ordinary life: supporting families whose child is dependent on medical technology or has complex health needs." Foundation for People with Learning Disabilities. May 2012
37. Lacey, P. (Ed) *People with Profound and Multiple Learning Disabilities : A Collaborative Approach to Meeting Complex Needs*, Goldsmith, J. Goldsmith, L. "Physical Management" David Fulton Publishers 15- 28, 1998
38. Mansell, J., "Raising Our Sights: services for adults with profound intellectual and multiple disabilities" Page 24. Tizard Centre, University of Kent. March 2010
39. Mason, M. (2005) "Incurably Human" Nottingham: Inclusive Solutions
40. Mencap. "Death by Indifference" March 2009
41. Michaels, Sir. J. "Healthcare for All, Independent inquiry into access to healthcare for people with learning disabilities" July 2008. Page 19
42. Mike, Julie, Ruth and Rebecca Ormian: "Postural Care – a Vital Therapy A Family's Story." PMLD Link: Therapies, Vol 23 No 3 Issue 70, pgs. 12 – 14. Winter 2011
43. Newlife Foundation. "It's not too much to ask" April 2007
44. Newlife: "From the Front Line; Reporting on the UK's Disabled Children's Equipment Provision." Summer 2012
45. Rennie, J. (Ed) *Learning Disability: Physical Therapy, treatment and management*. Goldsmith, J. Goldsmith, L. "Developing a service to provide postural care at night" London, Whurr Publishers 147 – 169, 2001
46. Supporting people with long term conditions to self care: A guide to developing local strategies and good practice. Department of Health 2006
47. Surowiecki, J. (2004) *The Wisdom of Crowds*. Anchor
48. Tardieu, C. et al. (1988) "For How Long Must the Soleus Muscle be Stretched Each Day to Prevent Contracture?" *Developmental Medicine and Child Neurology*, 30, 3-10.
49. Valuing People: A New Strategy for Learning Disability for the 21st Century. Department of Health 2001
50. Waugh, A. "Protect Body Shape, Protect Quality of Life" *ARC's Changing Perspectives*, Issue 4 - Health, December 2009



51. Whinnett, J. "PAMIS: Supporting People with Profound and Multiple Learning Disabilities and Their Families for a Better Life" Posture and Mobility, vol 27:2, pgs. 16 – 20. 2010
52. World Health Organisation Regional Office for Europe. "Better health, better lives: children and young people with intellectual disabilities and their families: Ensure good quality mental and physical health care" EUR/51298/17/PP/5. Page 3. October 2010

Appendix 1:



A Life with Value; a Life worth Living

Twenty one years ago, my life changed forever. Most parents say this on the birth of their first child, but my life changed again when my fourth son joined our family.

Craig touched us all from the start. He met every challenge with his beautiful smile, and over the years of his life, there were so many challenges for him to take on. Major surgery for a funduplication and then for it to be repaired, a gastrostomy to be fitted, and then in his teens a Baclofen Implant was inserted into his abdomen to help his muscle tone. In between the surgeries, he endured a number of serious bouts of pneumonia, unsettled seizure control, and a period of poor mental wellbeing. He fought his way back from each illness with his unshakable love of life, and people. The family were exhausted, but Craig revived us every time with his beautiful smile and obvious enjoyment in everything he participated in life. He loved his Kindergarten, sharing time with the children in his village, his wonderful school days, interspersed with visits to Badaguish a special holiday/ respite centre for children with disabilities up in the Cairngorms, and then his family time with many outings to cinema, ten pin bowling and family parties. His trip to the States to participate in his brother's wedding, saying his vows along with his brother! Amy had 2 husbands for a while!

But there was a deepening cloud on Craig's horizon that crept up, and prevented him from continuing the life he so enjoyed. That was the results of his deteriorating body shape, rotated hips and severe scoliosis. During his early life great emphasis was put into Craig being correctly seated and supported into standing frames by his therapists, and I duly followed all the instructions for his therapies and positioning as guided by his dedicated therapists, but nothing was advised for his sleeping position. A third of his life was quite appropriately spent in bed, sleeping. I requested and was given a hospital style bed while he was still young, and then this was replaced with a special care bed in his teens, but there was little advice given

about his sleeping, resting position. Funding for bed posture systems was not available, and in his early life I was not aware of any to examine. I became conscious of Craig's deteriorating scoliosis over his childhood, but apart from a serious effort being put into his seating, nothing was discussed around his resting position. A consultant intimated during his early teens that his poor body shape would shorten his life, but there was no advice from him to improve this prognosis!

A senior orthopaedic consultant did examine Craig with a view to spinal surgery to correct his scoliosis, but sadly by the time this consultation took place, Craig's body shape was too poor for surgery to go ahead. This was devastating news to us as a family, so we concentrated on giving Craig as full a life as possible.

Four years ago, I discovered information on the Sleep System and on protecting body shape. It was so important to us to help and improve Craig's shape as much as we could. We purchased a sleep system ourselves, as there was still no funding available, and then booked a training workshop for Craig's carers and myself to be given skills to support Craig's posture. Craig really enjoyed all the attention and joined in the workshop with great interest and amusement.

Over the last two years of his life, he had the support of a respiratory consultant, who informed us that Craig's respiratory function had become seriously impaired due to his poor body shape; however he gave Craig all the support he could, as he had developed serious respiratory failure. Craig received oxygen therapy in the home, and latterly was supported by a non invasive ventilator at night to aid his breathing.

Sadly during the summer of 2008, Craig became seriously ill, suffering great pain, and it became evident that the only support that could now be given was palliative care. We were able to take him home, and he was cared for to the end by me and those that loved him, passing away in the arms of his mum.

The sleep system helped him to enjoy added time, with a good quality of life, coupled with the effort of all the other professionals in his life, and the love of his family.

But Craig should not have had to live with such a poor body shape that it impacted on his quality of life and expectancy to such a degree.

He would want a person's body shape to be far better protected from the time of diagnosis, and continuing throughout the individual's life by the professionals involved with them, so that they will enjoy a healthier life than he did due to his severe scoliosis.

Jenny Whinnett



ⁱ Heslop et al: "Confidential Inquiry into the Premature Death of People with Learning Disabilities: Final Report." Norah Fry Research Centre, March 2013