

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

Further information and materials relating to the provision of postural care and the use of effective outcome measures can be found at

www.mencap.org.uk/posturalcare

It's My Life!



This Care Pathway puts
families in control to self manage
healthcare needs associated
with postural care

John and Liz Goldsmith
Sarah Clayton
Anna Waugh

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Where does this pathway of care fit?

From 2010 the Welfare Reform Act will include adult Community Care in the Right to Control. After listening to the views of disabled people through a wide-ranging consultation, the government is putting plans in place to give disabled adults more choice and control over the state funding or services they receive. Disabled adults will be able to take money with which to buy their own support services or equipment through the Right to Control.

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."

Appendix 1: "A life with value; a life worth living"

For individuals who have difficulty controlling and varying their posture, achieving thermal comfort and communicating pain this Care Pathway will form part of the person-centred plan to protect and restore their body shape, muscle tone and quality of life. It is acknowledged within 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.

Appendix 2: Protecting body shape: Craig's consensus for a mainstream future

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. We have no precise data on numbers, but it is estimated that some 60% of adults with learning disabilities live with their families." Valuing People (2001).

This care pathway supports current Department of Health guidance: Supporting people with long term conditions to self care: A guide to developing local strategies and good practice: "This guide explains how health and social care services can support people with long term conditions to self care through an integrated package which includes information, self monitoring devices, self care skills education and training and self care support networks. Improving care for people with a long term condition is one of the biggest challenges facing health and social care organisations and demands wholesale change in the way they think, train and deliver/design services. The role of self care is crucial in people maintaining good health and taking care of their condition. Supporting self care provides benefits all round". Dept of Health (2006)

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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 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.

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www.mencap.org.uk/posturalcare



"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.

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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

Variation 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.

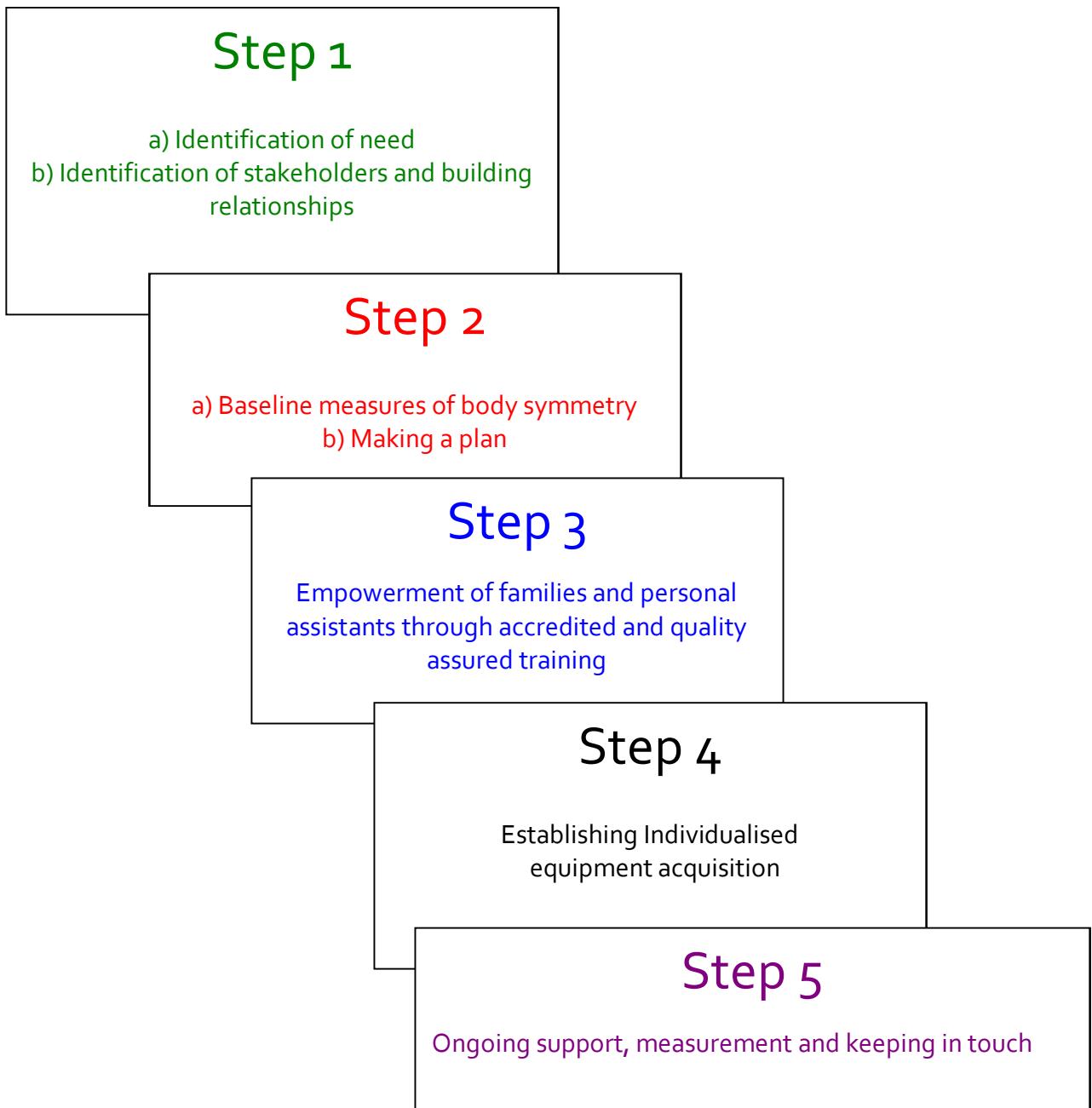
Inherent in this system is the possibility of variance from the expected course; however the process of families leading risk / benefit analysis and variance reporting forms the foundation of partnership working.

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Structure of the Pathway

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



Variance Reporting

Throughout this process variation reporting will be led by the person, family and personal assistants.

Recorded byDate.....

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S T E P 1	<p>Step 1</p> <p>a) Identification of need</p> <p>The Mansfield Checklist of Need for Postural Care</p> <p>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, <input checked="" type="checkbox"/> the box which best describes their situation:-</p> <p>Is the person limited to a restricted number of positions? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Does the head seem to turn mainly to one side? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Does the body seem to fall sideways? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Do the arms tend to be held in a position in which it is difficult to use them? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Does the body seem to fall forwards or backwards? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Do the knees seem to fall mainly to one side? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Do the knees seem to fall inwards or outwards? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Is the body shape already asymmetric? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>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.</p> <p>Does _____ and those who care for him/her want to be on the Postural Care Pathway?</p> <p style="text-align: center;">Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Signature of Care Coordinator..... Date.....</p> <p>The Care Coordinator will be qualified in postural care, they may be the person concerned, a family member, a personal assistant or a professional.</p>
S T E P 2	
S T E P 3	
S T E P 4	
S T E P 5	

Recorded byDate.....

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S T E P 1	Step 1																
	b) Identification of stakeholders and building 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																
	<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="text-align: left; padding: 5px;">Name / Role</th> <th style="text-align: left; padding: 5px;">Help needed Describe how this person needs to help to make postural care successful</th> <th style="text-align: left; padding: 5px;">Action Describe what action could be taken to develop a trusting, helpful relationship with this person</th> </tr> </thead> <tbody> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> </tbody> </table>		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												
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Recorded byDate.....

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Person led Variance Reporting

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

a) Identification of need

**STEP
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**STEP
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b) Identification of stakeholders and building relationships

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5**Step 2****a) Baseline measures of body symmetry**

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 _____

Recorded byDate.....

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

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5**Step 2****a) Baseline measures of body symmetry**

The Open College Network West Midlands Region accredits a qualification for measurers so they are always done properly.

UNIT TITLE: Measurement of Body Symmetry
LEVEL: Three CREDIT VALUE: 9
UNIT CODE: PT2/3/MR/011

Procedure 1:

- 1 / 1 Measurement in crook lying of angle of the pelvis when knees are upright
- 1 / 2 If the angle of the pelvis is not level, the angle to which knees must be taken to bring the pelvis level
- 1 / 3 Depth/Width ratio (d/w) of the chest at the level of the xiphoid process with the pelvis level
- 1 / 4 Right/Left ratio (r/w) from xiphoid process to lateral border of the chest with the pelvis level

Procedure 2:

Measurement in crook lying of symmetry of rotation of the pelvis, as influenced by movement of the flexed knees together in an arc right to left, with the shoulders and feet fixed.

Procedure 3:

Measurement of the segment of an arc described by flexed knee, indicating a range of external rotation/abduction at the hip, with the pelvis fixed level.

As a result of these measures a report will be produced which sets out what needs to be done either to protect or restore body shape

Date of measurements	Result sheet attached
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Recorded byDate.....

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

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Step 2

b) Making a plan

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

Recorded byDate.....

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

Person led Variance Reporting

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

a) Baseline measures of body symmetry

**STEP
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d) Making a plan

Recorded byDate.....

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

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5**Step 3****Empowerment of families and personal assistants through accredited and quality assured training****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".

The Open College Network West Midlands Region accredits a qualification 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. There are 3 related qualifications, a choice can be made depending on which are thought to be most appropriate:

UNIT TITLE: Postural Care Skills – Awareness Level
LEVEL: Three **CREDIT VALUE:** 3
UNIT CODE: PT2/2/MR/022

UNIT TITLE: Postural Care Skills – Advanced Level
LEVEL: Three **CREDIT VALUE:** 6
UNIT CODE: PT2/3/MR/013

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Step 3

Empowerment of families and personal assistants through accredited and quality assured training

Each Unit covers particular issues related to
Postural Care Skills:

① 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.

② 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.

③ Physical Assessment

Assessment of body shape and muscle tone to analyse risk / benefit of activities and strategies.

④ 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.

⑤ 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.

⑥ Use of equipment

Use of postural care equipment effectively, safely and humanely.

Name of student _____ Unit _____

Date / Start _____ Qualified _____

Name of student _____ Unit _____

Date / Start _____ Qualified _____

Name of student _____ Unit _____

Date / Start _____ Qualified _____

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

Person led Variance Reporting

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

Empowerment of families and personal assistants through accredited and quality assured training

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Step 4

Establishing Individualised equipment acquisition

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

Recorded byDate.....

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

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Step 4
Establishing Individualised and equipment acquisition

Families and professionals 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

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

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As qualified 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.

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The next steps for a radical shake-up of the way disabled people use state funding, were announced by Minister for Disabled People, Jonathan Shaw on 8th December.2009

"After listening to their views through a wide-ranging consultation, the government is putting plans in place to give disabled adults more choice and control over the state funding or services they receive. Disabled adults will be able to take money with which to buy their own support services or equipment through the Right to Control. Through our consultation, disabled people have told us what they want. They want better control over their lives and control over the services they use. Disabled people are the experts in their own lives and that is why, through the Welfare Reform Act, we have put this legislation in place."

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Recorded byDate.....

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

Person led Variance Reporting

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

Establishing Individualised equipment acquisition

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Step 5

Ongoing support, measurement and keeping in touch

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?

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Ongoing support, measurement and keeping in touch

Ongoing monitoring of body symmetry

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.

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Recorded byDate.....

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

Person led Variance Reporting

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

Ongoing support, measurement and keeping in touch

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S TE P 2
S TE P 3
S TE P 4
S TE P 5

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Postural Care Pathway: A Social Model of Empowerment

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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 fundiplication 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

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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

Appendix 2: Protecting body shape- Craig's consensus for a mainstream future

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This Consensus is the work of the *Protecting Body Shape Focus Group* of individuals and organisations dedicated to helping individuals and their first circle of support to self manage postural care that is gentle and respectful in order to protect and restore body shape, muscle tone and quality of life.

Contributors: Craig Whinnett

Jenny Whinnett: Pamis

James Heffernan: Self Advocate

Mike and Julie Ormion: Parents

Lynne Elwell: Parent, Partners in Policymaking and "In Control"

Janet Cobb: Foundation for People with Learning Disabilities

Ann Norman: Royal College of Nursing

Prof Bernie Carter: UCLAN

Dr Ben Thomas: Department of Health

Dominic Corry: National Patient Safety Agency

Peter Warburton: National Patient Safety Agency

Bella Travis: Mencap

Bas Jansen: Physiotherapist, Disability Services Commission, Western Australia

Sarah Hill, Anna Waugh, John and Liz Goldsmith: Postural Care CIC

Mission statement: The aim of this inclusive consensus is to set out a culture and provision within accountable, mainstream services so that every individual will be protected throughout treatment interventions by normal safeguarding procedures and that they and their first circle of support will be offered the information, capacity and support they need to protect body shape.

Background: Appropriate and person centred postural care supports people to protect and restore body shape by adopting symmetrical postures, particularly in lying. Habitual destructive postures compromise body shape, muscle tone, motor performance and function of the vital organs as a consequence of reduced internal capacity within the abdomen and thorax. These complications cause suffering and premature death.

Scope: The scope of indirect and direct socio-economic benefit of protecting body shape is vast. Direct beneficiaries will include a significant proportion of the population in three broadly identifiable groups:-

- a. Those who are easily identifiable because they have a movement difficulty, regardless of diagnosis, for example, older people and people with disability.
- b. Those with no apparent movement problem but for whom posture analysis and body measurement reveals habitual destructive postures which cause distortion. For example those with scoliosis referred to as idiopathic.
- c. Those whose needs are transient during episodes of reduced mobility such as post-surgery, rehabilitation, stroke, or trauma.

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Principles: The following inclusive principles will ensure protection of body shape is embedded in mainstream service culture and provision:-

1. **Statement of intent.** Earliest possible but life long conservative intervention and raised awareness will ensure that body shape and function is protected within mainstream service culture and provision.
2. **Safeguarding principles.** The unique qualities of people will be valued and protected; the principle "Primum Non Nocere: First - Do No Harm" will govern. Treatment will be evidence based and it will be acknowledged that inappropriate treatment is a form of abuse from which individuals need protection. Proposed interventions which could be degrading, abnormal, exclusive, restrictive, uncomfortable, bizarre, painful, damaging, risky or invasive will be anxiously examined and strictly regulated by formal safeguarding procedures.
3. **Education.** The straightforward concepts, skills and associated issues related to protecting body shape are not intuitive. Public awareness will be raised and earliest possible education provided for potential beneficiaries. It will be recognised that education is most effective when delivered to those who are likely to have encyclopaedic understanding and be in the best position to enact it, such as the individual, their family and/or first circle of support. The essential and emotive nature of this education will be acknowledged so an accredited syllabus will be quality assured and delivered with compassion by suitably qualified, regulated and competent teachers.
4. **Person led commissioning.** Potential beneficiaries will be offered a pathway to become qualified, financed and supported to commission their own inclusive services and the equipment they need to use in their own homes and daily lives. Timely provision, improvisation and maintenance of equipment will be acknowledged as essential in the effort to protect body shape.
5. **Auditing/regulation.**
5.1 Measures of body symmetry and posture analysis will be used to predict those at risk and monitor outcomes. 5.2 Services will be accountable for timely provision of equipment including wheelchairs. 5.3 Quality of education services and resultant skills will be audited and regulated. 5.4 Designated professionals will be regulated to demonstrate their capacity to deliver accountable, effective services to protect and restore body shape. 5.5 Safeguarding procedures will be anxiously and strictly applied to all proposed interventions to ensure an effective, humane approach.

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