

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

It's My Life!



This Care Pathway puts families in control to self manage complex and continuing healthcare needs

Recorded byDate.....

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

Where does this pathway of care fit?

Valuing People (2001) stated that "All people with a learning disability (are) to have a Health Action Plan by June 2005".

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."

For individuals who have difficulty controlling and varying their posture, achieving thermal comfort and communicating pain this Care Pathway should be considered and 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.

This Care Pathway recognises that "carers make a vital contribution to the lives of people with learning disabilities, often providing most of the support they need. They are a crucial resource for ensuring that people with learning disabilities can live in the community. We have no precise data on numbers, but it is estimated that some 60% of adults with learning disabilities live with their families. Statutory agencies do not always properly recognise the extent of carers' contribution or its value." 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". **Department of Health (2006)**

Recorded byDate.....

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

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.



“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.

Recorded byDate.....

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

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.

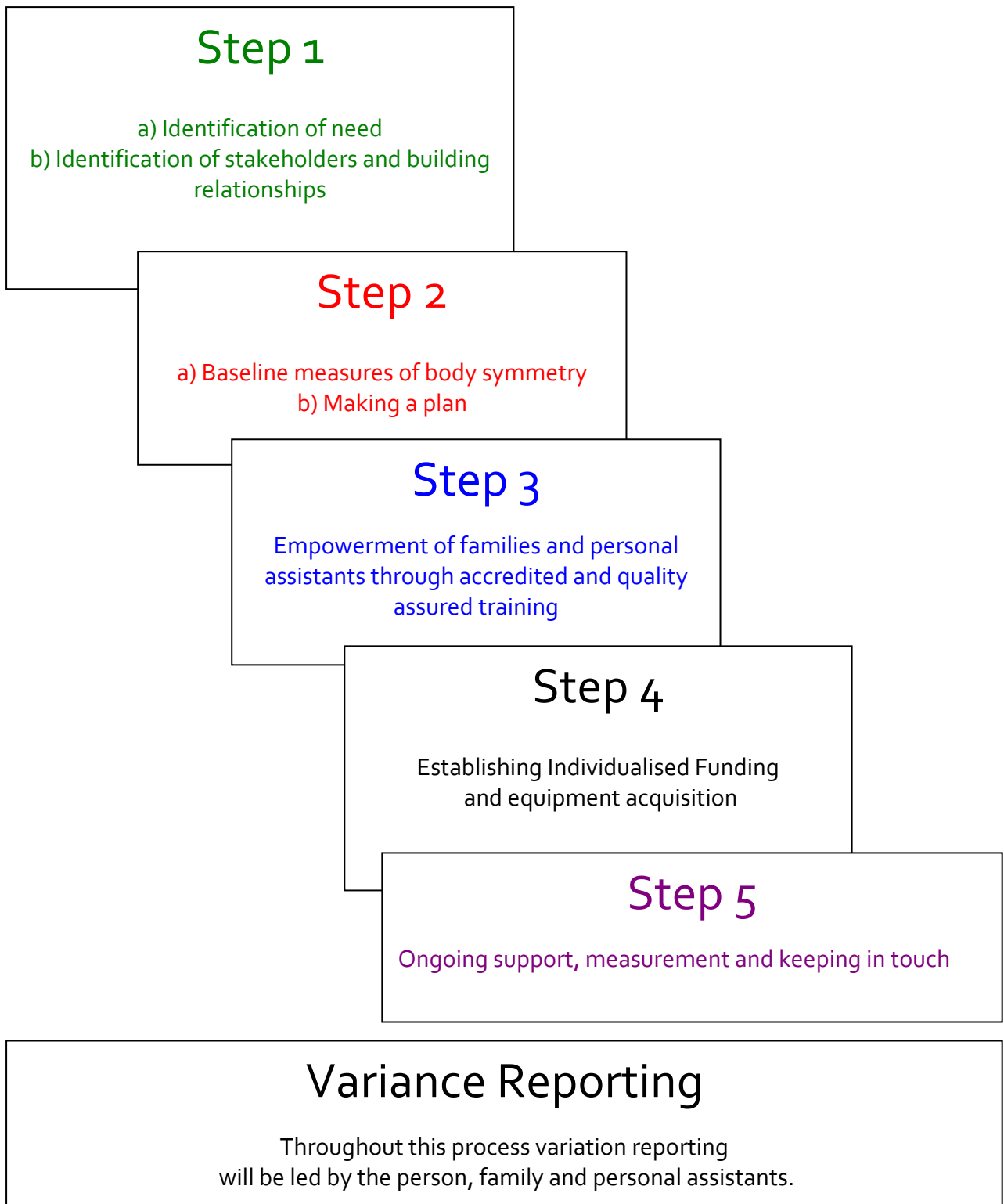
Inherent in this system is the possibility of variance from the expected course; however the process of families leading risk / benefit analysis and variance reporting forms the foundation of partnership working rather than the didactic approach of **the medical model.**

Recorded byDate.....

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

Structure of the Pathway

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



Recorded byDate.....

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

S T E P 1
S T E P 2
S T E P 3
S T E P 4
S T E P 5

Step 1

a) Identification of need

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

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.

Recorded byDate.....

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

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

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

S T E P 1
S T E P 2
S T E P 3
S T E P 4
S T E P 5

Recorded byDate.....

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

<p>Person led Variance Reporting</p> <p>Describe any factors which have prevented the Postural Care Pathway from taking it's expected course during Step 1</p> <p>a) Identification of need</p>
<p>b) Identification of stakeholders and building relationships</p>

S T E P 1
S T E P 2
S T E P 3
S T E P 4
S T E P 5

Recorded byDate.....

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

S T E P
1
S T E P
2
S T E P
3
S T E P
4
S T E P
5

Step 2

a) Baseline measures of body symmetry

What is it? Who needs it?

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.....

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 – Technique
 LEVEL: Three CREDIT VALUE: 9
 UNIT CODE: HF83CE007

- 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

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

Recorded byDate.....

S
T
E
P
1

S
T
E
P
2

S
T
E
P
3

S
T
E
P
4

S
T
E
P
5

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

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

S T E P	1
S T E P	2
S T E P	3
S T E P	4
S T E P	5

Recorded byDate.....

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

<p>Person led Variance Reporting</p> <p>Describe any factors which have prevented the Postural Care Pathway from taking it's expected course during Step 2</p> <p>a) Baseline measures of body symmetry</p>
<p>d) Making a plan</p>

S T E P 1
S T E P 2
S T E P 3
S T E P 4
S T E P 5

Recorded byDate.....

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

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 – General Skills
 LEVEL: Three CREDIT VALUE: 3
 UNIT CODE: HF83CE003

UNIT TITLE: Postural Care Skills – Person Related Skills
 LEVEL: Three CREDIT VALUE: 6
 UNIT CODE: HF83CE004

UNIT TITLE: Postural Care - Self Help Skills
 LEVEL: Three CREDIT VALUE: 3
 UNIT CODE: HG4/3/CE/014

Recorded byDate.....

S
T
E
P

1

S
T
E
P

2

S
T
E
P

3

S
T
E
P

4

S
T
E
P

5

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

Step 3

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

Each Unit covers particular issues related to
General 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 Learner _____ Unit _____

Date / Start _____ Qualified _____

Name of Learner _____ Unit _____

Date / Start _____ Qualified _____

Name of Learner _____ Unit _____

Date / Start _____ Qualified _____

Recorded byDate.....

S T E P	1
S T E P	2
S T E P	3
S T E P	4
S T E P	5

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

S T E P 1
S T E P 2
S T E P 3
S T E P 4
S T E P 5

Recorded byDate.....

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

Step 4

Establishing Individualised Funding and equipment acquisition

As a result of completing the previous training families and personal assistants will understand what equipment is needed and why they need it. They will also know what best suits their own personal 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

S
T
E
P

1

S
T
E
P

2

S
T
E
P

3

S
T
E
P

4

S
T
E
P

5

Recorded byDate.....

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

Step 4
Establishing Individualised Funding 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

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

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.

Recorded byDate.....

S T E P	1
S T E P	2
S T E P	3
S T E P	4
S T E P	5

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

<p>Person led Variance Reporting</p> <p>Describe any factors which have prevented the Postural Care Pathway from taking its expected course during Step 4</p> <p>Establishing Individualised Funding and equipment acquisition</p>
--

S T E P 1
S T E P 2
S T E P 3
S T E P 4
S T E P 5

Recorded byDate.....

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

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?
- How can problems with lack of equipment be overcome?
- Are there any ways in which the family/PA can be helped?

Recorded byDate.....

S T E P	1
S T E P	2
S T E P	3
S T E P	4
S T E P	5

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

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.

S T E P	1
S T E P	2
S T E P	3
S T E P	4
S T E P	5

Recorded byDate.....

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

Person led Variance Reporting

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

Ongoing support, measurement and keeping in touch

S
T
E
P

1

S
T
E
P

2

S
T
E
P

3

S
T
E
P

4

S
T
E
P

5

Recorded byDate.....

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

Postural Care Pathway: A Social Model of Empowerment

References and Background Reading

Benner, P. (ed) (2001) "From novice to expert: excellence and power in clinical nursing" 2nd edition. California: Pearson Education

Carnaby, S. Pawlyn, J. *Profound Intellectual and Multiple Disabilities: Nursing Complex Needs*. Hill, S. Goldsmith, L. "Posture, Mobility and Comfort" Wiley Blackwell Publishing 2008

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

Goldsmith, L. Golding, R.M., Garstang, R.A. Macrae, A.W. (1992) "A technique to measure windswept deformity" *Physiotherapy*, 78, 4, 235-242

Goldsmith, S. (2000) "The Mansfield Project: Postural care at night within a community setting" *Physiotherapy* 86, 10, 528-534

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

Health Action Planning and Health Facilitation for People with Learning Disabilities: Good Practice Guidance, The Department of Health, 2009

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

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

www.macintyre.com as available March 2006

Mason, M. (2005) "Incurably Human" Nottingham: Inclusive Solutions

Mencap. "Death by Indifference" March 2009

Michaels, Sir. J. "Healthcare for All, Independent inquiry into access to healthcare for people with learning disabilities" July 2008

Newlife Foundation. "It's not too much to ask" April 2007
Supporting people with long term conditions to self care: A guide to developing local strategies and good practice. Department of Health 2006

Surowiecki, J. (2004) *The Wisdom of Crowds*. Anchor

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.

Valuing People: A New Strategy for Learning Disability for the 21st Century. Department of Health 2001

Recorded byDate.....