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Craig's Experience and the Postural Care Campaign

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People who find it hard to move are most at risk of developing body shape distortions and failure to protect body shape can have serious consequences for a person's health and quality of life. It can even cause premature death.

A Family's Perspective

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. He underwent 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 smile and obvious enjoyment in everything he participated in. 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 the cinema, ten pin bowling and family parties. His trip to the States to participate in his brother's wedding was particularly special, saying his vows along with his brother - Amy had two 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. It was as a result 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 in standing frames by his therapists, and I duly followed all the instructions for his therapies and positioning as guided, 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



A Life with Value; a Life worth Living

in his teens, but there was little advice given about his sleeping, resting position. Funding for sleep 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.

Five years ago, I discovered information on the Sleep System and on protecting body shape. 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 his posture. Craig really enjoyed all the attention and joined in the workshop with great interest and amusement. The training given by Postural Care Skills really opened our eyes as it all made such sense! We were given the information to work with Craig in positioning him safely and comfortably at night to prevent further postural deterioration, and to work towards improvement in body shape. However, we sadly did not know then how little time we still had with Craig.

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 severely impaired due to his poor body shape and the compression of his internal organs, but he gave Craig all the support he could. He had developed serious respiratory failure so he 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 his family and those that loved him, passing away in the arms of his mum.

The sleep system and the training given to us on Postural Care by Postural Care Skills 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 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 support throughout their lives by the professionals involved with them, so that they would enjoy a healthier life than he did, due to his severe scoliosis.

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The launch of the Postural Care Campaign

In 2008 Jenny and a number of other individuals and organisations – including, Postural Care Skills, the Chartered Society of Physiotherapy, the Royal College of Nursing, the College of Occupational Therapy, Mencap, PAMIS and Simple Stuff Works - came together and established the Postural Care Action Group. The purpose of the group is to raise awareness about the importance of protecting body shape for people with complex healthcare needs and movement difficulties.

The group has had articles published in a number of journals and we have now launched our Postural Care awareness raising campaign. The campaign is aimed at all those who support people with multiple disabilities or who commission services for them.

We want:

- -to challenge the assumption that distortion of body shape is inevitable for people with multiple disabilities
- all people with multiple disabilities to get the support they need to protect their body shape, 24 hours a day.

A booklet and 6 short film clips are now available explaining why postural care is important and what you can do to take action and to ensure that appropriate postural care services are developed in your local area. We have also developed a PowerPoint presentation you can use to tell other people about the importance of postural care.

The booklet, film clips and presentation can be viewed at www.mencap.org.uk/posturalcare. Free copies of the booklet and film can be ordered at publications@mencap.org.uk or Tel: 020 7696 6900.

