



**DAVID THORBERRY (1950-2009)**  
*A Founding Member of PMG – Obituary on page 7*

*this  
issue...*

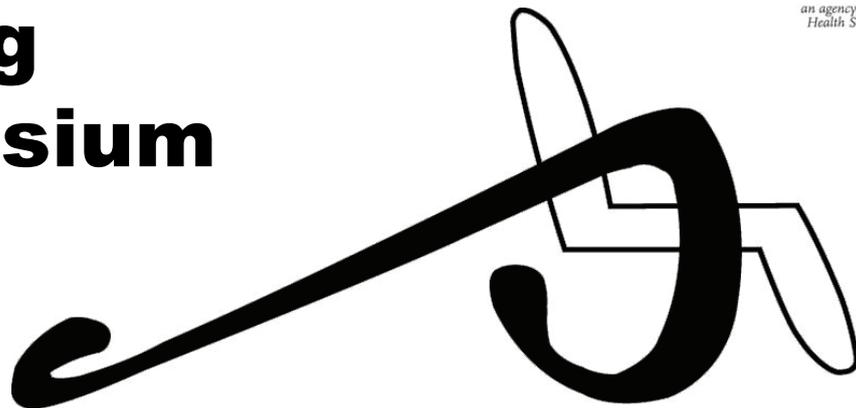
## Best Practice: Lessons from the Field

- Working Together to Protect Body Shape
- The Development of an X-Ray Protocol for Children on North Devon's Integrated Care Pathway for 24 Hour Postural Management
  - The Redesign of the Clinical Delivery Model of a Regional Seating Service
- ATcare: Promoting the Development of Assistive Technology to Enable Individuals to have Choice and Control

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# 26<sup>th</sup> International Seating Symposium



**March 10<sup>th</sup> - 13<sup>th</sup>, 2010**

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## Editorial

Welcome to another issue of the PMG Journal. This is my first effort at writing an editorial, which is quite daunting, particularly following on from Jo McConnell's easy style. I am grateful that she remains on the committee as a co-opted member, and is always available at the end of an email. I am discovering why Jo so often singled Oliwen out for a big thank-you – the same from me, Oli (but not in Welsh, I'm afraid!).

We are grateful to our many contributors, and hope you enjoy the articles we have gathered around the theme "lessons from the field". Many will know of John and Liz Goldsmith, who have worked in the field of complex disability for many years, particularly in the area of teaching carers and families regarding postural care. Their article describes different but related aspects of their work – their pathway, means of monitoring its effectiveness, how a public health model might be developed, and a personal reflection from the family's point of view.

Ginny Humphreys, Head of Therapy at Vranth House in Exeter, was the prime mover in the development of the North Devon Postural Care Pathway, which incorporates the work of Terry Pountney, the Goldsmiths, and David Scrutton's research and recommendations regarding hip surveillance. With that pathway in place, related developments can be incorporated, and one of these is well described in Sally Bunney's article.

Dr Michael Dolan, Head of Seating Service in Edinburgh, describes the changes made in the delivery of special seating services in Lothian, resulting in reducing waiting times, rationalizing the number of appointments for each client, and achieving more timely intervention for those with deteriorating conditions. His team hopes to eventually incorporate planned clinical reviews – don't we all!! One of their problems was that "it was difficult to determine from referral information

which was the most appropriate clinic resulting in some patients attending the wrong clinic." I wonder if this happens because referrers do not really understand which information is important to relay, and would be interested to hear if there are similar problems in areas where wheelchair / seating services provide training for their referrers. One of the aims of PMG is to bridge that gap between the various services and disciplines.

Christine Asbury describes the work of ATcare, which was started in March 2008 having received a start up grant of £2.35 million from the London Development Agency. According to the website, their aims are to bridge "the product development gaps between university-based research, small and medium sized research-based businesses, the NHS and the market place." It will be interesting to see how their work develops.

We have decided to publish the entire Aldersea lecture, given at the NTE by Linda Marks, which not only makes entertaining reading and gives us an engaging view of the history of our services, but also provides us with some definite suggestions for maintaining our current services, and for improving them. Linda has now retired, but continues to be involved in the politics sub-committee of PMG. We of course are very grateful for her many years of input to PMG, and wish her well in her retirement.

Linda Marks and Nigel Shapcott have given evidence to an in-depth inquiry carried out over the past year by the All Party Parliamentary Group for Muscular Dystrophy and now published in the Walton Report, which Nigel briefly describes in his Chair's column. Nigel's and Linda's contribution to this inquiry is an example of the kind of networking that PMG are becoming involved in, and also serves to raise PMG's profile. The Walton Report can be found on the PMG website under

### Journal Production Team:

**Editor:** Carolyn Nichols

**Editorial Team:** Julianna Arva, Jane Chantry, Barend ter Haar, Geoff Harbach, Joanne McConnell and Jane Menzies

**Production Editor:** Olwen Ellis

**Design:** Nicholas Smith

**Printer:** SPS Communications, Ilford, Essex.

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Publications (where I notice there is a growing list of relevant documents).

We are grateful to our bursars for their reports from the NTE. Webcasts of many of the NTE presentations are available to members only on the PMG website. The pre-PMG training day was very well attended, with some very good feedback, and we appreciate the hard work from all the presenters.

We look forward to seeing many of you at the International Conference in Glasgow in June. The next journal will have an international theme, so any of you who have been involved in work in other places and cultures – please let us know about it – what was different, what worked and what didn't, what can we learn.

### Carolyn Nichols, Editor

I am taking the liberty of adding a small tribute here to both Joanne McConnell the previous editor, and to Carolyn.

Joanne and I held each other's hands a great deal in the early days, neither of us having had any previous experience of producing a publication of any kind!

For me Joanne was a great person to work with, as she seemed to know exactly when to trust my judgment or to intervene; together we produced 5 journals – 24:1 to 26:1. We were never sure if anyone ever read them except us, but we were proud of our achievement none the less! I want to thank Jo for all the help and support she has given me, both professionally and personally, and to wish her the very best in her recent career move to Otto Bock. Fortunately, she is staying on with the Publications & Marketing sub-committee, so we shall continue to have the laughter-filled meetings for some time to come! Diolch o galon Jo.

The handover to Carolyn Nichols, our new editor, has been seamless for me, and I love working with her too. I feel so lucky to have two such great editors in succession, and am certain that the journal will continue to thrive with Carolyn at the helm.

We must acknowledge as well the huge contribution from Nicholas Smith at SPS who guided me so patiently through the first issues, and is a continuing source of advice and support. Thank you Nicholas.

### Olwen Ellis, Production Editor

## The Journal in 2010

The Spring 2010 issue of the PMG journal is due out in May, just before the international conference in Glasgow, and we would therefore welcome articles with an **"international"** flavour.

Additionally we are calling for research or clinical articles about **complex physical disability and postural management:**

- training, pathways, or service development
- assessment and prescription
- product development – design criteria and modifications required for specific purposes
- this can include management of posture in lying, sitting, or standing.

The deadline for copy for the next issue is: **28th February 2010.**

Articles submitted can be between 500 and 2,000 words.

For details of the format, or if you need to write something longer, please contact: [olwen.ellis@pmguk.co.uk](mailto:olwen.ellis@pmguk.co.uk) Tel: 0845 1301 764

## Letter from the Chair

### Credit Crunch

There are several developments to report to you in my letter this time around. The one with most immediate impact for most of us is the way the credit crunch and recession has and is affecting NHS services around the country – many of us are all too aware of budget changes, efficiency drives and cost improvements – and it looks as if these will be a fact of life for some time to come. My message to you is to keep your thoughts on your clients, the users of our services in spite of the difficulties. We are here for our users and some changes may also provide opportunities to improve services – which we should try to grasp and implement.



*Nigel Shapcott*

### 4th International Conference on Posture and Wheeled Mobility

Can I urge you to go to [www.mobility2010.org](http://www.mobility2010.org) to look at how next year's conference is shaping up? It looks like it is going to be a cracker, with leaders in our field from across the world participating, as well as whisky tasting to get things warmed up and to help with networking! This 4th International Conference follows on from the success of the two conferences held in Dundee, and the 2005 conference held in Exeter, and is held in collaboration with the British Society of Rehabilitation Medicine (BSRM) and the Scottish Posture and Mobility Network (SPMN). The venue is the Scottish Exhibition and Conference Centre (SECC) in Glasgow, Scotland. There are an increasing number of international conferences on offer including ISS, RESNA, the Nordic Seating Symposium, and the ESS. To complement the programmes of these other conferences, we are placing an emphasis on creating, presenting, and discussing proposals for Best Practice in a number of areas around seating, posture, and mobility. The topics are a mix of updates on existing best practice guidelines and proposals for new ones, and are being worked on by interdisciplinary teams of therapists, medics, engineers, and manufacturers.

### Alliances

PMG is moving ahead with developing alliances with other organisations, with the purpose of making PMG a more effective organisation.

**RESNA** – As mentioned above we are in discussions with RESNA (the Rehabilitation Engineering and

Assistive Technology Society of North America) on how we might best work together; as a result we are using three of their RESNA Position Papers as themes in our Best Practice Topics in the 4th International Conference on Posture and Wheeled Mobility.

**ESS** – We have an ongoing partnership arrangement with the European Seating Symposium (ESS) organisers and as a result have had reciprocal visits to each other's conferences this year.

**UKRC** – Additionally as a result of approaching the UK Rehabilitation Council (UKRC), we now have representation on their board. The UKRC is an umbrella group, recognised and funded by government and set up to promote rehabilitation, exchange information and co-ordinate initiatives; it has already produced the UK Rehabilitation Standards, launched in May by the DWP minister Lord McKenzie. Elections are shortly to be held and more information on them and the UKRC can be found at [www.rehabcouncil.org.uk](http://www.rehabcouncil.org.uk)

### Treasurer

As you may have heard we are losing our treasurer Henry Lumley. Henry has provided sterling service to PMG for many years – my understanding is that Henry is expecting to become Prime Minister round about May 2010 and so will be a bit too busy to look after PMG after that time. Either that or the thwack of the golf balls is calling him. Seriously, we owe Henry an enormous vote of thanks for all the work he has done for us and he will be very hard to replace. Which brings me to my next point – do we have anyone in the membership who would be interested in taking up the challenges of being PMG Honorary Treasurer? If so, please contact Olwen or myself at [olwen.ellis@pmguk.co.uk](mailto:olwen.ellis@pmguk.co.uk)

### The Walton Report

The Walton Report: Access to Specialist Neuromuscular Care was published recently and had significant input from PMG with Linda Marks and myself providing information. The report looks at the inequities of provision of services to those with neuromuscular diagnoses, provides constructive criticism of those services and makes important recommendations for immediate improvements, including:

- A named Muscular Dystrophy lead who is

responsible for service development in each of the ten NHS Specialised Commissioning Groups in England and the three devolved countries;

- The Department of Health to recognise neuromuscular services as specialised;
- The establishment of a NICE clinical guideline for muscular dystrophy;
- An urgent review of workforce needs and professional development.

(ref. [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org))

To download copies of the report go to the PMG website page [www.pmguk.co.uk/Home/Publications](http://www.pmguk.co.uk/Home/Publications)

Helen Hislop and Linda Marks have also worked with the Muscular Dystrophy Campaign on a report they are producing about wheelchairs.

### Special Interest Groups (SIGs)

Finally I would like to remind you that we have a SIG structure in place which I hope will become much more widely used as a result of the Best Practice Topics featured in the 4th International Conference on Posture and Wheeled Mobility (did I already mention that!?).

With kind regards and thanks,  
**Nigel Shapcott, PMG Chair**

## Obituary: David Thornberry (1950-2009)

David N. Condie

*David Thornberry was one of the founding members of the Posture & Mobility Group, and chaired the group for a term during the early years. He was a regular at the PMG annual conferences, as a speaker or delegate, up to 2008.*

This is more of a personal tribute than a professional one although inevitably the two elements are interlinked.

I first met David in about 1985 following the implementation of the McColl Report which entailed the transfer of responsibility for the Artificial Limb and Wheelchair Services from the Ministry of Health to the NHS. David was one of the “new wave” of young Rehabilitation Medicine consultants who had assumed the clinical responsibility for these services. Typically, he recognised the need to establish contacts in his new field of responsibility, and very soon became a familiar face both at the National Centre for Prosthetics and Orthotics in Glasgow and within ISPO UK at whose meetings he was a regular and enthusiastic attendant. Those of us who became acquainted with him at this time quickly warmed to his genial, open and sociable personality.

However it was towards the wheelchair and seating arena that David soon gravitated. Following the success of the Scottish Seating and Wheelchair Group, David was a member of the like-minded group of enthusiasts who promoted and masterminded the creation of its English counterpart the Posture and Mobility Group. He served on the Group’s committee for seven years, between 1993 and 2000, three of these as Chairman.

In the later phase of his career, David’s professional interests and responsibilities broadened to encompass the wider aspects of the field of Rehabilitation Medicine.

He played a major role in the creation of the Chair of Rehabilitation Medicine at the University of Plymouth; however he never lost his interest and enthusiasm for the activities of ISPO and PMG.

One of David’s many attributes was his curiosity. He was always eager to learn of any new devices, techniques or service delivery methods and to employ them whenever appropriate in his own professional setting. His natural instinct as a team member made him ideally suited to working in the field of disability.

David was a devoted family man. He is survived by his lovely wife Judi and their three talented and charming children, Kate, Thomas and Alice, our god-daughter. During the time since we first met him, my wife Liz and I have had the pleasure of sharing their company at their home in the West Country and, on one memorable occasion, while on holiday in the South of France.

David suffered from a neurological disorder for many years, in spite of which he led a full and active social and professional life. It was the additional problems caused by a metastatic skin cancer which led to his early retirement in June 2008. We had the privilege of visiting him at his home in Tavistock just weeks before his death. In spite of his obvious difficulties he was the same warm, cheerful and welcoming David we had always known.

With his untimely demise, our community has lost a talented colleague and we a dear friend.

## Letter from Mark Schmeler: Issues with my Vision

*Many of you will know Mark Schmeler as a regular at PMG and International Conferences over many years. Mark recently sent an email to his friends, family and colleagues describing issues with his vision, and he has given permission for us to reproduce the correspondence here.*

Dear Friends, Family, & Colleagues,

As many of you are aware, I have had a visual impairment since 8 years old due to optic nerve damage caused by spinal meningitis and hydrocephalus. I have about 30% vision remaining, with virtually no vision in my right eye and tunnel vision in the left. Because this loss of vision is neurological (i.e. brain vs. the eyes), it is difficult to process visual input. My limited vision has been stable over the years; however I am now experiencing further decline due to ageing and years of over-straining. The purpose of this letter is merely to inform all of you, as it might impact on how we interact and will help you to understand how I function in various situations.

As a result of further impairment, my eyes take much longer to focus from near to far sight, and longer to process visual information, especially in very dark, very bright, or otherwise overwhelming environments. This is further challenging in less familiar or crowded settings such as restaurants, airports, and conferences. I also have increased difficulty recognizing people right away even if I know you well (i.e. you all look the same unless I see you everyday and/or have very distinct features). The situation is not as much an issue at home or work as these environments are familiar whereby I have a defined cognitive map. It has not affected my ability to perform work duties, especially with providing patient care, because this is a routine and natural role for me. Many of you may be surprised by what I am explaining because I am very competent with some challenging activities such as crossing a busy street, skiing and riding a bike. I am able to perform these types of activities because

1. they are outdoors where I do better with distance focusing on large objects or landmarks, and
2. I typically perform these tasks in familiar environments, preferably with someone leading me.

There is no one simple resolution to the issue. I have been assessed by the best experts in this area. Glasses do

not help. Instead, I need to use other vision support options in order to preserve what is left. The use of Assistive Technology is now a big part of my life, including use of a computer screen reader and adjusting my computers/PDA to high contrast/larger fonts. I am now using a white cane in unfamiliar environments especially when travelling the world with no one to follow or assist with guidance. I am fortunate that, with my current work positions, I have more personnel support to assist with many projects. This has been a tremendous help.

A few examples of where you might assist or improve our interactions include:

- Say your name as you approach me. For example at conferences, the mall, or situations out of context such as in line at Starbucks (i.e. instead of “Hey Mark” say “Hey Mark, it’s John Doe... from...”)
- In potentially challenging or unfamiliar environments, ask if I need assistance navigating food at buffets, reading a menu, finding the men’s room, etc.
- Send information to me electronically such as email compatible with a screen reader versus writing notes or leaving hard copies in my mailbox.
- If you introduce me to a new person, by the end of the conversation, please advise them I do not see well to avoid awkward encounters in the future.
- In challenging environments, allow me to closely follow you as you navigate through a crowd or dark room, or down a set of stairs.

I am perfectly accepting of this situation and have no qualms that it will not impact my relationships or the roles that I play in my day-to-day life. I just wanted you to be aware of the issue and understand some implications of my limited vision.

Thanks,

**Mark R. Schmeler, Ph.D., OTR/L, ATP**  
**Director, Continuing Education Program &**  
**International Seating Symposium,**  
**University of Pittsburgh ([www.rstce.pitt.edu](http://www.rstce.pitt.edu))**

# Best Practice: Lessons from the Field

## Working Together to Protect Body Shape

John & Liz Goldsmith and Sarah Hill, Postural Care Principal Tutors,  
Postural Care Community Interest Company,  
The Sharratts, School Lane, Hopwas, Tamworth, Staffordshire, B78 3AD

**Abstract:** Supporting the body in symmetrical supine lying protects and restores body shape, muscle tone and quality of life for those who would otherwise adopt destructive postures. This powerful and potentially life preserving intervention is a complex and deeply personal aspect of care to be developed within a public health model and led by families.

This article considers: future policy direction; a postural care pathway to enable families to self manage; relating measures of body symmetry to positioning strategies; recruiting widespread support to develop a public health model; working together from a family's point of view.

### Introduction

Increased use of therapeutic positioning at night has resulted in acceptance that supporting the body in symmetrical supine lying protects and restores body shape, muscle tone and quality of life. This powerful and potentially life preserving intervention is a complex and deeply personal aspect of care which must be broadly developed within a public health model and led by families (Waugh and Hill 2009).

This article will consider:

- indications for future policy direction
- a postural care pathway to enable families to self manage
- relating measures of body symmetry to positioning strategies
- recruiting widespread support to develop a public health model
- working together from a family's point of view

By qualifying families to self manage postural care, healthcare professionals are able to enjoy good results for the people they support and the pleasure of working in harmony with families (DoH 2009). However, many acknowledge the need for maturity of services if they are to work together with families to protect body shape.

### Indications for future policy direction

Sir Jonathon Michaels' Inquiry (Michaels 2008) 'Healthcare for All' written in response to Mencap's 'Death by Indifference' (Mencap 2009) 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."*

The following extract from David Cameron's recent speech on "The five lessons I learned as father of a disabled child – and intend to put into practice" may well give us a vision for policy direction and help us to find the levers we need for others to appreciate the huge contribution therapists make to disabled people's welfare (Cameron 2009).

*"The very painful thing about disability – whether your own or your loved one's – is the feeling that the situation is out of your control. When the system that surrounds you is very top-down, very bureaucratic, very inhuman, that can only increase your feelings of helplessness. So a really big difference we can make is to put more power and control right into the hands of parents, carers or those with disabilities – through personal budgets and direct payments. That means that instead of giving a little bit of money from health, from education, from children's services, we say to people: "Here is the total budget for you or your child; you choose how it's broken down."*

### A postural care pathway to enable families to self manage

A structured approach and tangible outcomes will secure family led commissioning of healthcare professionals' services in the future. A care pathway will provide

evidence of successful protection of body shape and families with the training to be “in control” and self manage postural care.

The care pathway “It’s My Life” follows a 5 step approach (Hill and Goldsmith 2009):-

#### *Step 1*

- a. Identification of need: The Mansfield Checklist (Goldsmith, S. 2000)
- b. Identification of stakeholders and building relationships

#### *Step 2*

- a. Baseline measures of body symmetry: The Goldsmith Indices (Goldsmith et al 1992) (Goldsmith, J and L. 2009)
- b. Making a plan

#### *Step 3*

Empowerment of families and personal assistants through accredited and quality assured training ([www.posturalcareskills.co.uk](http://www.posturalcareskills.co.uk))

#### *Step 4*

Establishing individualised funding and equipment acquisition (Newlife Foundation 2007) (Mason, M. 2005)

#### *Step 5*

Ongoing support, measurement and keeping in touch

### **Relating measures of body symmetry to positioning strategies**

The conventional chest is a vulnerable and mobile structure which distorts immediately and predictably in lying but also features the elasticity to recoil to original proportions on movement. Those who adopt static lying postures acquire progressive fixed distortions as a result of loss of recoil which are predictable according to the following principles. The sterno-spinal line (SSL) is an imaginary line which runs between the sternum and the spine. If the SSL is either vertical or horizontal in the habitual lying posture, over time the chest will compress symmetrically. If the SSL is not vertical or horizontal it will rotate towards the horizontal causing predictable distortion of the chest. To protect and restore chest shape, rotational and containment forces are applied in the lying posture.

Measuring and understanding balance and structure of the body in lying is an essential precursor to

understanding challenges posed by the seated posture; the body has only approximately one third of the surface area on which to balance in upright sitting as compared to the lying posture. If a person is structurally asymmetric and unable to balance in lying, the gravitational pull in prolonged upright sitting will cause kyphotic, asymmetric, rotated distortions of the thorax which reduce internal capacity, in turn affecting the function of internal organs. Development of wheelchair design offers tilt in space and also allows the person to lie back, with an open angle at the hips, in a reclined position with deep accommodation of the asymmetric thorax; in this posture gravity can be used to centralise the body. Developing the first building block of movement ability by maintaining symmetry and establishing balance in the lying and semi-reclined posture will safeguard internal capacity of the abdomen and thorax and, in turn, defend function of the internal organs. As such monitoring body symmetry is indispensable in preventing complications with digestive and cardio-pulmonary function, dysphagia, reflux, suffering and premature death.

The results of any positioning strategy can be continuously reviewed using the Goldsmith Indices of Body Symmetry, and changed if they are not succeeding in protecting body shape. The 1992 study revealed: “It can be concluded that the measurements obtained in this way consistently differentiated among subjects even when made by different testers.” The results of these procedures will only be recognised if they are standardised by being carried out by fully trained and qualified measurers using the Anatomical Measuring Instrument – AMI (Simple Stuff Works 2009). To protect integrity of the measures no alterations may be made to the procedure without permission of the authors. Work to establish construct validity with other variables is ongoing.

### **The Procedures**

Each of these procedures is carried out in crook lying with the knees flexed to 70 degrees. They are carried out four times and the mean of these four measures is calculated so that both the average result and the range of readings provide information and an indication of intra-rater reliability. Procedure 1 measures critical proportions of the chest which will indicate internal capacity of the abdomen and thorax; procedure 2 provides information about symmetry of movement as the knees are taken from side to side and will pick up the early signs of windswept distortions; procedure 3 measures symmetry of a range of movement at the hips.



Pic 1



Pic 2



Pic 3



Pic 4

*Procedure 1:*

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

*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. (Pic 3)

*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. (Pic 4)

**Recruiting widespread support to develop a public health model**

Developing public awareness of the principles of postural care requires involvement of a large workforce such as the nursing profession. In their recent article published by the Royal College of Nursing in Learning Disability Practice, Waugh and Hill identified three groups of people who would benefit from more generalised understanding and provision of postural care and three levels involved in prevention of distortion within a public health model:

“Three broadly identifiable groups of beneficiaries to include people with:-

- Movement difficulty, regardless of diagnosis. For example people with complex needs, older people and people with disability.
- No apparent movement problem, but for whom posture analysis and body measurement shows habitual postures that can cause distortion.
- Transient needs during episodes of reduced mobility such as post surgery, stroke or trauma.

Three levels of prevention of body shape distortion within a public health model:

“Primary prevention:

- Raise public awareness about how, and why, static, destructive postures distort body shape; how this reduces the capacity of the abdomen and thorax, compromises internal organs and can contribute to suffering and premature death.
- Develop understanding that symmetrical supine lying prevents distortions of body shape caused by static, destructive postures.
- Promote strategies to safeguard capacity of the abdomen and thorax, and in turn protect the internal organs.

Secondary prevention:

- Educate professionals to be alert to the early signs of asymmetry of the costal margin and the implications for internal capacity.
- Ensure reliable, objective measurements of the chest.
- Promote posture analysis.

Tertiary Prevention:

- Provide quality assured training for beneficiaries and their first circle of support to self manage postural care.
- Provision of the necessary equipment, both improvised and specialist.
- Provide ongoing monitoring and support as required.”

Nurses are a large workforce in continuous contact with the general population; they are used to monitoring, measuring and relating outcomes to interventions in order to promote health and maintain homeostasis. The profession is keen to add monitoring of the costal margin and simple measures of critical chest dimensions to their repertoire; their contribution to the generalisation of postural care will be essential to the ongoing success of protecting body shape.

### **Working together from a family's point of view**

A good friend describes having a disabled child as being like Alice when she falls down the rabbit hole. Suddenly you are in a strange land where everyone seems to be talking a different language; they all seem to understand what they are talking about but to you it's all gibberish. There are new places to go to and people you have to meet. There are people involved in your life that haven't been invited and you feel powerless to control anything.

My little girl was 6 when we fell down the rabbit hole. A malignant brain tumour threatened to take her from us and the following 12 months saw her battle for her life. During that time we were privileged to meet some of the most talented and dedicated professionals you could ever wish to come across. Her treatment was complicated; some of our time was spent in hospital but most was at home with the support of community nurses. In total we had contact with over 20 different professions, from neurosurgeons to healthcare assistants, radiologists to play therapists, all had a valued and vital role to play in supporting our family. This time was a struggle financially as well as emotionally. Hospital appointments and a very poorly child at home meant that I didn't work for over a year; we relied on my husband's wage and the kindness of friends and family. We have two other children, both of whom continued to need us. We had no money, no social life, and very little sleep as for most of the time our daughter was on 4-hourly anti-sickness medication during chemotherapy; our social networks changed dramatically as we came to know other families in our situation. We don't know if our brush with childhood cancer is over, but we do know that we'll never view our lives or relationships in the same way again.

Working together with families is hard. Sometimes as parents we're so stressed out we might get annoyed, we might be close to the end of our rope and take it out on the people trying to support us. Sometimes you might not agree with the path we choose to take with our children, sometimes you might be disappointed that we haven't done as we were told. There may be times that you simply don't understand where we are coming from or what we are talking about (this feeling is often mutual!) but we are doing our very best. Working together means ensuring that systems, language and outcomes reflect the needs of families, rather than those of services. When working with families is hard, perhaps it's those systems, language and outcomes that need studying, rather than the commitment of family carers?

### **Conclusion**

Indications of policy direction suggest that in the future families will be in control of their own budgets and will need the qualifications to provide postural care. For providers the question must be answered: “When families have their own budget would they buy your service?” Postural Care Pathways will provide a structured approach to identifying need, recruiting support, measuring body symmetry, making a plan and monitoring results. Positioning strategies will be driven by objective measures of body symmetry and

widespread understanding will be developed by the adoption of a public health model. Compassion for the individual and their family will underpin the values of every professional involved in the provision of postural care. By following these principles therapists have the opportunity to play a key role in ensuring that protection of body shape will become a reality for individuals and their families in the future.

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## The Development of an X-Ray Protocol for Children on North Devon's Integrated Care Pathway for 24 Hour Postural Management

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**Abstract:** *An Integrated Care Pathway for 24 Hour Postural Management was developed for children with moderate or severe physical difficulties in North Devon in 2003. An X-ray protocol has recently been developed by a multi-disciplinary team alongside this pathway to ensure that all children receive timely routine hip X-rays in a standardised position allowing measurement of hip migration percentage that can be repeated and reviewed with subsequent images.*

There is evidence to show that children with cerebral palsy who have bilateral increased muscle tone and who are unable to walk 10 steps independently by the age of 30 months, are at risk of progressive subluxation of the hips (Scrutton et al 2001). Carefully managed postural management programmes can be effective in reducing this risk (Pountney et al 2002). A postural management programme is a planned, individually tailored approach, made in agreement with the child and their family. This

may involve therapeutic activities, provision of equipment, and surgical intervention aiming to maximise functional independence, and reduce the risk of soft tissue contractures and skeletal deformity (Gericke 2006). An Integrated Care Pathway for 24 Hour Postural Management was developed for children with moderate or severe cerebral palsy in North Devon in 2003 to provide a structure and a signpost for clinicians.

Recently an X-ray protocol for children on this care pathway was developed to support effective hip surveillance. This was a multidisciplinary project involving the local radiographers, physiotherapists, paediatricians, consultant radiologist, and orthopaedic surgeon. The lead radiographer is continuing to attend and is a valuable member of the Postural Management Group which meets twice a year.

The community paediatric physiotherapists attended training on the application of the Ionising Radiation (Medical Exposure) Regulations (IRMER) 2000 for referrers. This allowed the physiotherapists to request imaging investigation of paediatric hips for children on the Integrated Postural Care Pathway (IPCP). Guidelines to ensure standardised positioning of children having hip X-rays were provided for the radiography department. These follow the recommendations by Scrutton and Baird (1997). Gonad protection is not used in the initial X-ray to avoid obscuring the image and preventing accurate measurement of hip migration.

The X-rays are taken digitally and the radiographers use a computerised program which allows them to mark the image and measure the migration percentage (Reimers 1980), establish the degree of abduction/adduction (if it is > 15 degrees abduction or > 10 degrees adduction then the X-ray is considered to be not valid), and degree of rotation of the pelvis by calculating the interforamina ratio (if the value is <0.5 or >2.0 the X-ray is considered not valid). Measurements are checked by the consultant radiologist and a report is completed. The referrer is responsible for ensuring that the child's paediatrician and orthopaedic surgeon are aware of the outcome.

The hip migration percentage will determine whether the orthopaedic surgeon needs to review the child, when subsequent hip X-rays should be taken, and as therapists whether we need to increase the intensity of postural management and consider a sleep system.

Every effort is made to obtain standardised positioning for imaging and measuring of hips and although the process is somewhat imprecise (Pountney et al 2003) it is still considered the best measure to date.

Postural management for children at risk of soft tissue contractures and skeletal deformities needs to include a formal process of surveillance of their hips by X-ray. In North Devon this has been achieved through working together with the local radiography department. The multi-agency Postural Management Group continues to meet regularly to review policies and current practice in the light of new research and to discuss best practice for the children and families with whom we are involved.

Acknowledgements to: Sarah Stone, Senior Children's Physiotherapist and Gill Kite, Senior Radiographer, North Devon District Hospital, for their help in the development of this protocol.

For a copy of the protocol please contact the author.

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# The Redesign of the Clinical Delivery Model of a Regional Seating Service

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**Abstract:** This article describes the redesign of the clinical delivery model of the Seating Service for South-east Scotland. The aim was to improve the service to patients by taking advantage of the co-location of all the clinical staff involved in the service, and to make waiting times fairer by reducing unnecessary delays, reducing the reliance on referral information and the number of attendances per patient.

Over the first year, the number of patients awaiting assessment has been reduced by 57% and the average projected waiting time to assessment was reduced by 16 weeks.

## Introduction

Specialist wheelchair seating is needed by people who require a wheelchair for mobility but due to deformity or instability need additional support in order to function (BSRM, 2004). Underlying clinical pathologies include cerebral palsy, learning disability, multiple sclerosis, muscular dystrophy, motor neurone disease, brain injury and spinal cord injury. The basic philosophy of wheelchair seating is that the body should be maintained in a balanced, symmetrical and stable posture that is both comfortable and maximises physiological and physical functions (Barnes, 1993). There is good evidence that wheelchair seating can enhance cognitive function, dexterity, communications skills, respiratory capacity and physical endurance, reduce spasticity and the development of contractures, and facilitate activities of daily living (Farley et al., 2003; BSRM, 2004; Kirkwood & Bardsley, 2008). Due to the changing clinical needs of people with disabilities their wheelchair seating systems need to be replaced on average every 3 to 5 years (BSRM, 2004).

The role of the Seating Service is to satisfy, on an ongoing basis, the postural support requirements of patients who cannot sit comfortably, safely and/or appropriately within standard wheelchair seats. The service covers three health boards (Lothian, Fife and Borders with an overall population of around 1.3 million) and serves around 650 active patients (around 3% of wheelchair users). A comprehensive service is provided from initial assessment to delivery and ongoing maintenance. The seating systems provided are either manufactured internally or purchased from commercial suppliers. The service was delivered by clinical staff from two different departments (Rehabilitation Engineering Services and the Mobility Centre) that were co-located to a new purpose built facility in January 2007.

Rehabilitation Engineering Services and the Mobility Centre are part of Southeast Mobility and Rehabilitation Technology (SMART) Services. All the SMART Services were co-located to the purpose-built SMART Centre, Astley Ainslie Hospital, Edinburgh in January 2007, having previously operated from two hospital sites. The Seating Service was delivered by a multidisciplinary clinical team consisting of two clinical scientists, one occupational therapist and one physiotherapist with medical support from the Consultant in Rehabilitation Medicine. The two therapists also worked within the Wheelchair Service delivered by the Mobility Centre. Each health profession brings different expertise and skills essential to assessing patients with complex neurological and physical disabilities, and determining the most appropriate equipment required to meet patients' clinical and functional requirements. The equipment is manufactured, assembled and maintained by the technical team consisting of five clinical technologists. The service was supported by two administrative officers.



(from left to right) standing: Mike Hood, Dougie Nicholson, Lesley Inglis, Michael Dolan and Lesley Purves, and seated: Karen Muir

The redesign took place against a background of change. The key drivers included:

- The Scottish National Review of Wheelchair and Seating Services (Scottish Executive, 2006).
- Increasing demand due to changing demographics and care in the community (Scottish Executive, 2006).
- National performance improvement targets (HEAT Targets A4 and T7) that aim to improve access times and the quality of the healthcare experience (Scottish Government, 2007).
- Complaints from patients about excessive waiting times of up to 14 months.
- Difficulties in recruiting experienced clinical team members.

The key enablers were:

- The co-location of the whole clinical team at a purpose built centre in January 2007, having operated previously from two hospital sites.
- The provision of additional funding for commercial equipment provided as part of the National Review of Wheelchair and Seating Services (Scottish Government, 2008).

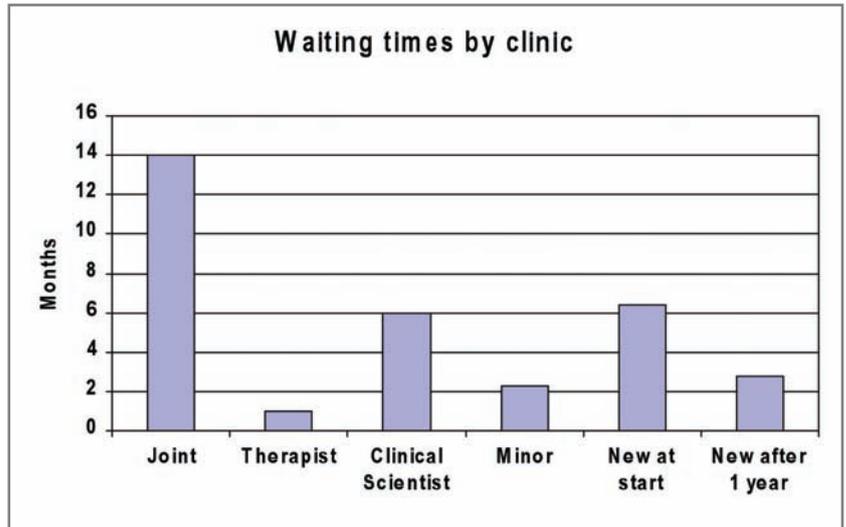


Fig 1

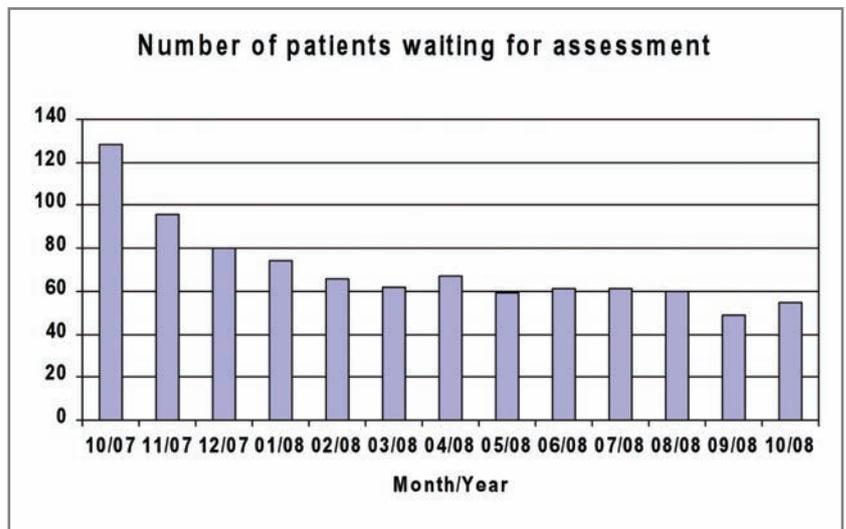


Fig 2

### Existing Delivery Model

The existing patient care pathway consisted of four distinct clinics. Referrals were screened and allocated to one of the four waiting lists. Due to differences between available clinic appointments and referrals rates, waiting times for each clinic varied from 1 to 14 months (Fig 1).

Many problems with the existing model were identified:

- it was difficult to determine from referral information which was the most appropriate clinic resulting in some patients attending the wrong clinic,
- patients seen by the Consultant in Rehabilitation Medicine at the Wheelchair Service’s Powerchair Clinic had to be referred on to the Seating Service and attend for another assessment, and
- patients assessed in the community by one of the therapists as part of their Wheelchair Service duties then had to attend a clinic.

These problems resulted in:

- a waste of clinical and administrative staff resource,
- patients waiting much longer than required, and
- some patients being assessed more than once.

### New Delivery Model

The initial proposal for the new clinical delivery model was developed following a review of the problems with the existing delivery model and the potential for change brought about by the co-location of services and the possibility of increased equipment funding. It was discussed and developed in consultation with service staff. The proposal was finalised in August 2007 and included an action plan. Actions included:

- Obtaining agreement of service managers.
- Amalgamating the four existing waiting lists into a single waiting list.
- Agreeing and setting up a single administration process to appoint patients and clinical staff to clinics.

The actions and target deadlines were achieved, allowing the first new format clinic to go ahead on 2nd October 2007.

The new model was designed to:

- Target the most appropriate staff skill mix.
- Minimise the number of unnecessary patient appointments.
- Reduce the time required to design bespoke equipment by increasing the range of adjustable, commercial equipment available.
- Reduce the need for interim solutions or minor modifications to equipment whilst patients wait for a clinical assessment.

The changes made were three fold:

- A single scheduled seating clinic was established with multi-disciplinary staff cover replacing the four existing clinics.
- Clinical Scientist cover was provided for the Consultant-led Powerchair Clinic.
- A framework was introduced for the direct prescribing of seating equipment by the Wheelchair Service therapists.

The new delivery model was formally reviewed by the Seating Team after 1 month, 3 months and 1 year.

### Outcome

Over the first year, the number of patients awaiting assessment has been reduced by 57%, from 128 to 55 at the beginning of October 2007 and October 2008 respectively (Fig 2). Over the same period, the average projected waiting time from referral to assessment has reduced by 16 weeks, from 28 to 12 weeks (Fig 1). For the most complex patients requiring a multi-disciplinary assessment the reduction was 48 weeks, from 60 to 12 weeks.

The earlier intervention resulting from the significant reductions in waiting times has numerous health, functional and social benefits for patients. For example, patients may develop pressure sores if their seating no longer fits correctly or their general health deteriorates. This can result in patients having to reduce the time they spend in their wheelchairs, reducing social contacts, and in severe cases can lead to prolonged hospital stays and plastic surgery. Some patients with rapidly deteriorating conditions have benefited from two clinical interventions over a period when previously they would still have been waiting for their first assessment.

Patients have also benefited from a reduction in appointments. Patients are seen for seating when they attend the Consultant-led Powerchair Clinic. Other patients that are seen in the community by one of the therapists (in their Wheelchair Service capacity) are directly prescribed seating equipment.

There has been a positive impact on clinical staff's job satisfaction as they are now able to meet patients' needs more quickly and directly.

### Conclusion and Future Work

An increased throughput of patients was achieved by:

- Minimising the number of unnecessary patient appointments.
- Targeting the most appropriate staff skill mix.
- Reducing the time required to design bespoke equipment by increasing range of adjustable, commercial equipment available.
- Reducing the need for interim solutions or minor modifications to seating equipment whilst patients wait for a clinical assessment.

Providing there are sufficient funds to purchase equipment, significant reductions in waiting times can be achieved within existing staffing levels by looking afresh at the existing patient care pathways, targeting the most appropriate staff skill mix and eliminating unnecessary processes.

Further initiatives are underway to target specifically the time to process and screen referrals and between assessment and issue of new equipment, so as to reduce the overall referral to treatment time. This includes a wider examination of the equipment available commercially with a view to reduce further the reliance on in-house design and manufacture and to increase the range of stock available, so that increasing numbers of patients can be issued with their new equipment on the day of their assessment.

As the waiting time is reduced further it will be possible to move to providing scheduled clinical reviews. This is in accordance with the requirement for planned reviews of complex cases in the proposed tiered delivery model in the Wheelchair and Seating Services Modernisation Action Plan (Scottish Government, 2009) and the anticipatory care approach (Scottish Government, 2007).

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## ATcare: Promoting the Development of Assistive Technology to Enable Individuals to have Choice and Control

Christine Asbury, Chief Executive, ATcare  
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**Abstract:** *ATcare was established to encourage innovation and new thinking in the field of assistive technology (AT), driven by the recognition that increasing numbers of baby boomers will demand more choice and control over how they live their lives. There needs to be a change in the way that assistive technology products are designed, developed and marketed so that lives can be transformed.*

We live in an ageing society. By 2025, one in five of us will be over 65 and over six million older people will be suffering from a debilitating long term condition requiring assistance to live. In 20 years time, 1.7 million more people will need care and support to get on with their lives.

But how are we addressing this emerging challenge? A recent report suggests that, to date, we have not made the right strategic plans. The report, *Roadblocks to Market*, highlights the lack of investment in assistive technology (AT) products and services. Many AT products remain on the drawing board because of a lack of knowledge and commercial expertise which could develop and market them. The research found that of 362 AT products that were researched between 2004 and 2007, less than one quarter made it through to final product development. This is a lamentable situation: potentially millions of people miss out on the choice and control that well-designed, practical and affordable AT could bring to their daily lives.

That's why ATcare was established in July 2008. A number of key organisations including the Foundation for Assistive Technology (FAST), NHS Innovations

London (NHSIL) and Professor Martin Ferguson-Pell, Dean of Faculty of Rehabilitative Medicine, University of Alberta made the case for innovation and new thinking in the field of AT, and a £2.35m grant over three years was secured from the London Development Agency. ATcare was launched at the House of Commons in March 2008.

ATcare has three main areas of activity: involving users at every stage of design and development of AT, supporting the delivery of new products to the market, and ensuring that designers and companies recognise the opportunity that AT provides in terms of new business opportunities.

The new ATcare Design and Development Centre, which was opened by the Lord Mayor of London in 2009, provides help and support to designers and small businesses in a number of ways: design and product development, regulatory advice and approval, user and market assessment and product business case development. It also provides professional development and knowledge transfer for London-based small and medium sized enterprises (SMEs) and it works with academics, commissioners, clinicians and other stakeholders to influence the debate about the need for

high quality assistive technology products and service. Overarching all these specific activities is a commitment to transform the market in assistive technology and by doing so, to transform the lives of those people who need additional support in their daily life.

### User involvement is key

But it's not only investment and business acumen which is needed to ensure that AT is successful in the market place. Too often people who might use AT say that products and services 'don't do what they say on the tin'. That is why a major drive for ATcare is to make the convincing case for users to be involved at every stage of design and development. ATcare works closely with voluntary organisations such as *Enabled by Design* and *Innovations in Dementia*. Disabled and older people have individual needs, preferences and requirements whether they are living at home or are part of the 10% of the UK working population who are disabled. It is vital that design solutions for products and services are flexible and adaptable and that it is recognised that no single solution will suit all.

Users also report that some AT products are unappealing, ugly or stigmatising. Older and disabled people are just as likely to want aspirational, attractive and well designed products.

### Progress so far

Over the past year, ATcare has worked with single designers beaver away in the garden shed as well as medium-sized companies with products on the market that need only small adjustments to make them useful for people with different or wider needs, for example, dementia or mobility problems. The innovation is out there but a lack of funds, know-how or understanding means these potentially useful products have not made it onto the market. Since March 2009, ATcare has assessed some 35 assistive technology products and five are well on their way to market already.

### Plans for the future

It may sound naive but ATcare wants to change the world. We coordinated a seminar in collaboration with the Royal Society for the encouragement of Arts, Manufactures and Commerce (RSA) to stimulate debate and behaviour changes in designers around the design and use of AT, and to explore how language influences our understanding. We are also planning a 'challenge workshop' next year in conjunction with the Royal College of Arts (RCA) to encourage more SMEs to see the potential in AT as an emerging market. On-going plans for user consultation days are aimed at stimulating users, whether disabled or older people, to articulate and prioritise their requirements and aspirations for assistive technologies, and to engage them further in influencing design. All the work is driven by the need to raise awareness about AT as a general issue that we all need to understand and appreciate more fully.

### Small is beautiful

ATcare is a small organisation with only 7 full time staff and a number of consultants supporting particular functions. So it must work constructively with partners from a range of different fields in order to achieve its objectives. And this is also its strength. ATcare must develop a strong commercial basis on which to operate but we also recognise that our business has an important social value. ATcare has at its heart a driving mission: to transform lives through technology, and that is what will be achieved by working in partnership in this important – and exciting – field.

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Assistive Technology: Roadblocks to Market, ATcare 2009.

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## NTE Will Never Be The Same Again...

**Abstract:** Martin Moore served on the PMG Executive committee from 2002 to 2009, and was involved from the start with Conference (NTE) organisation and then the breakaway Education & Training sub-committee, taking responsibility as chair of both for several years. Latterly he became vice-chair of PMG, standing down from that office in April 2008.

For many of you, the PMG conference and Martin Moore are synonymous. Over the best part of this decade, Martin has devoted a large part of his life to helping create the group's annual meetings – as well as becoming the father of twins, Rosie and Cameron, during this same period!

Martin brought to the task of PMG conference co-ordinator, and to the executive committee generally, his own particular brand of commitment and dedication – that is, with a great dollop of gallows humour, and it's what we all miss so much about him! Olwen gleaned a great deal of her knowledge about the conference



Martin Moore rallying the troops, February 2006 NTE at Pontins in Blackpool

“formula” from Martin during their various site visits up and down the land, trying to find locations for the annual event – the most surreal of all being in June 2005 as honoured guests of Pontins in Blackpool!

Thank you Martin for your support and advice over the years – always at the end of the phone in a crisis, to bring perspective and clarity. No-one is indispensable, but Martin Moore is definitely irreplaceable!

**Jane Chantry and Olwen Ellis, also on behalf of PMG executive committees past and present, and the wider membership.**

## FAST's researcher joins PMG R&D Sub-committee

Pat Sweet, Researcher, Foundation for Assistive Technology (FAST),  
31 Scarborough Street, London E1 8DR

**Abstract:** The Foundation for Assistive Technology (FAST) is a charity whose aim is to support innovation in assistive technology (AT) product development and good practice in service provision. FAST works as an umbrella body, independently representing the AT sector, and is supported by government contracts and consultancy work with a variety of organisations.

FAST's researcher is joining the PMG's R&D sub-committee. Pat Sweet has worked for FAST for three years, with primary responsibility for the organisation's website and database. Prior to that, Pat worked as a technology journalist and, as the parent of a child with cerebral palsy and impaired mobility, has experience of assistive technology in use.

Assistive Technology (AT) is 'any product or service designed to enable independence for disabled and older people' (King's Fund consultation 2001). FAST has been working with the AT community since 1999 with the aim of making well-designed AT available easily and quickly to those who can benefit from its use.

In support of this goal, FAST is active in a number of

different areas. Our website provides a database of research and development activity in the AT field, ranging from multi-million pound projects involving multiple European partners to small scale investigations carried out by one researcher. The research may be funded by the UK government, the European Commission, or by other UK organisations such as charities. Around 110 new projects are added to the

database each year, and details of approximately 350 projects entered over the previous five years are regularly updated with details of progress and outcomes. This information is fully searchable by project name, funding source, project partners and keyword, and is a free resource for researchers, policymakers and the general public.



Pat Sweet

As part of our dissemination role, FAST is responsible for providing an annual report to Parliament on government-funded R&D activity in AT on behalf of the Department of Health. This year's report, along with all previous reports, is available on the FAST website via this link: [www.fastuk.org/research/fastannualrdreport.php](http://www.fastuk.org/research/fastannualrdreport.php)

The FAST website also contains listings of jobs, events and training courses in the AT field, and we publish monthly e-bulletins on both policy issues and R&D developments. Currently we have over 800 subscribers to our AT policy bulletin, including rehab engineers, OTs, physios, commissioners and commercial companies, and around 400 subscribers for the R&D bulletin. All editions of both bulletins are also available on the website.

As well as providing information, FAST works to identify issues relevant to the AT community across different practice areas in order to develop generic standards and guidance. For example, FAST has produced a series of reports looking at AT workforce development and has reported on standards in service provision. We are currently working on two projects designed to increase the involvement of disabled and older people in the decisions around the use of AT. One project is looking at the development of a training course to help people with long term conditions or disabilities choose and use AT for self-care, while the other is looking at ways of engaging older and disabled people in the design and development of AT products.

I was very pleased to be asked to join the PMG R&D sub-committee. FAST already holds details of PMG-funded projects on the FAST database, and I am always looking for ways to connect with researchers, both to learn more about their specific projects and also to increase my understanding of the challenges and issues facing the research community. By sitting on the sub-committee, I will be able to find out about project progress and gain an insight into new projects under

consideration for funding. I will also be able to provide information from FAST's database about projects which have similar aims or address similar problems to those under discussion. In addition, I will be able to publicise PMG's research work in FAST's bulletins and as part of the support FAST provides for the annual RAaTE conference.

I view joining the PMG R&D sub-committee as bringing benefits to both organisations. I will be able to expand the scope and depth of FAST's R&D project information, while PMG has access to another channel for promoting news of current activities.

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King's Fund. (2001). Consultation Meeting on Assistive Technology, London, King's Fund.

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## Research & Development Sub-committee

The main work of PMG's R&D sub-committee continues to be the administration of the small research study funding scheme. Since 2005 the sub-committee has overseen the provision of funding to 14 projects. These are listed below. Some of the studies are now completed, and you will find full reports on the PMG website in the Research section. For the projects still in progress, there are outline abstracts available to read there.

1. *Wheelchair mobility for people following stroke with perceptual problems.* **David Punt** (completed)
  2. *Balancing manual wheelchair stability and 'tippiness' for functional independence.* **Lynne Hills** (completed)
  3. *A study of the biomechanics and kinematics of standing during development, and in children with cerebral palsy. A three phase study.* **Alice Wintergold**
  4. *What is the effect of postural management at night on hip stability and quality of sleep in children with bilateral CP, and how do the children and their parents view it?* **Ginny Humphreys**
  5. *A single blind controlled study to assess advantages of power assist wheelchairs (E-motion project).* **Joyjit Sarkar, Edward Laskey, Rachael Harwood, Dr Bandara Panagamuwa**
  6. *Postural management programmes for children with physical disabilities – a pilot study of teachers' views and experiences.* **Eve Hutton** (completed)
  7. *Can generic shape patterns be obtained by examining a series of customised postural support systems?* **Lorna Tasker** (completed)
  8. *Wheelchair navigation and unilateral neglect: can the use of technology improve performance?* **Geoff Harbach/David Punt**
  9. *The impact of caregiving for physically disabled children who use wheelchairs on their caregivers' occupational performance, health and satisfaction.* **Jackie Casey/Rachael McDonald**
  - 10 *Positioning patients in low awareness states in wheelchair and bed – experiences of nurses and health care assistants (HCA's).* **Rasheed Ahamed Meeran**
  - 11 *What does a wheelchair represent to its users? A phenomenological study into the experiences of a group of adult permanent wheelchair users.* **Linda Walker**
  - 12 *An exploration of communication during wheelchair & adaptive seating system assessments for disabled children and their families.* **Sally Kyle**
  - 13 *Does the use of dynamic seating reduce movement of the pelvic position forward, following extensor movement, in individuals with cerebral palsy?* **Nicola Holbrook**
  - 14 *How are children included in decisions affecting their postural management programme in mainstream primary schools? To what extent, if any, does postural care impact on their inclusion in school?* **Lesley Ann Perry**
- Olwen Ellis (administrator)  
and David Porter (co-chair)  
PMG R&D Sub-committee**

**If you have a project you wish considered for funding through this scheme, please submit your outline proposal via the PMG website by December 31st 2009.**

**[www.pmguk.co.uk/Research/Information](http://www.pmguk.co.uk/Research/Information)**

# Book Reviews

## “Postural Disorders & Musculoskeletal Dysfunction: Diagnosis, Prevention and Treatment”

Author: Dr Gill Solberg • Published 2008 (Second Edition)

Publisher: Churchill Livingstone (Elsevier)

Review by Joanne McConnell

**Target Audience:** Therapists, therapy students, rehabilitation engineers working in the field of posture.

**Recommended experience level of reader:** All levels

**Overview/Summary:** This is a useful book for therapists working in the field of postural disorder and deformity, and would also be an excellent tool for students especially OT and Physiotherapy students. The book would also be a useful read for clinicians working in paediatrics.

I found the book to be a really useful read, and the type of book you can pick up and review a chapter at a time. It is laid out in a very easy to read format with some excellent illustrations and photos.

Part one revises such aspects as movement planes, basic movement terms and anatomical aspects of maintaining posture. Part one also has detailed illustrations in straightforward tables of all the muscles affecting the joints of the ankle, knee, hip, pelvis, spinal column, rib cage and shoulder girdle.

Part two moves on to analyse disorders of the spine, initially in the sagittal plane, namely kyphosis and lordosis, and injuries to the intervertebral discs. This section has excellent photos to illustrate how these disorders affect posture in everyday life and in different positions.

The second focus of Part 2 (chapter 4) looks in detail at disorders of the spine in the frontal plane, namely scoliosis and diagnosing scoliosis, again this is illustrated extremely well; it really helps the reader understand scoliosis and its implications for practice. There is also a section on postural deformities in the lower extremities and identification of gait disorders; this section will be of great interest to physiotherapists. Part two closes with a focus on postural disorders and dysfunction in the upper extremities; as you would imagine this goes into great detail about both gross and fine motor activities in the upper limbs.

Part three looks at diagnosis and treatment of postural deformities, and is of great relevance to therapists,

suggesting activities for every postural disorder. It has a very useful checklist for parents, as well as a chapter on hydrotherapy and its benefits, and a chapter on orthopaedic support braces for children with postural deformity.

One of my favourite chapters is chapter 12: movement and postural development in early childhood. This is a great revision chapter for all paediatric therapists, looking at normal development and milestones. When we work for so long with disability and postural deformity it's always good to remind ourselves about “normal” postures and abilities. This chapter would also be very useful for therapy and nursing students as well as rehabilitation engineers who are new to the field and are working with children in their caseloads.

To summarise, this is a useful book to have on your shelf, giving you a greater understanding of this key area that many of us work in. I found it very easy to read, the chapters flowed neatly into each other, and there are helpful, impressive illustrations.

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**Editor's comment:**

*I have this book as well and, as someone who has worked mainly with people with very low levels of ability, I find it to be very useful and interesting with regards to postural disorders in people who are relatively able.*

# “Finnie’s Handling the Young Child with Cerebral Palsy at Home”

Author: Eva Bower (editor) • Published: 2009 (Fourth Edition)

Publisher: Butterworth Heinemann (Elsevier)

Review by Carolyn Nichols

**Target Audience:** Parents and families of children with cerebral palsy, carers, nurses, therapy students, assistant therapists as well as experienced therapists and other relevant clinicians.

**Recommended experience level of reader:** Intelligent layman, with assistance from the glossary and possibly some explanation from relevant professionals.

**Overview/Summary:** Nancie Finnie’s well-known book was first published in 1968. Since that time it has been used by many, many families to help them come to terms with their child’s problems, and learn to handle their child in ways which make the most of their abilities and minimise their problems. This new edition, edited by Eva Bower, has been predominantly re-written and updated, and new chapters have been added including chapters on brain imaging techniques, epilepsy, emotional health, orthotics, spasticity, and complementary and alternative medicine. The book is intended to cover the early years (0-5 years of age), although much of the information and suggested activities are useful and relevant for older children and adults.

The fourth edition of Nancie Finnie’s book, described as their “bible” by many parents of children with cerebral palsy, now includes even a greater wealth of information. The chapters have been reorganized and many have been revised and updated by the editor, Eva Bower. Seven new chapters have been written, and many chapters completely re-written, each by a specialist in the relevant field.

The early chapters provide practical advice on communication between parents and professionals (questions to ask, planning intervention together, handling numerous professionals), and dealing with and planning for hospital appointments and admissions (importance of providing information regarding the child’s means of communication and how to recognize discomfort/pain; planning for coming home from hospital). The third chapter gives a clear description of the causes and associated problems of CP. There are new chapters on epilepsy and on brain-imaging techniques, which also provide a good synopsis for experienced clinicians. An updated chapter on parents’ problems provides advice regarding dealing with the diagnosis, telling family and friends, the role of parents as teachers, early communication, play, and discipline. Chapter 7 presents the role of the psychologist, including descriptions of how children learn, how to help those with additional impairments (visual, hearing, attention, perceptual), and formal education provision and the assessment of educational needs.

A new chapter on emotional health addresses forming a relationship with your child, dealing with a child who

cries and with temper tantrums, preparing for school, play, and pre-school ADHD. However, it does not consider the more severely affected/less able child (GMFCS IV/V).

The chapter on understanding movement has been extensively revised, and is supported by an appendix giving an overview of the early stages of sensorimotor development.

The following 9 chapters are the real heart of the book – they address all the various aspects of daily life, with reams of generally well-presented, practical advice on how to benefit the child, and also how to make life easier and safer for the parents, family and carers. Included are chapters on: handling, sleeping, feeding, lifting and carrying, toilet training, bathing, dressing, communication, and hand function. Throughout the book there is generally an emphasis on taking the hands away as the child’s ability improves, but not such a good explanation of how to grade your support, for example from proximal to distal, or from higher up the trunk to lower. The chapter on sleep includes a very relevant description of sleep problems and potential causes, stressing that sleep difficulties are usually not a result of the diagnosis of cerebral palsy. It also covers advice regarding night time routines, positioning (although an emphasis is placed on sidelying which is quite a difficult position to maintain symmetrically), and dealing with seizures. The chapters on feeding and on communication are excellent, well organised and easy to understand. The suggested methods for lifting and carrying are based more on the type and distribution of abnormal muscle

tone than on the child's postural ability, and the main emphasis of the chapter is on safe manual handling rather than on how to use these frequent situations to reinforce and develop communication and interaction and encourage active participation.

The increasing use worldwide of the Gross Motor Function Classification System (GMFCS) is now reflected in the book. It is referred to in a number of chapters to describe a child's level of ability, particularly when discussing the more severely affected child (level IV or V). A new chapter describes the development of the GMFCS and the Ontario Motor Growth curves which provide us with a means of predicting a child's gross motor function and particularly his level of mobility independence. One appendix consists of a chart using the GMFCS for intervention planning. Another appendix presents a list and brief description of relevant validated measures of motor development and function.

In a new chapter called 'deformity: growth and the problems of getting taller', David Scrutton describes why deformity develops, how it is assessed and

monitored, and current knowledge regarding prevention, management and treatment.

Finally, there are three further new chapters: one on orthoses; one describing the medical management of spasticity; and the final chapter provides a précis of the evidence regarding complementary/alternative therapy – helpful when we are asked about these by parents.

As previously, the book is generally easy to understand and very practical. The numerous illustrations are clear and helpful. This is a welcome new edition and should be recommended to new parents of a child with cerebral palsy at the appropriate time. It provides them with a good basis for understanding their child's condition, and will therefore support discussions with professionals. The book is also useful for families, support staff, carers, and relevant clinicians.

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# National Training Event 2009

*The presentations mentioned in this section were recorded, and are now available for viewing by kind arrangement with Paul Hewett and Active Design. For information on how to access the webcasts from NTE 2008 and 2009, please go to the PMG Home Page: [www.pmguk.co.uk](http://www.pmguk.co.uk)*

## “Doctor, Engineer or Architect”

**Dr Linda Marks FRCP, Director, Stanmore Disablement Services Centre  
Stanmore DSC, RNOHT, Brockley Hill, Stanmore, Middx HA7 4LP**

**Abstract:** *The Aldersea Lecture at NTE 2009 was given by Dr Linda Marks. We are publishing the whole lecture here, but we strongly recommend that members of PMG who didn't hear it at the time should take the opportunity to view the webcast to get the full flavour of Linda's entertaining presentation.*

Chairman, ladies and gentlemen,

The year is 1964; I am fifteen years old and have just taken my GCEs. My father, despairing of what I was going to do with my life, sent me off to a Vocational Guidance company on the Marylebone Road in London, where I spent a whole morning doing multiple choice questionnaires. The answer came back “Doctor, Engineer or Architect”. I therefore propose to spend the next half an hour or so, examining the truth in that prediction.

A few months later my father was playing golf with Myles Formby, an ENT surgeon, family friend and Dean of University College Hospital Medical School. “What is Linda going to do when she leaves school?” he asked my father. “I'm not quite sure, but she's been to look at becoming an Occupational Therapist” answered my Dad. “Goodness me, Geoffrey, what a waste! She ought to do medicine! I'll send her some prospecti”. The prospecti duly arrived and my father just said “Well you had better get on and apply then”. (Please note I did not come from even a vaguely medical family!). So I applied for six medical schools with The Middlesex, in London, being my first choice. Amazingly I got offered a place at The Middlesex, and I say amazingly, as when asked why I had put The Middlesex as my first choice I replied: “I'm female, I like shopping, and you are the nearest to Oxford Street!!”

Medical school was great fun, and the time went by very fast. There was of course lots of work, but there were plenty of extra-curricular activities as well, such as coxing the second eight and amateur dramatics – the latter getting four of us on one of the Dave Allen TV shows! But in spite of all this I qualified, on time, in 1973. After MRCP and various training posts, I became a senior registrar in Rheumatology and Rehabilitation. Towards the end of my four year post, my husband got

his Consultant post, and it became obvious there were too many Rheumatology trainees for the available posts. So, one Saturday morning, my husband was browsing the BMJ, and happened to see the advert for a Medical Officer in the ALAC service (only prosthetics at that stage), based at the RNOH Stanmore. “Here's your job, dear” he said as he pushed the journal over to me! “I don't know anything about artificial limbs!” I replied, and pushed the journal away. Well, the rest is history. I heard that I had got the job on July 29th 1983, just two hours after giving birth to my son, James. I started my induction at Roehampton in November that year, and my first day at Stanmore was February 1st 1984.

We move on to 1986 when the McColl report (Department of Health, 1986) was published. Although only some of the recommendations were implemented as written, this report was to have a profound (and beneficial) effect on wheelchair services. It was the blueprint for the creation of local (then District) wheelchair services and rightly recommended that ‘therapists’ became intimately involved in delivering these services. The DSA (Disablement Services Authority) was set up in 1987 to oversee the transfer of the ALAC services to the NHS by 1991. In order to achieve this, the ALAC boundaries were re-drawn, co-terminus with NHS Regional and District Health Authorities. Stanmore became the Regional Wheelchair Service for North West Thames, and this is how I came to be involved in wheelchairs.

Between 1987 and 1990, I did twice weekly wheelchair clinics with the Technical Officer (T.O.) initially at the ALAC in Ealing and then later in Ministry of Defence premises in Acton. I screened all the requests for ROHO and Jay cushions, answered numerous ‘file’ queries and, at the discretion of the T.O., assessed people for manual

chairs, EPIC's, 28B's, buggies and the occasional Matrix or MSI. At one clinic when I insisted on examining a patient, they had to go and find an examining couch from another part of the building!

Stanmore Wheelchair Service officially opened in January 1990. While the fifteen District services were being set up, the entire service was run from three rooms at Stanmore. By April 1991, the Districts had taken over all the manual chairs, but Stanmore still did all the powered chairs, any special seating, specialised buggies and provided second opinions for Districts if requested. We had about 400 cases at Stanmore, plenty of money, and no waiting list! Apart from assessments, the doctor also did the occasional review, undertook all the post delivery checks for bespoke seating, and 'guarded' the budget! Increasingly patients were routinely examined, and the postural issues of seating began to be recognised.

Between 1991 and 1997, the seating element of the work became the dominant area. Powered chairs and buggies were devolved to District services and increasingly the doctor worked with company representatives (rather than the T.O's), the newly trained 'Rehabilitation engineers' (R.E's) and then Clinical engineers. Special seating systems proliferated, mainly for the paediatric market. We employed our first dedicated seating therapist in 1991 and our first seating engineer in 1992. By 1997, the doctor was still seeing all the new patients (now as part of a multi-disciplinary team) and the majority of informal reviews, but the therapist and engineer did all the seating deliveries, post-delivery checks, repairs and maintenance, file queries, and general advice. 69% of the caseload (nearly 1000 cases) was under 18.

In 1997 EPIOC's (electric powered indoor/outdoor chairs) and vouchers arrived! In North West Thames it was decided to site the EPIOC service alongside the existing Regional resource. More doctors, engineers and therapists were employed for the increasing volume of work. However the seating element was beginning to show some strain, with waiting lists for MDT appointments and budgetary pressures. Formal domiciliary review mechanisms were established at schools and day centres to ease the waiting list issue – good for the clients but not the budget! As we moved into the new millennium, patient numbers in both the EPIOC and seating services grew, with many patients common to both services. As a result, in 2002 we started 'joint' Seating and EPIOC clinics in order to streamline

the patient experience. In 2003 we rebranded ourselves from Stanmore Special Seating service to Stanmore Specialist Wheelchair services.

Between 2003 and 2009 our caseload rose to 1646 patients, and the age profile changed, with the largest group in the 18-60 age range, only 27% paediatric and our oldest patient was 92 (an EPIOC user!). Assessments became more complex as people survived multiple trauma and premature babies thrived. Wheelchairs needed to accommodate ventilators and feeding pumps, and powered chairs needed intricate switching facilities to control communication aids and environmental controls as well as drive the chair itself. Increasingly, my medical role became focussed on the assessments and the postural elements that required attention, whether from the seat/chair itself or from interaction with surgeons, spasticity services, paediatricians, education and social services.

So, in 2009, is there a medical role in posture and mobility services? I would of course argue 'yes', but primarily for the most complex and postural problems. For the very reasons just outlined, postural issues overlap with many other aspects of a person's care and lifestyle, and doctors are in a unique position when it comes to liaising and negotiating with these many and varied parties. Whilst we operate under the umbrella of 'posture and mobility' services, we are here to optimise outcomes for our clients and if that means "moving outside the box" to solve the problem, then so be it.

However a poll within our own service demonstrated several other perceived roles for 'the doctor' – to provide leadership, arbitrate if/when there are differences of opinion, introduce new practice, lead on audit and clinical governance as well as taking an active managerial, strategic and even political stance as required. These are clearly not medical attributes, but may reflect the fact that Consultants are often among the older members of the team, and may well be in post longer than other professionals. The expertise and experience of a mature clinician can have its uses!

Let me move on now from 'the doctor' to 'the engineer'. I haven't had any formal training in engineering and there is no way I can claim to be an engineer, but... just look at the services in which I work: prosthetics and wheelchairs – both equipment services, relying on mechanical devices. As such I rub shoulders, on a daily basis, with prosthetists, designers, Rehabilitation and Clinical engineers. Consequently I have had a fair

induction into biomechanics, durability, stability, standardisation of measurement, correct nomenclature, and risk management (to name just a few areas!), and I hope I have been a good student. But I would like to add a further comment about engineers in 'posture and mobility' services. No-one would dispute the value and critical role of our Rehabilitation engineers, but the role of Clinical engineers seems less well defined. From a personal view point I feel that Clinical engineers are better equipped to solve the multi-faceted problems in complex seating and postural areas, and I would welcome an increase in their numbers.

I move on to 'architect' now, as there are some important matters I wish to touch on before we close. I will take a liberal interpretation of the word architect and use it in the context of 'developing services'. You have just heard me talk about the evolution of Stanmore's services. However, financial issues became apparent as far back as 1997, and this resulted in long waiting lists which became unacceptable. The financial issues are partly caused by the fact that commissioners have not understood that seating patients 'stay with the service for life' i.e. their chair needs repair and ultimately replacement, but other factors such as surgery, change in medication/underlying condition, insertion of a gastrostomy or just growth will all necessitate re-assessment and possibly new provision. As this whole process is a continuum it is more difficult to identify specific 'episodes of care' that more readily generate new funding episodes. The caseload grows inexorably, but the funding rarely grows to match, and crisis occurs sooner or later. At Stanmore we initially had a very productive on-going dialogue with our Commissioners, and I know that some of our discussions back in 2000 fed into the first Specialist Definition Sets published in 2000. These definitions determined which services were deemed at risk in a competitive market because they were low volume and high cost.

Alternative commissioning arrangements known as Specialised Commissioning were set up for these services, and wheelchairs and special seating services are covered under Definition Set 5. Essentially this definition recognises that equipment provision is only part of a package of care for the individual concerned, and provision will be life-long. Full details can be found on the Department of Health website, although all definitions are currently being reviewed and revised.

So, if we have a separate mechanism for commissioning our services, and the services themselves are accurately

defined, why is there a funding problem? Part of the answer has been provided by the Specialised Health Care Alliance, which is an association of the consumer groups for the conditions covered by Specialised Commissioning. In 2008, the SHCA wrote to all Special Health Authorities (who are responsible for overseeing specialised commissioning) asking them to identify the named commissioner in their SHA for each of the definitions. Only 50% of the SHA's had a named commissioner for Definition Set 5. So if there is no lead at the SHA, who is monitoring and measuring the performance of the individual PCT's to see that they are providing an appropriate service for that particular group of patients?



*The 2008 and 2009 PMG Aldersea Lecturers:  
Robin Luff and Linda Marks*

Let us now take a look at what has been happening at Department of Health level. In 2000, the Audit Commission published "Fully Equipped" which looked at 'equipment' services (including the wheelchair service) and was critical of the findings. A follow-up report in 2002 found little improvement and, as a result, the Modernisation Agency launched the Wheelchair Collaborative, which ran from 2002-4 and worked with approximately one third of the wheelchair services in England. This Collaborative clearly demonstrated the improvements that could be made with good management support, appropriate information technology, and clear but challenging timescales. The outcomes were published in the 'Improving Services for Wheelchair Users and Carers – Good Practice Guide' (Department of Health 2004). However, there was ongoing concern that this process needed to be rolled out to ALL the wheelchair services to achieve a national improvement. Instead, the Care Services Improvement Partnership (CSIP) was asked to review how best to reform wheelchair services. Several members of PMG

were involved in this review. This review clearly understood the issues involved in providing effective wheelchair services and in 2006 published these in a further report 'Out and About – Wheelchairs as part of a whole-systems approach to independence' (Department of Health 2006). What the CSIP report failed to do was define how these changes would be achieved, and even before the report was published, it was announced that a further programme, 'Transforming Community Equipment and Wheelchair Services' (TCEWS) was to be run by the Care Services Efficiency Delivery Programme (CSED). Again PMG members were involved in the working parties, but were discharged early in 2007 after only two meetings, being told a report would be produced imminently. In the event a draft report did not go to ministers until February 2008 (but PMG have never seen any drafts) and nothing has been heard since!

Now, the reason for giving you this information is to provide a background to the events which were starting to happen at Stanmore. In May 2007, two of our eleven commissioners gave notice to withdraw from the PCT consortium. There was much discussion over the summer but in September 2007, a further three commissioners gave notice to withdraw and the Consortium became non-viable. By November 2007, the Stanmore Service was invited to a meeting with the lead PCT commissioners, but instead of being allowed to work collaboratively to resolve the problems, we were told there would be a competitive tendering exercise for the service. An independent management company was employed, drew up a specification, and the tender exercise ensued. However, by the end of the process in July 2008, no contract was awarded. At this point, North West London Hospitals Trust challenged the legality of the whole process, and won. By August 2008 we were awaiting information about the Project Board that would write the specification for a five year contract. However, in October 2008 the Consortium appeared to have changed its mind and we heard that the EPIOC service would be devolved to local services by April 2009 (this we had initiated) and that the seating service would also be disbanded by April 2010. Most recently, just last month, we were further advised that the seating service dissolution had been brought forward to September 2009.

Looking back, is there anything we could have done differently which might have avoided this outcome? First, I think we could have ensured that we had an accurate and contemporary specification of our service at all times – we knew what we did but clearly our

commissioners did not! Second, we should have more rigorously monitored our capacity to ensure we could deliver a timely service, and in turn this would have provided more accurate information to inform negotiations with the commissioners. Finally we should have set up formal contracts with our own sub-contractors, detailing the required levels of service.

But what other messages are there in here? At PCT level, there is so little importance placed on wheelchair services that there is often no nominated lead for the service and even if there is, they seem to change frequently. Furthermore, wheelchair and seating services are poorly understood by commissioners, particularly the funding to provide a sustained and continuous service. Improvements in commissioning were highlighted as a key issue in the CSIP report.

As regards Specialised Commissioning, it is appropriate that wheelchair and special seating services are covered by this arrangement, and I am pleased that they have been retained in the new set of definitions. However, as shown by the Specialised Health Care Alliance, 50% of SHA's do not have a nominated lead for this area, again demonstrating the lack of priority accorded to these services at SHA level. It has also become apparent to me during recent months that PCT's can commission and decommission Specialist Services without reference to the SHA, providing they follow "general commissioning guidelines". At the same time the Department of Health is aware that most wheelchair services are cash strapped, and that year on year this is being worsened by changing population demographics. However, despite this knowledge and a plethora of reports over the years, there is still no plan for any change.

So what are the take home messages for you here today?

To individual wheelchair services I would recommend two things:

First, be clear about what you do and what you need to be able to deliver the service. Review this annually and document it.

Secondly, work at local level to get wheelchairs and seating recognised, not just as important pieces of equipment, but as an integral part of a much broader health and social agenda.

For PMG I would add that they should consider setting up a session at PMG NTE for sharing service delivery

experiences and achievements. Clearly, as a national charity, we need to continue to lobby for recognition and better commissioning for wheelchair and seating services.

And so to my 'end of term' report. Yes, I am a doctor and have had a very enjoyable career. I am not qualified as an engineer, but by constant proximity to engineers in my daily work I have at least grasped some of the basic principles. As far as being an 'architect' for wheelchair and seating services, I have participated in some of the recent blueprints for change; however in the meantime my own 'house' has fallen down, but I hope I have managed to pass on some of the lessons learned.

In closing, I would like to thank the many patients with whom I have had the pleasure to work and who have taught me so much. I would like to acknowledge my colleagues who have put up with me through the ups and downs and have always given 100%. And finally, my

thanks must go to PMG for all their excellent work in the field and for the opportunity to give this lecture today.

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## Pre-conference Training Day 2009

One of Nigel Shapcott's initiatives as new chair of PMG was to push for a pre-conference training day at the annual NTE. This format had proved very successful at the Exeter International Conference in 2005, and is a regular feature of other major conferences in the field, such as the European and International Seating Symposia.

The small PMG Education & Training sub-committee – Jo Jex, Nigel Shapcott and Monica Young – put together a diverse range of courses to offer the membership. Some were practical courses, others highlighted very new technological developments, and some were by expert clinicians teaching specific elements of practice.

To view webcasts of several of the courses, use the links on the PMG home page:

[www.pmguk.co.uk](http://www.pmguk.co.uk)

The Warwick Conferences team was extremely supportive, providing rooms free of charge for this extra day. Over 200 delegates took the opportunity to update

their CPD practice, many attending both a morning and afternoon course, thus taking full advantage of the day.

Jo Jex, current chair of the PMG Education & Training sub-committee, encourages you all to take up a similar opportunity at the International Conference in June 2010, stating:

*"The Glasgow conference will provide a unique opportunity to gain some continued practice with members of other professional bodies, as the training day is being sponsored by BSRM, PMG and SPMN. It's always healthy to challenge your practice and find out how others work things out".*

**Olwen Ellis**  
**Administrator of PMG Education & Training**  
**Sub-committee and Co-ordinator of the**  
**2010 Pre-conference Training Day**  
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**See page 47 for information about the 2010 Pre-conference training day in Glasgow.**



Delegates on Roy Wild's Practical Wheelchair Skills workshop, Warwick University, 2009

## Bursar Report: State of the Science in Clinical Applications of Telerehabilitation

Presenter: Mark Schmeler, University of Pittsburgh,  
Department of Rehabilitation Sciences & Technology

Reporting Bursar: Eve Hutton, Senior Lecturer, Canterbury Christ Church University

**Abstract:** Mark Schmeler gave a fascinating insight into how clinical specialists based at the University of Pittsburgh contributed to complex wheelchair assessments in remote locations using a telerehabilitation model of consultation. The model devised also provided mentoring and support to the therapists based in remote clinics enabling them to carry out assessments without assistance.

I had no prior experience of telerehabilitation; I was simply interested to find out more about it. A quick review of other members of the audience confirmed that most were present for the same reasons – curiosity to find out something about the topic.

Mark started by talking about some of the better known applications of telemedicine. Examples such as the remote interpretation of x-rays by clinicians in different time zones provided an insight into how the technology has been developed within medicine.

Other applications include job coaching, where a remote mentor can observe and provide feedback to workers; also, 3D modelling with the use of CAD (computer aided design) systems to assist in assessing homes for suitability for adaptation and equipment. Rehabilitation provides different challenges and the model of telemedicine is possibly more difficult to apply. Mark has some doubts and concerns that the technology

should not be seen to be replacing the practitioner.

He described how the team at the University of Pittsburgh had developed a method of providing remote consultations to areas where there was no specialist therapist. Clinics in more remote areas access advice and support in a real time assessment with the patient present using computer web cameras and technology to support this. Mark stressed the importance of having a secure server where confidentiality of patient information can be assured.

As a model it worked well in areas where there are underserved populations, and where skilled professionals are in short supply. Earlier discharge from hospital had added to the demand. Recent advances in technology make the model more feasible and possible where earlier attempts were fraught with difficulties due to poor internet connections and limited band width in remoter areas.

Therapists in remote areas who participated in a series of these assessments acquired skills and gained confidence sufficient to enable them to carry out assessments without assistance. The telerehab model in this setting has the potential to offer remote mentorship and CPD opportunities for therapists. The University offered on-line training modules associated with assessment and prescription of wheelchairs to support learning in the therapists' places of work.

In conclusion, the telerehab model of wheelchair prescription cannot replace the intervention of a therapist. It should be viewed as a consultation tool rather than a replacement for the practitioner. However, it does seem to have benefits in areas where there are few skilled professionals, and provides a useful model of remote mentoring and education. Telerehabilitation

has the support of the professional associations and as further technology becomes available other applications could be developed. Those interested would need to have a strong technical team to support them.

I was interested in the educational potential of telerehab and will want to explore how, as a University, we could exploit this model in developing interactive CPD opportunities for our post-graduate students. This was an entertaining and interesting presentation provoking discussion and debate amongst the audience. Those interested in finding out more are directed to the University of Pittsburgh website ([www.shrs.pitt.edu/rst](http://www.shrs.pitt.edu/rst)).

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## **Bursar Report: Is posterior tilt of the pelvis inevitable for many of those who are dependent on a wheelchair for mobility? Are we as providers of postural support compounding the problem?**

**Presenters: Dave Long, Clinical Scientist and Pat Postill, Physiotherapist  
Specialist Disability Service, Oxford Centre for Enablement, Nuffield Orthopaedic Centre,  
Windmill Road, Headington, Oxford OX3 7LD**

**Reporting Bursar: Rebekah Marks-Hubbard (Occupational Therapist)  
Wheelchair Service Team Leader, Southend Integrated Occupational Therapy,  
Unit 8 The Forum, Coopers Way, Temple Farm Industrial Estate, Southend-On-Sea, Essex SS2 5TE**

**Abstract:** *The session was led jointly by Clinical Scientist Dave Long, and Pat Postill registered Physiotherapist and Clinical Team Leader, both based at the Oxford Centre for Enablement Posture Independence and Mobility Service. Dave Long has previously been Chair of PMG and is now heading the Special Interest Group in Posture Management. The presentation consisted of directed questions, audience participation through discussion, feedback, and presenters aiding discussion through a clear PowerPoint presentation. Clearly, for those of you who prescribe seating equipment to complex clients the subject has paramount relevance. The session was well attended, although it was in the Arts Centre Theatre which has seating for hundreds, so a cosier location could have been more sympathetic to both the presenters and audience.*

The opening request by the presenters was for the audience to sit with their pelvis in neutral and with hips/knees at 90 degrees. This caused quite a stir with audience members; they moved out of asymmetry into symmetry, re-positioning themselves in order to sit on the back of the seat cushion, placing their feet squarely on the floor and generally sitting up. So you, the reader, are part way through this article – please do exactly what the audience did by putting your pelvis into a neutral position with your hips and knees at 90 degrees. Does

that feel better than before? Just bear with me for a while on this, as your view has important relevance. The presenters asked whether, as service providers, we have contributed to the issue of causing posterior tilt. They questioned the audience's current sitting position, querying how achievable can this posture be as a long term solution? The presenters explained the aim of the session was not to give answers, but to explore the subject, looking into the strengths and limitations of posterior pelvic tilt and to consider solutions. The

audience were asked to relax, analysing how relaxation is achieved, the article reader should also do the same. It appeared that the audience shifted from symmetrical to asymmetrical positions, reportedly changing into a more “comfortable” position, and that they adjusted their base of support to include using the backrest of the chair. The presenters explained Hare’s (1987) “human sandwich” theory: as individuals we are coping with two opposing forces: gravity pulling us towards the earth’s core, and the supporting surface (floor, chair, bed etc) stopping us from going any further – we are the filling in the middle.

Dave Long explained that on a daily basis we choose to relax our bodies with normal muscle control and normal structure, so what would we consider elements of good posture to be? The audience came back with a good range of options:

- functional positioning
- a position which allows re-positioning
- good base of support
- something comfortable
- must be sustainable
- energy efficient
- in symmetry if it allows more function
- able to move in and out of symmetry
- creating equilibrium of muscle tone
- facilitating good head balance
- recognising that no one is 100% in symmetry
- allows dynamic movement
- not causing damage to the body
- how the body appears to others

The presentation slides explained that good posture has been defined by Pope (2007) as “that body attitude which facilitates maximum performance for minimum energy consumption and without causing damage to the body system” and poor posture as “that which results in less accuracy, is carried out with increased effort and leads to damage to the body”. The author notes that Pope’s book, *Severe and Complex Neurological Disability*, has been reviewed by Arva (2009) who explains that “as a treating therapist you may learn more about positioning methods”.

It was discussed that at times prescribing practitioners can “rush” assessments, therefore not gathering enough detailed information. The author certainly agrees with this point, having seen evidence of this firsthand. This shortcoming is especially relevant in some NHS wheelchair services that are reducing their waiting times in line with the Department of Health’s 18 week waiting pathway (2005).

The presenters and audience gave consideration to the benefits of keeping the pelvis in neutral, following a postural assessment. Strengths for having a neutral pelvis are symmetrical positioning and loading through the spine which promotes improved limb and head positioning, and increases functional ability.

Limitations of a neutral pelvis are that some clients use high levels of energy to maintain this position, so it reduces concentration levels for other activities, and if the position is fixed it could reduce the ability to move into asymmetry and relaxation.

The results of sitting with a posteriorly tilted pelvis are wide ranging:

- loss of stability
- if unstable, can create high muscle tone
- increased shear
- deformity – kyphosis
- lack of lumbar lordosis
- pressure on spine
- head position either flexed or with chin “poke”
- reduced eye contact
- communication
- compromised swallowing
- compression of the lungs/airways
- bladder control
- shortening of the hamstrings
- reduced upper limb function i.e. reach

Therefore, the presenters recommended that a service provider assesses carefully. Analyse what positioning *can be corrected*, and what positioning is *unable to be corrected*, so that the outcome will accommodate that particular individual’s positioning needs without imposing further deformity. The following physical limitations which can relate to a posteriorly tilted pelvis must be considered during the assessment:

- tight hamstrings
- kyphosis
- control of centre of gravity (fore/aft)
- leg length discrepancy
- trunk weaknesses

The presenters suggested methods of providing postural stability whilst also providing an energy efficient seating position solution such as tilt in space wheelchairs and the SAM Seating System. The author was not previously aware of this seating system, and notes its availability from Smirthwaite (2008). Finally the presenters gave warnings of “potential pot holes” which include riser/recliner chairs, elevating leg rests on wheelchairs,

excessive (cushion) ramping, and overly long seat depth measurements. The presenters concluded that equipment can create problems through inappropriate recommendation due to the lack of a thorough assessment.

In conclusion for this article, the presenters did achieve their aim of not giving answers about pelvic tilt, but used the session to explore the issue. The author endorses the useful postural resource given by the presenters to the audience: [www.posture24.com](http://www.posture24.com). The author is aware that prior to the seminar, her basic knowledge about posterior tilt has been learnt from colleagues in the wheelchair service and from attending a highly recommended postural management course run by Active Design Ltd (2009). Having attended the seminar, the author notes the need for quality, in-depth analysis about posterior tilt and careful consideration when prescribing equipment. A further recommendation by the author is that service providers should share their knowledge through practical case study sessions. Finally, service providers should put forward for publication their research work on this topic.

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## Bursar Report: Development of the Rehabilitation Engineering Profession

Presenter: Simon Fielden, Director, HDTI Coventry University

Reporting Bursar: Andrew Bryant, Trainee Rehabilitation Engineer,  
Bristol Wheelchair and Special Seating Service

**Abstract:** *Simon Fielden is the Director of Health Design Technology Institute (HDTI) Coventry University ([www.hdti.org.uk/index.php](http://www.hdti.org.uk/index.php)). The HDTI has positioned itself at the centre of providing qualifications in Rehabilitation Engineering (R/E), attracting funding to deliver the Graduate Diploma (2008) and the BSc (2009).*

*Rehabilitation Engineering as a profession is undergoing big changes under the direction of the Department of Health to bring it in line with other health professions. Compulsory state registration is looming, although the dates had not yet been finalised at the time of writing.*

*Simon's presentation provided an informative overview of the shape of things to come for the training and development of the R/E Profession (guided by 'Modernising Scientific Careers' draft document). The audience discussion provided a glimpse of the frustrations that appear when there is lack of clear national leadership to provide direction and guidance at a time of change for a profession.*

#### Previous knowledge and experience of the areas covered by the presenter:

My background is based in both Engineering (British Aerospace) and Healthcare (Physiotherapy).

For my first proper job (don't think a paper round counts) I joined British Aerospace and completed an apprenticeship which culminated in working as a sheet metal worker and coppersmith. During this time I also gained an HNC in Production Engineering.

The day came when standing in the darkened factory hanger I thought there must be more to life, so I took voluntary redundancy and headed out for adventure. Having had some adventures (none of which I am going to tell you about!) I decided it was time to get serious again and I returned to study. In 2005 I qualified as a Physiotherapist at Southampton University. I came into a profession at a time when thousands of pounds had been spent in training Physiotherapists but with almost no jobs available (the government had pledged to train

lots more therapists – however it did not provide funding for the jobs required by the newly qualified therapists). After a very stressful period of job searching I got the job I wanted (North Bristol NHS Trust) as a Physiotherapist.

Three years later a job description caught my eye that described a combination of clinical and engineering skills (my ideal!) and my application was done by return of post.

August 2008 I joined the Bristol Wheelchair and Special Seating service and I am currently training to be a Rehabilitation Engineer through work based IPEM moderated competencies and studying for a Graduate Diploma in Rehabilitation at Coventry University and keeping my fingers crossed that I will be eligible for state registration (it all seems a little vague currently!).

### Discussion on the presentation

Simon Fielden stressed that the R/E profession should have the same professional standing as other health care professions and that this is the focus of registration with the Voluntary Register of Clinical Technologists (VRCT) and ultimately compulsory registration with the Health Professions Council (HPC). The professional standing will only come with degree level professional learning and qualifications.

This transitional period to compulsory state registration is proving to be a painful process! As a trainee in the middle of the transition I have had uncertainty and increased stress levels as a direct result. Nationally there are major discrepancies between the work being conducted by trainee R/Es across the country. Within some NHS Trusts there is no autonomy in practice for trainee R/Es; in others a service is being virtually run by unregistered R/Es. Simon appeared to suggest that unregistered R/Es working without supervision could be leaving NHS Trusts open to criticism in the event of an incident.

### The Future...

There are glimmers of what the future can hold! Once this transitional period has been completed and registration is under the HPC, the development of the profession is offering amazing opportunities. As R/Es our scope of practice (available at [www.vrct.org.uk](http://www.vrct.org.uk)) will open doors in meeting the need for future health care technologies, for example tele-health, environmental controls and assistive technologies. We need to be brave and step into new and developing roles (ensuring of course that we are working within our scope of practice!).

### Simon's presentation provided the following key learning points:

- 'Modernising Scientific Careers' (MSC) is a draft document that will provide a structure to the future careers and education of R/Es and other Health Care Scientists (Department of Health 2008);
- Registered Rehabilitation Engineers will be considered to be at the level of Health Care Scientist Practitioners;
- The move to a degree level entry qualification for Rehabilitation Engineers will provide the profession with the same standing as other health care professions;
- The VRCT is currently a voluntary register, but in the future state registration will be compulsory for R/Es through the HPC;
- The BSc Degree in Rehabilitation Engineering (Coventry University) which started in September (2009) will have work placements as an integral part of the package;
- It appears likely that the first 2 years of the BSc degree will be generic engineering modules, and the last part of the course will run in conjunction with the graduate diploma in Rehabilitation Engineering to provide the specialist knowledge.

### Audience discussion topics associated with degree level qualifications for R/E:

- R/E has a practical and academic base, with many people in the profession coming from industry with a wealth of experience enriching the profession; will the profession still attract applicants from industry?
- Concerns over a lack of work force planning; do we know how many R/Es are required for the future? (don't want to make the same mistakes as happened within Physiotherapy – see my earlier comments) ;
- Will degree level R/Es still have the base of practical skills that are currently so useful within the work place?
- Currently most degree level courses cost approximately £3000 per annum, and from 2010 the cost is likely rise to about £5000. The BSc R/E degree course will have no course fees (funded by the NHS) making it very attractive.

On this last point I would suggest the NHS is leaving itself wide open to funding a degree course with no assurance that it will receive any return, especially with the first two years being generic engineering modules. For all the investment, graduates could go straight to private industry. An agreement that after the BSc there is a requirement to work for the NHS for at least 3 years would go some way to protect the large financial investment made by the NHS.

**In summary**

It is very worthwhile reviewing 'Modernising Scientific Careers' to be able to understand the future shape of the R/E profession.

I feel that the R/E profession offers an exciting combination of skills and varied working environments, but the transition to full state registration and changes in the development of the profession are causing uncertainty and frustration that will only be alleviated once clear time scales and direction for the profession are in place. I look forward to HPC registration for this reason.

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## Bursar Report: Beating the 18 Week Deadline

**Presenters: Peter Gage, Clinical Service Manager, Mid & West Essex Wheelchair Service, Gemini Centre, Chelmsford**

**and Alex Winterbone, Independent Living Service Manager, Chantry Clinic, Ipswich**

**Reporting Bursar: Tess Starkey, Wheelchair Therapist, Leeds Wheelchair Service, Seacroft Hospital, York Road, Leeds**

**Abstract:** *The presenters set out to convey their experience of implementing the 18 week target. They used PowerPoint, discussion and a question/answer format; a lively session highlighted how they had managed the 18 week policy. They discussed definitions, clinical pathways, problems and pitfalls and gave ideas to enable other services to take up the challenge.*

**Introduction**

The presenters did a fine job of engaging the audience in a topic that usually would be considered quite dry, using their own service experiences as a template to give sound advice on how to manage changes and implement the 18 week target. They welcomed discussion, debate and lively interaction between presenters and participants.

**Prior Knowledge**

Prior to the presentation I did not have much knowledge about this policy. Our service does monitor waiting times and has IT systems in place to do so. However, before the conference, I had not given it a great deal of thought. Waiting lists made me think about waiting times for surgery or a consultation with a specialist. As a fairly new wheelchair therapist, of only a few months standing, my focus had been directed towards other aspects of my role rather than the 18 week target. I did manage to look at the 18 week website prior to conference, so had some ideas. I can recommend this and other information online, easily accessed by putting 18 week pathway into a search engine.

**Background**

The session started with an introduction to the background of the 18 week target. This came in the form of the NHS Improvement Plan July 2004 that emphasised the need to reduce hospital waiting times. They explained the idea was broadened into waiting times for other treatments, for example therapies. Also, at this time, there was a move towards patient choice between services and the ability for patients to choose alternative service providers. The main focus of the document was that 'no patient would have to wait longer than 18 weeks from GP referral to hospital treatment.'

**Definitions**

The presenters clearly outlined the means of monitoring their service targets by utilising the terms: *start clock, pause clock, stop clock.*

**Start Clock:** on receipt of referral into wheelchair service

**Stop Clock:** on delivery of wheelchair/seating equipment

**Pause Clock:** example, if patient declined 2 appointments



clock to stop due to special seating manufacture. The presenters said policies should back up the 18 week target system i.e. EPIOCs awaiting ramp fitting therefore unable to handover. Policies should be friends that cover these eventualities.

### Discussion

The expectation is that services should reach 95% of the 18 week target, only leaving a 5% tolerance. There were many questions regarding this. What will happen if targets are not met? Will there be penalties, financial? Would services be allowed to fail/flounder and patients go elsewhere? As always there seemed to be more questions than definite answers, and particular service configuration will determine how individual services manage the 18 week policy.

My personal concern is how focus on waiting times may interfere with stress levels and staff morale; how worrying about the waiting list may impact on administrators, engineers, therapists and others trying to do a difficult job. A colleague of mine commented on a recent visit to A&E where staff were engrossed in the waiting board times rather than the patients. We need to keep our focus on patients' wheeled mobility needs rather than statistics and government targets.

### Conclusion

The message from the presenters was one of urgency to those services who were saying, 'we have not been asked for statistics yet.' To start sooner rather than later. Not to wait until commissioners were demanding statistics. To start the process gradually and not have it forced upon you – to take up the challenge.

I enjoyed the presentation and felt that participants, whether implementing the 18 week target or not, got some useful ideas and suggestions to take back to their own services. The discussion was dynamic and interactive and it was particularly helpful to see how other services were interpreting definitions and guidance. I personally will be much more aware of timescales and try to be more pro-active in articulating this to suppliers and other outside services. However, I do want my main ambition to be quality assessment and provision of appropriate equipment.

I would like to thank the PMG for providing my bursary to attend this year's conference – it was thought provoking and most valuable. Thanks again.

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## Bursar Report: Pressure Care

**Presenter: Dan Bader, Professor of Medical Engineering, Queen Mary University of London**

**Reporting Bursar: Sarah Carter, Occupational Therapist, York Wheelchair Centre, Blue Beck House, Blue Beck Drive, York, YO30 5SF**

***Abstract:** This session was presented by Dan Bader, Professor of Medical Engineering at Queen Mary University of London. The aim of the session was to present evidence of the importance of pressure-related issues and how this can inform clinical practice. Dan explored the external mechanical forces of pressure, shear and friction that influence skin and internal deep tissue damage. Associations were made between mechanical and physicochemical factors, such as temperature and humidity, that occur at the skin surface when sitting, and the ways in which these can be influenced by cushion materials and seating configurations. Dan also considered the effects of externally applied, prolonged pressure on internal tissues. He then provided a critical appraisal of the reliability of pressure mapping and the interpretation of resultant data by the clinician.*

When I first started working for wheelchair services as an occupational therapist a year ago I had no previous experience in this specialised area. I don't think I fully appreciated how vulnerable wheelchair users are to tissue damage, not only from pressure but also contributory factors such as shear, friction and posture. It was a revelation to me to learn that Christopher Reeves, with all the most high tech up to date equipment available to him as a tetraplegic, still

developed a grade four pressure sore which ultimately contributed to his death. As Dan stressed in his presentation, despite great efforts to prevent pressure sores, figures for their incidence still remain high. This is believed to be attributed to a lack of consensus regarding the pathophysiological response to mechanical loading that contributes to soft tissue breakdown. Identification and prevention has mainly focused on skin tissue.

Traditionally, pressure-induced ischemia has been thought to be the main cause of pressure sores. More recently developments have been made in looking at mechanisms causing tissue breakdown, such as lymphatic restriction. Dan stated that 'interface pressures well above capillary pressures can be supported by the soft tissues before blood flow is seriously impaired'. In his presentation he reported 'we have to know the internal mechanical effect of an externally applied mechanical load (shear, pressure) to the tissue.' Recent research with combined animal-experimental numerical approach proposes tissue deformation as another contender for initiating pressure induced deep tissue damage (Ceelen et al, 2008). With improved technologies such as MRI, ultrasound, and other mathematical techniques, advances have been made in the study of deeper tissue damage. With pressure sore management being high on the agenda for government and medical lobbies, international directives from Europe and America have been produced providing evidence based information on treatment and prevention.

Dan also covered several key issues around the external and intrinsic factors that influence skin and internal deep tissue damage, and how these factors interact with one another, as gradient pressure is only one element in the causation of tissue damage.

Interacting factors include:

- Pressure and Shear
- Shear and Friction
- Friction and Moisture
- Moisture and Temperature
- Interface and Interstitial Pressures
- Extrinsic Factors and Tissue Viability/Status
- Length of time sitting/lying

The combination of increased gradient pressure with shear and friction can greatly influence tissue damage: this can be seen when lying or sitting in a reclined posture where gravity is pushing down and the bed or chair interface is preventing sliding, so the skin and tissues are stretched.

The composition of cushions, their material and covers, offer a wide choice for clinicians – one which I initially found quite daunting. Manufacturers produce many ranges of different materials and covers and I quickly learnt that selection and thermal properties of cushions need careful evaluation by the clinician when choosing the right cushion for clients. A one degree rise in temperature caused by humidity and sweating increases

metabolic demands by 13% (Bader et al 2005). This increase in moisture can increase the coefficient of friction (Naylor 1955), influence the allowable normal pressure threshold, and increase the risk of pressure ulcer formation (Dinsdale 1974, Bennett et al 1979). Shaped cushions can help to distribute the pressure forces between the ischial tuberosities and the trochanters (Ferguson-Pell 1990). Research into changing pressure relief practice with individuals with spinal cord injuries found that brief pressure lifts of a few seconds are ineffective and that strategies such as forward leaning and tilt back are more effective (Coggrave & Rose 2003).

One issue discussed that I often find difficult when prescribing cushions is the balance between achieving the optimal pressure-reducing cushion and comfort as perceived by the user. Studies by Stinson & Porter-Armstrong (2008) and Stockton & Rithalia (2009) using pressure mapping and a selection of cushions found that the cushions which provided the lowest IP (interstitial pressure) were not always found to be the most comfortable as perceived by the user.

Pressure mapping is an area I have little experience of as yet. I learnt that there are many pressure measurement systems on the market, and that clinicians can interpret findings in different ways using peak value, average value, symmetry, highest 10 values, colour distribution or peak gradients. I also gathered, from listening to other delegates' questions, that there can be a tendency for clinicians to be guided by the colour changes on a pressure map. However, Dan pointed out that it is important to look at the peak values as well because, although you may have an area of red, the peak value may be low. It is important that mapping systems are regularly calibrated and multiple measurements are needed to average out data.

Pressure mapping is a well-established clinical system for comparing support surfaces for individual subjects and providing feedback to clients and carers to show support postures and areas of high pressure. However, pressure measurements alone are not sufficient to alert the clinician to potential areas of tissue breakdown, and should be used as an additional tool alongside data collection of external and intrinsic factors affecting an individual.

In conclusion, Dan suggested that to obtain a better overall assessment of the integrity of cells and deeper tissue in vulnerable patients, one could use more non-invasive screening tools in hospital, such as:

- Biosensors
- Computational modelling
- Live cell imaging
- Ultrasound (Elastography), Terahertz technology
- Magnetic Resonance Imaging

Many thanks to Dan for a very informative and thought-provoking presentation. I have already applied this acquired knowledge within my clinical role, and hope to develop further learning in pressure mapping and material composition of cushions. Also thanks to PMG for the great opportunity of attending this year's conference.

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## Bursar Report: Risk Considerations for the Transport of Wheelchair-Seated Passengers in Motor Vehicles

**Presenters: Bob Appleyard, Technical Advisor, Unwin Safety Systems and Alison Johnston, Clinical Specialist Physiotherapist, Bromley Wheelchair Service, Bassetts House, Broadwater Gardens, Farnborough, Orpington, Kent, BR6 7UA**

**Reporting Bursar: Louise Swan, Senior Physiotherapist, SeatTech, Enable Ireland, Sandymount, Dublin 4**

**Abstract:** This article reports on the presentation looking at the risk considerations for transport of wheelchair seated passengers in motor vehicles. During the presentation last year it was shown how risk control measures adopted by the automotive industry influenced the development of standards for wheelchair seated passenger safety in motor vehicles. However, because of very important differences between both hardware and, more importantly, the passenger, these risk control measures were not always appropriate. The results of an audit carried out on SEN Transport at a special school concluded that "real life"/"common practice" can be very different from "best practice".

The objective of this year's presentation was to build on last year's work, presenting a discussion on: local, national and international developments; information on the "travel passport scheme"; details of the risk orientated draft standard "Wheelchairs for Use in Transport" proposed as a European CEN (Committee for Standardisation) document; how local practice is being influenced and developed.

Alison commenced the presentation with an overall recap of last year's presentation and some developments that have happened since. Two BSI (British Standards)

initiatives – the "Travel Passport Scheme" and the draft standard on "Wheelchairs in use in Transport" which is being proposed as a European CEN document – are

good developments towards achieving best practice. Bob went on to outline how “desired best practice” is difficult to achieve when one accepts the realities of transport for wheelchair seated passengers. He explained that we need to accept that transfer from a wheelchair to a vehicle seat may not be possible, and that our primary objective must be to seek a similar level of safety for that wheelchair seated person as for a person who sits in a standard vehicle seat. He gave background information on Medical Devices Directives (MDD), explaining that wheelchairs need to adhere to these as a wheelchair is a class one medical device, and as such there is an emphasis on the “removal of risk” inherent in the design of a wheelchair. There are also International Standards relating to a “wheelchair as a seat in a motor vehicle” and relating to “seating systems for use in transport.” He outlined that the three key International Standards are: ISO 7176 Part 19 relating to the wheelchair as a seat in a motor vehicle; ISO 16840 Part 4 relating to seating systems for use in motor vehicles; ISO 10542 Parts 1-2 relating to wheelchair tie-downs and occupant restraint systems.

These standards are all derived from automotive risk control measures. Bob then went on to make a comparison between automotive standards and the wheelchair seated passenger. In the automotive industry the provisions are based on an established risk model i.e. a surrogate human occupant. However when a wheelchair is being used as a seat in a vehicle there is poor control over occupant restraint (OR) geometry. Effective OR becomes more difficult as the complexity of the disability increases. Some slides were shown by Bob highlighting the fact that the surrogate human occupant does not come close to representing the wheelchair users we may know who use their wheelchair in transport. In essence this means that we have to consider additional risks and “factor” these into our risk assessments. His pictures of the impact of a “submarining injury” were horrific, showing the damage that can be caused if the lap belt comes up over the pelvis and encroaches into the abdominal cavity.

Bob went on to talk about “risk” – what our understanding is of risk and why it is important. He gave some commonplace examples of the normal risks that might affect any of us during our daily routine or work. He explained that in any risk management process in which assessment and evaluation are carried out, followed by an analysis and controls being put in place, the process helps us make informed decisions about the

situation. He felt that a risk benefit analysis was very important in relation to making informed decisions around wheelchair seated transport.

Alison proceeded to detail the work she had commenced as part of an audit she undertook (as part of her Masters dissertation) in conjunction with Special Educational Needs (SEN) Transport Coordinators in Bromley, Kent. Her objective was to look at some “real life” situations and see what was really happening. She decided to take a “snapshot overview” by looking at one school on one day, watching all the buses carrying wheelchair seated passengers. To help define how these passengers were being positioned in the buses, she established ten audit criteria. The audit criteria were as follows:

- the positioning and angling of the rear tie downs (30 to 45 degrees)
- the position and angle of pull on the front tie downs (40 to 60 degrees)
- the position of the pelvic portion of the occupant restraint (OR)
- the position of the shoulder portion of the OR
- whether the belt was mounted at floor or shoulder level
- whether the tray had been removed
- whether bags had been removed
- whether all items removed from the wheelchair were secured elsewhere in the bus
- whether the space in front of the wheelchair was adequate, i.e. in excess of 450 mm.

The results of the audit were as follows:

1. none of the criteria were met completely
2. none of the students met all of the criteria
3. the position of the tie downs was more consistent than the angle of pull of the tie downs
4. the pelvic belt was more accurately positioned than the shoulder belt
5. space was a big issue in general.

This helps highlight to us how important it is to know what does happen in the real world.

Since the audit took place Alison could see that training was needed. Some of the ideas she had envisaged have been difficult to put in place due to some communication breakdown and staff changes; however she detailed some that have gone ahead. She established a Training Plan, involving a 15-minute awareness session for bus drivers and escorts, and a 2-hour training session for drivers, assistants and bus managers. The 15-minute awareness session was carried out at one school where

she does a clinic. It occurred at the end of the school day, 15 minutes before the buses departed. She gave a handout, detailing the front tie down positions. The plan is for more in-depth training consisting of a 2 hour classroom session and a hands-on session. The classroom session would involve training around a basic understanding of the importance of correct positioning of the wheelchair seated passenger, the responsibilities of the driver and assistant, the importance of the manufacturer's instructions, WTORS (wheelchair transport occupant restraint systems) and some "video nasties"! She feels that it is important to emphasise that 50% of the injuries that do occur are due to normal vehicle movement e.g. braking and cornering, rather than a "big crash", plus incorrect use of the wheelchair tie downs and occupant restraints. The hands-on session she felt should comprise of a demonstration of how to actually secure the wheelchair correctly in the bus, emphasising the need for the appropriate floor space and the preferred routing of the occupant restraint.

Bob then continued the presentation with an update on some engineering and technical developments. He mentioned some virtual crash testing of seating systems and wheelchair combinations that are now available on bespoke designs. He recommended a research fellow called Paul Rogers (progers@glam.ac.uk) as someone who offers a service to pre-test bespoke designs in order to provide a prediction of seating system performance. He described developments which have been made in the area of tie downs for heavy powered wheelchairs. Unwin has devised equipment to secure wheelchairs up to a mass of 200 kg, not including the weight of the occupant!

There have been improvements to occupant restraint system geometry to reduce the risk of abdominal intrusion, and some advancement in wheelchair securement in some Otto Bock products. He outlined that, from the "Achieving Mobility for Life Conference"

in 2007, three items were highlighted:

- i. audible inclinometer (which has been put on the "back burner")
- ii. a passport scheme,
- iii. improved visibility of the tie down points for attachment of the restraints during transportation.

The Travel Passport Scheme was explained in more detail by Bob. He explained that there is currently no national scheme, and that any in existence are local ones. The scheme is a means of relaying information to the vehicle drivers and passenger assistants regarding the essentials necessary for safe transportation of the wheelchair and the seated occupant while in the vehicle. It is a means of avoiding mistakes. Basically it works in conjunction with a risk assessment and it would include details of the make and model of the wheelchair, and the preferred occupant restraint systems specific to that person and equipment. The compiled information can be kept in a small A7 "pocket" with the wheelchair, making it easy to amend and the cost is low. However, it would not be suitable for a public bus or taxi. In ongoing efforts to move this scheme from a local to more national level, Bob explained that he is to make presentations to representatives from 9 regions around the country.

Bob outlined information about the risk orientated draft standard "Wheelchairs for use in Transport" proposed as a European CEN document. This document would be aligned to the Medical Device Directive (MDD). Finally, another development described by Bob was the BHTA (British Healthcare Trades Association) Initiative which involved the production of the "Get Wise Leaflet" providing advice to wheelchair users and their families regarding product purchase and transport requirements.

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## New Year's Resolution!

### January 1st 2010: Renew PMG Membership

This is a reminder to go online as soon as possible in January to renew your PMG membership for another year.

Go to [www.pmguk.co.uk/members/login](http://www.pmguk.co.uk/members/login) and have your payment card ready.

Membership subscription is £25.00.



The International Society for Prosthetics and Orthotics

## “RECENT CONSENSUS ON DEVELOPMENTS IN THE MANAGEMENT OF CEREBRAL PALSY”

Thursday 14<sup>th</sup> and Friday 15<sup>th</sup> January 2010

**The Centre for Life  
Newcastle Upon Tyne, UK**

A major national multi-disciplinary meeting on the findings of an international consensus conference on cerebral palsy.

In autumn 2008 the International Society for Prosthetics and Orthotics (ISPO) organised its second international consensus conference on cerebral palsy. The published report is available in full at [http://www.ispweb.org/HTML/2009/ispo\\_cp\\_report.pdf](http://www.ispweb.org/HTML/2009/ispo_cp_report.pdf) This detailed report covers the wide ranging findings of the multi-disciplinary group of experts who reviewed current evidence on the major therapy, medical and surgical interventions in use today.

This event brings together an international faculty who will be reporting the conclusions and continuing the dialogue. It will be instructive but also provide a forum for exploring remaining unsettled issues. Topics covered include:

- Surgery
- Medical management
- Therapy
- Orthoses
- Seating
- Posture management

This event will be of greatest appeal to multidisciplinary teams involved in the management of cerebral palsy

Full price registration: ISPO members £200, non-members £230.

**Register by 16<sup>th</sup> November 2009 to receive an early bird discount of 10%  
(members £180 / non-members £207)**

Registration deadline 21<sup>st</sup> December 2009.

Further information and application forms from:  
[http://www.ispo.org.uk/events\\_Meetings-W.html](http://www.ispo.org.uk/events_Meetings-W.html) and [www.cpconsensus.org.uk](http://www.cpconsensus.org.uk)

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## PRE-CONFERENCE TRAINING DAY

**6<sup>th</sup> June 2010**

**SECC, Exhibition Way, Glasgow, G3 8YW**

<b>Full day course</b>	<b>Prices</b>
<b>A.</b> <i>Postural Management for People with Cerebral Palsy</i> Jo Jex	<b>£99.00 + VAT</b>
<b>Half- day courses</b>	
<b>1 course</b>	<b>£59.00 + VAT</b>
<b>2 courses</b>	<b>£99.00 + VAT</b>
<b>Morning</b>	
<b>B.</b> <i>Normal Movement Development and Neuroplasticity: Applying Theory in Practice</i> Marion May and Peter Lane	
<b>C.</b> <i>Choosing an Outcome Measure for Your Service</i> Rory O'Connor and Mark Schmeler	
<b>D.</b> <i>Muscular Dystrophy (workshop title TBC)</i> Damien McCormack and Margaret Phillips	
<b>E.</b> <i>Measurement, Positioning &amp; Mobility Considerations for Bariatric Consumers</i> Stephanie Tanguay and Jane Fontein	
<b>F.</b> <i>Influences on the Seated Position</i> Menno van Etten	
<b>Afternoon</b>	
<b>G.</b> <i>Educational Workshop on Treating Spasticity</i> C W Roy, Alison Barclay, Lynda Williamson & Barry Meadows	
<b>H.</b> <i>A Specialised Equipment Service – This is How it's Done</i> Emlyn Williams	
<b>I.</b> <i>Physiologic Relationship Between Posture, Skin and Function</i> Stephanie Tanguay	
<b>J.</b> <i>Practical Wheelchair Skills</i> Roy Wild	
<b>K.</b> <i>Head Positioning: Problems or Possibilities?</i> Kathy Fisher	

For full course descriptions and details about the workshop presenters, see

[www.mobility2010.org/workshops.asp](http://www.mobility2010.org/workshops.asp)

to book for these courses, go to the main conference booking page

[www.mobility2010.org/delegate-booking-form.asp](http://www.mobility2010.org/delegate-booking-form.asp)



**JUNE 6<sup>TH</sup> 2010**  
**PRE-CONFERENCE TRAINING DAY**  
*see previous page for details*

# 4th International Interdisciplinary Conference on Posture and Wheeled Mobility

**SECC, Glasgow, Scotland**

**7<sup>th</sup> to 9<sup>th</sup> June 2010**

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