



DAVID THORNBERRY (1950-2009)

A Founding Member of PMG – Obituary on page 7

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issue...*

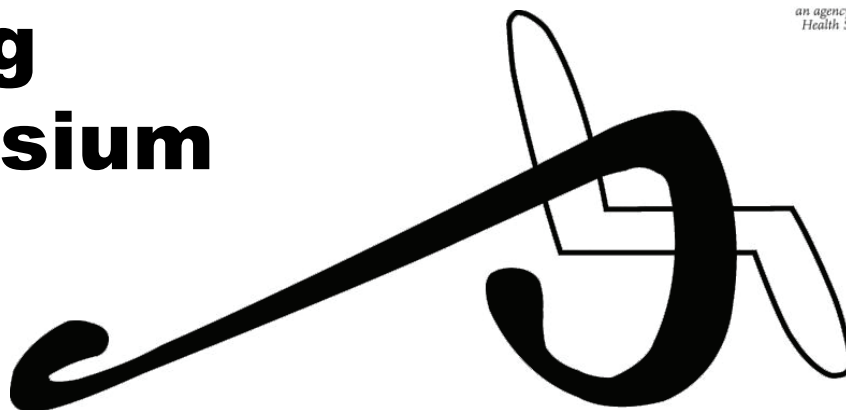
Best Practice: Lessons from the Field

- 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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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 Olwen 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

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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, for the next two issues, 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: **31st March 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 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 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

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

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)

To download copies of the report go to the PMG website page 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

Abstract: 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 aging 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 traveling 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 hardcopies 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)

??? Box to fill here ???