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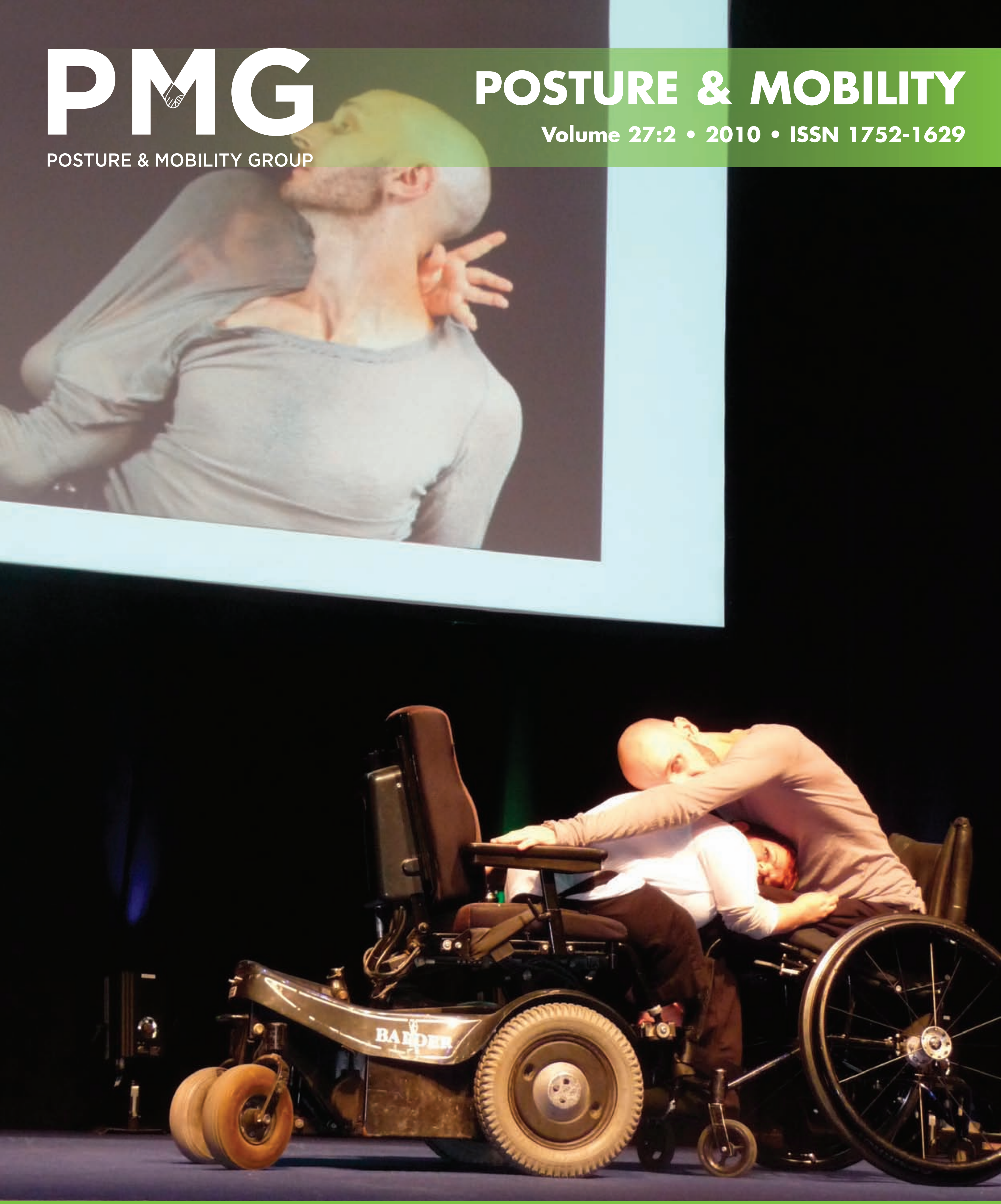

this issue...

Glasgow International Conference 2010

Webcasts Now Available to View

Thanks yet again to the hard work and dedication of **Paul Hewett** of **Active Design**, there is now a brand new programme of selected presentations for PMG members to view from the 2010 International Conference on Posture & Wheeled Mobility in Glasgow.

This means that, as a PMG member, you can watch 3 years worth of conference presentations online – from NTE 2008, NTE 2009 and now Glasgow 2010.

How to access the webcasts

1. click on www.pmguk.co.uk/members/login/?error=mustmember&bounceback=/NTE+(Conference)/Webcasts

2. log in using your PMG user name and password

3. Follow the instructions given

It takes a couple of seconds only, and will give you access
to hours, even days, of great viewing!

James Hollington, Chair, PMG Website Sub-committee

New Year's Resolution!

January 1st 2011: Renew PMG Membership

Why not make a note in your diary now to go online as soon as possible in January to renew your PMG membership for another year.

Visit www.pmguk.co.uk/members/login with your payment card at the ready. Membership subscription is still only £25.00pa

It is particularly important to renew early if you are planning to go to Warwick for the PMG National Training Event (NTE) in April, and be eligible for the discounted delegate rate.

Bookings for the NTE are opening early in January 2011. Check the PMG website home page for details: www.pmguk.co.uk

Front Cover: Marc Brew & Caroline Bowditch performing at the opening session of the Glasgow International Conference in June. Photo by Anne Munn. See Anne's bursar report on page 35

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4th International Interdisciplinary Conference on Posture and Wheeled Mobility

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Editorial

Welcome to the Autumn 2010 PMG Journal.

In order to get a flavour of how fantastic our international conference was, have a look through the reports on pages 29 to 48. For further information about the conference, get hold of a copy of the proceedings which were so ably compiled for us by Barend ter Haar; these were given to attendees, and a few remain – contact Olwen at PMG HQ if you wish to buy a copy. PMG members can now access webcasts from many of the conference sessions – very useful for CPD, particularly in the current economic climate.

We are aware that only a small proportion of our membership is from the community sector, for example therapists from child development centres and community therapists working in health, education, and social services, and that many of their clients have posture and mobility needs. Those of us who are from the community sector are members because we feel that we benefit from the inter-disciplinary links and learning gained via PMG. It is also a chance for us to liaise with and influence wheelchair and community equipment services, product manufacturers, and suppliers. Please encourage your colleagues in the community to join us, learn from us, teach us, share with us, and improve inter-disciplinary working. Additionally, we would welcome articles from people working in these areas – if you become aware of work being done that PMG members would like to know about, please let us know or encourage the clinicians to contact us directly.

We are in the process of writing more detailed guidelines for authors of various sorts of journal contributions – book reviews, research articles, product reports, and bursar reports. We hope that this will assist our contributors in writing their article, act as a reminder of what sorts of information to include, and encourage reflection on their subject. We are also updating the guidelines for writing references, which will follow a fairly simplified version of the Harvard (author-date) method.

Product reports are a new addition to the journal (see pages 27 and 28). Development of a new product requires a long process often including clinical input and testing with revision of design criteria along the way. We feel that there is a lot for members of PMG, clinical members and rehabilitation engineers, as well as suppliers and manufacturers, to learn from this information, and also that inter-disciplinary communication might be enhanced. We would therefore welcome short contributions, with a photo, describing this process: the original motivation for designing the product, a description of the client group it is aimed at, the design criteria, and a description of how the product meets the clinical needs. We would also welcome descriptions of modifications that have been made to existing products.

And finally, if you have read a good book, used or even improvised a good bit of kit that seems to work, we would love to hear about it…

Carolyn Nichols, Editor

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Letter from the Chair

Clare Wright

Hello to you all! As the first woman, therapist and industry Chair of PMG, I am both honoured and proud to be writing my first Chair's Letter for our inspiring journal. PMG is an amazing organisation, dedicated to advancing and disseminating knowledge about the posture and mobility needs of people with disabilities. The charity is run by a committee passionate about these aims, and I am greatly privileged to be working alongside such a devoted bunch.

Before I go any further, I'd like to say a few words of thanks. Firstly, to my predecessor Nigel Shapcott for his ongoing guidance – I have large footsteps to fill; secondly to the international conference committee for a superbly run conference in Glasgow; and finally, before it starts to sound like an Oscar speech, the support of the executive committee for agreeing to let me take the reins.

PMG, like many of your own services, has had to review its priorities for the next year to ensure we are targeting our efforts in a cost-effective manner. The committee, dedicated as we are, have full-time jobs, and are all expected to do more with less in our day jobs. As a result, we will focus on three key aims for PMG in the next 12 months: to establish a new website under the guidance of James Hollington; host another successful National Training Event at Warwick, led by Kirsty-Ann Cutler; and to increase our membership numbers, a responsibility shared by us all. PMG is an organisation which can't exist without members – encourage your colleagues to join or renew their membership – there is strength in numbers, and much learning to be shared with each other.

The PMG executive committee has been working hard to strengthen the foundations of PMG in order to be able to support growth. As part of this strengthening, we now formally employ Olwen Ellis as our administrator, and we really are delighted to have Oli with us on this firmer basis. The committee has also recognised the individual roles we have as Trustees for PMG as a charity, and we are putting the necessary indemnity into place to support us in these roles. We are also privileged that Dr Linda Marks accepted our invitation to become our first ever Advisory Trustee – Linda is a well known and respected figure in the field of posture and mobility, and has already given invaluable advice to us as we discuss various aspects of our business. Small steps, but important building blocks to a bigger, stronger and more influential PMG!

Dr Linda Marks

On another note altogether, we give our heartiest congratulations to committee members Helen Hislop and James Hollington who are attempting to increase PMG membership in their own way! Helen gave birth to little Caleb on 6th October, and James's daughter Evie Jessica was born on 14th October. We wish both families all the very best with their new additions.

Finally, some of you will know that I'm from Northern Ireland, where the people are known for their warmth, hospitality and unique way of expressing themselves. Therefore I thought I would share a couple of "Ulsterisms" with you – just to make communication easier of course. Upon greeting, please ask "wadda boutcha?" ("how are you?") and, in order to immediately sound more Norn Iron, add "so it is/was/does" etc on to the end of every sentence. It's not easy at the start so it isn't, but you soon get used to it so you do. I'll leave it there for now (so I will)!

Clare Wright, PMG Chair

For the next journal we would like to invite articles relating to **the active user**
• service provision – assessment, supply criteria, set-up of chairs, training of users
• health, fitness and injuries of active users
• wheelchair sports, even chairs and training for the upcoming Olympics!
Copy deadline is 28th February 2011. Details from **olwen.ellis@pmguk.co.uk**.

Equity and Excellence: Liberating the NHS

Mark Oaten gives his views on the Coalition's White Paper

Since retiring as an MP in May 2010, Mark Oaten has become BHTA's Media & Public Affairs Adviser. Mark kindly wrote the following article for PMG members in September. The post script was his immediate response to the Chancellor's Spending Review of October 20th 2010.

It's hard to keep up with the pace of change under the Coalition government as new initiative follows cut follows re-structure. Although it's early days, the impact for PMG members and those working in the disability equipment sector looks significant. There are four main measures that will impact:

1. New structures move power from Primary Care Trusts to GPs/Local Government
2. A Long Term Care Commission which will look at keeping people at home longer
3. Pilots on wheelchair provision
4. Review of arms length bodies

Taking each of these in turn

1. The new structures put enormous power in the hands of GPs. As PCTs end by 2013/4 new GP consortia will be established – it's difficult to see how these will not end up looking like PCTs but with a different name. It will certainly mean new contract arrangements in relation to health work currently commissioned by PCTs. The GPs are unlikely to have a strong understanding of the sector. The other winners from the re-structure appear to be local government as they will take on the public health work carried out by PCTs. This might be a first step towards a bigger merger of social services and health budgets and if this did take place it seems that local government would hold the budgets.

2. The new **adult social care policy** will demand an end to barriers between the NHS and Social Services and there is to be a Commission on funding of long term care headed up by Andrew Dilnot. The aim is for a paper by 2011 and legislation to follow from 2012. There is an opportunity here for the PMG members as the Coalition have already said in their joint agreement that they see home adaptations and wheelchairs having a role to play in helping care for people longer at home.

3. The **new wheelchair pilots** were announced by Paul Burstow in June. He announced that the Government will be pursuing a pilot programme specifically to examine the commissioning of wheelchair and seating services. The work in the two regional sites that have been selected – the East of England and the South West – will see PCTs, councils, NHS trusts and clinicians examining new ways of commissioning wheelchair services. They will make recommendations for new models. Of course he made the announcement before PCTs were abolished and so it's not clear how much role they will now have.

4. Finally, the **review of arms length bodies** has already taken place with a number of organisations being axed – more may follow in the NHS area. The Medical and Healthcare Products Regulatory Agency is to be kept but the NHS Institute for Innovation and Improvement and the Health Protection Agency are abolished.

Post script

Below is a précis of the BHTA response written by Mark Oaten an hour after the Chancellor, George Osborne, finished his spending review announcements to the House of Commons on 20th October 2010.

The first key point is that today's announcement should be seen against the backdrop of a number of other government initiatives, in particular the change to setting up GP consortia, changes to procurement, and pilots on wheelchair services.

Secondly, although the main heading figures are now known, it will take some months for the detail to spread down by each department into the front line.

Thirdly – although the headlines say the NHS budget has been protected this does not mean there are no cuts: it means that savings will still be made but are ring fenced within the NHS.

NHS Savings

The NHS will need to make savings via better value for services – target £20 billion by 2014. This is certain to impact on suppliers and contracts.

NHS/Health Money going into Local Government

There had been worries that with the new arrangements to give local government some of the PCT responsibilities, funds could get lost and, although Central Government is going to remove all ring fencing in local government, it WILL be kept for health money.

Mobility Care

Changes planned on delivery but the budgets protected.

Disability Living Allowance

This is going to be kept and, importantly, will not be subject to a new measure which limits any benefits given to the same as a working family would earn.

Adult Social Care

They are looking for new providers.

Social Care Funding

An extra £1 billion to social services and an extra £1 billion given jointly to Health and Social Services on condition it is used to encourage joint working and remove the gap between the two.

Disabled Facilities Grant and Supporting People

Under changes to the housing budgets both of these will be protected and increased.

Personal Budgets

To be protected for children with disability and those with long term care needs.

Department of Health Wheelchair and Seating Services Advisory Group Meeting, 28 October 2010

Kirsty-Ann Cutler

With seven months having passed since the last meeting, and a change of government, Henry Lumley and I were keen to learn about the Department of Health (DH)'s progress on this project.

The opening address was from Paul Burstow, Minister for Care Services. He spoke for 10 minutes before taking questions. He

- advised that he is committed to the project and to leading any improvements. He understands there is frustration due to numerous reports over many years, with no significant action.
- spoke of 'personalisation' and the shift of power from current methods of commissioning, about giving emphasis to the service user rather than the service and, in particular, seeking to learn from experiences in other areas where personalised budgets had already been introduced.
- stressed he will take advice from the group and the pilot sites regarding any reforms.
- feels there will be more opportunities to work with the 3rd sector and increased social enterprise.
- reiterated that half the cost of wheelchair services is in *back office costs*. The accuracy of this statement was challenged, given that it was based on figures from the initial data collection that is widely believed to be flawed. He said he will investigate the evidence for this.

A number of questions were posed regarding commissioning:

- **The move towards GP commissioning:**
    - there is no firm guidance in place as to how services would be commissioned in the aftermath of the PCT reorganisation, but GPs may need further training in commissioning.
    - there may need to be guidelines around commissioning wheelchair & seating services within the Specialist Commissioning agenda and there is general uncertainty about how to commission regional specialist services.
    - Burstow hopes the pilot sites will assist in their findings. The NHS Commissioning Board may need to help in providing tools or a framework.
    - potential areas for NHS Commissioning Board:
        - Develop commissioning framework
        - Recommend structure of contracts
    - joint commissioning offers many opportunities for seamless provision:
        - Education
        - Social Care
    - ministers from different parties need to discuss and be open to joined-up working in the future to make savings.
    - White Paper sets out Health & Well-Being Boards to lead joint commissioning models.
- **3rd sector partnerships:**
    - concern that support for 3rd sector may fall off during recession.
    - stressed that the opportunity was for statutory

  - bodies to share responsibilities with 3rd sector, not just to see it as an opportunity to save money.
  - there will be no 'offloading' to the 3rd sector but sharing of delivery of services.
- **Personalisation agenda:**
  - Burstow feels lessons can be learnt from the social care experience.
  - the model is not yet clear enough; may or may not include vouchers/direct payment.
  - Audit Commission recent report on personal care (www.audit-commission.gov.uk/nationalstudies/localgov/personalbudgets/Pages/default.aspx).
- **How will the postcode lottery be eliminated?**
  - he spoke of services being evidence based and having robust outcome measures.
  - there was a suggestion that NICE may move into looking at standards for social care.
  - QUIPP (Quality, Innovation, Productivity and Prevention) must be on the agenda and a driver for change.

The Scottish Experience

The group were given a presentation by the project manager for the reorganisation of Scottish wheelchair and seating services, Janet Garcia.

This was very interesting, and it would be good to use some of their experiences. Further information can be found at www.scotland.gov.uk/Topics/Health/health/wheelchair

Not all the funding that was made available for the Scottish services to invest in service improvement was actually used (£14m over three years). Based on a per capita allocation, this would amount to approximately £150m for England over the same time period, an investment that none of us saw as likely.

Best Practice Document

This document had been produced prior to the meeting for comment but, as the group had not been advised about it beforehand, there was some confusion as to its purpose. It contains examples of best practice, new initiatives and joint working.

The group felt that it should be renamed and made clear it is for service provision only, as it would not be relevant for others outside of these services.

Pilot site feedback

Two pilot sites have been chosen – South West England and East of England SHA's are leading these and are looking at models of service provision and opportunities for improvements. They are required to report back to DH by March 2011. Both pilots are looking at different aspects of service provision. Both have agreed project plans and the same delivery timescale.

David Bearman, project lead for the South West of England pilot

He reported that they are:

- collecting data.
- looking at access criteria, triage and assessment processes.
- emphasising the use of equipment inventory to reduce product diversity and supplier base.
- assessing stakeholder engagement.
- investigating the potential for regional or even national product preference.
- in discussions about an NHS designed standard wheelchair.
- keen to develop a national approach to cost reduction.

They have had discussions with two other regions – East of England and West Midlands.

They report the challenges are: tight consultation guidelines; cross agency alignments (budgets and processes); highlighting key players; long term commissioning.

Russell Foster, project lead for the East of England pilot

His is a team of three that have been working on this pilot for only a month. The previous pilot group was dissolved. Hence they have not yet achieved as much as the other pilot team.

Their objectives are to:

- develop proposals for new commissioning models.
- develop proposals for alternative approaches to wheelchair service provision.
- present these as an Options Paper to the DH.

To do this they have asked the following questions:

- what information would we need to enable a fair comparison of your services?
- what fundamental elements of service provision would you expect to see changed within a commissioner/provider model?
- what are the key issues for overcoming organisational boundaries to ensure high quality service provision?

Russell appealed for any advice and information to assist him in gaining information and data.

Next steps...

The Minister for Care Services is keen to progress and assist process. He will continue to receive updates and attend meetings; next meeting in early 2011. He also wants to hear of any examples of ‘poor’ service provision.

There is encouragement to look at alignment of provision through discussions with other government agencies, such as DWP and Education.

He also emphasised the opportunities that may be presented through the personalisation agenda and how this might fit into wheelchair services.

DH to look at working with NICE regarding production of guidelines, and gain information from the Scottish experience.

For further information please contact olwen.ellis@pmguk.co.uk

Kirsty-Ann Cutler

Project Gambia 2010 in association with Schools for Gambia

www.schoolsforgambia.org.uk

In December 2010 Kirsty-Ann Cutler joined other volunteers on a trip to the Gambia to assist in distributing medical supplies and mobility equipment.

Throughout 2010 they have been raising sponsorship to buy building materials, gardening materials and clean water facilities, as well as hospital equipment and school resources. Donations can still be made, so if you wish to help, please contact kirsty-ann.cutler@sbpct.nhs.uk

Current Studies Towards Using a 3-D Visualization Approach in the Assessment of Pain: A Cohort Overview

Fotios Spyridonis, Research Student and Gheorghita Ghinea, Reader,
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Abstract: *Pain is a very common problem that all people experience at some point in their lives, whether associated with any specific medical condition or not. Although advancements in medical practice have provided physicians with very effective methods of treatment, there is no common definition of what pain is, something that affects the understanding of its underlying mechanisms. Consequently, considering its usually subjective interpretation, there is currently no adequate assessment method that could successfully address pain, resulting in this way in poor treatment results.*

One of the most traditional assessment methods of conceptualizing pain is the collection of related information on a paper-based, 2-dimensional representation of the human body, which normally has limited ability in accurately visualizing the patient's experience. Taking into consideration, however, that adequate pain management is possible, it is important to propose a solution that exploits 3-dimensional techniques, with the purpose of overcoming the aforementioned limitations for more effective pain assessment.

Keywords: *Pain assessment and management, pain visualization, 3-D visualization, pressure mapping, objective pain measurements, pain drawing*

1. The Prevalence of Pain Across Medical Practice

Owing to its subjective nature, pain is considered to be a multidimensional phenomenon (Mannion et al, 2007), both in terms of the number of factors it is influenced by (psychological, cultural) besides physical injury, as well as regarding its appearance in various medical conditions (Coll et al, 2004).

In any medical practice, thus, the existence of pain is a frequent problem whether associated with chronic or acute conditions. One of the most common chronic conditions is back pain, affecting an estimated 60-80% of the population (Vaughn et al, 1999), with that percentage remaining the same in 2009, with 4 in 5 experiencing it in the UK (Backcare, 2008). Back pain alone costs the UK industry about £1.6 billion per year, with nearly 5 million working days lost as a result of such pain in 2003-04 in the UK alone (Backcare, 2008).

Accordingly, pain occurring as a result of a Spinal Cord Injury (SCI) is a very common acute condition. According to the Spinal Injuries Association's Impact Report (2009), every day in Britain 3 people are permanently paralysed (approximately more than 1,000 people per year) with the majority of them being between 21 and 30 years old, whereas in the USA the annual figure of new SCI cases is approximately 12,000 people (NSCISC, 2010). Although the prevalence of SCI is less compared with back pain, if we consider the severity of the most likely consequences, including loss of mobility, bladder and bowel control, and sexual function, then pain resulting after a SCI may have a great impact on a person's daily living, affecting the ability to carry out daily activities.

Taking into consideration the impact of both medical disorders, the provision of a better understanding of such pain constitutes an essential part of our current endeavours, which are described in this work.

2. Understanding the Subjectivity of Pain

As a result of their incidence, considerable research efforts have been reported so far (Lin et al, 2006; Malliou et al, 2006; Tanimoto et al, 1999), in order to identify more efficient ways to diagnose, classify, and treat pain arising from the aforementioned medical conditions. Yet, pain has proven to be a complicated phenomenon to understand and manage, specifically due to two basic factors: a. *the lack of a common pain definition*, and b. *its subjective nature*.

To be more specific, controversy in the literature indicates that there is no established definition of what pain is, a fact that could otherwise unveil its underlying mechanisms that would enable the understanding of this multidimensional phenomenon. Yet, as the word multidimensional indicates, pain has been established as a private experience characterized by physical discomfort, and influenced by complex qualities associated with psychological and cultural factors (Provenzano et al, 2007; Coll et al, 2004).

Consequently, considering that the only information that can be used in assessing pain is suggestive descriptions or self-reports from a patient, due to the fact that self-report is considered to be subjective by definition, and patients that self-report pain may have been influenced by such psychological or cultural factors while dealing with such pain, the overall assessment could be then naturally considered as a subjective interpretation. This view is also supported by Katz and Malzack (1999) who describe pain as “a personal and subjective experience that can only be felt by the sufferer”.

Therefore, although back pain and SCI are two different medical conditions in nature, they do share pain subjectivity as a common characteristic, which ultimately affects the ability of the current assessment methods to understand, and further, communicate more effectively and manage, the pain arising from both conditions.

3. Current Pain Assessment Methods

In order to get a better understanding of the situation, perhaps it would be beneficial to discuss the most important tool currently in use to measure pain – the traditional *‘Pain Drawing’*. This is considered to be a simple *self-assessment method*, often used by patients as a visual aid tool to enable the recording of the spatial location and type of his/her pain on a 2-dimensional human diagram (Ohnmeiss, 2000) as shown in Fig. 1. This could be achieved by marking this pain location on a blank diagram using a monochrome symbol to demonstrate the pain type. More information regarding pain drawings can be found in Ohnmeiss, 2000 and Ransford et al, 1976.

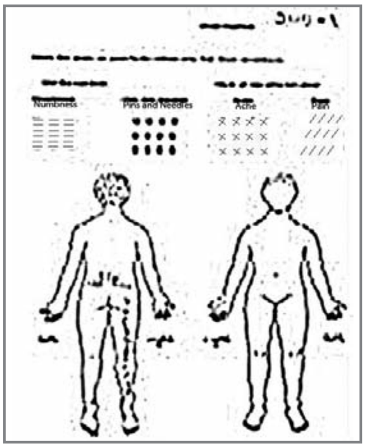

Fig. 1 2-D Pain Drawing

Nevertheless, although the pain drawing is widely considered to be valid (Ghinea et al, 2008; Ohnmeiss, 2000; Ransford et al, 1976), there also seems to be a lot of debate as to whether assessments of pain drawings alone are sufficient in determining whether someone really suffers or not from pain (Haefeli and Elfering, 2006; Jamison et al, 2004; Lee, 2001; Mannion et al, 2007). The main reason behind this debate is the fact that the only information that can be used in assessing pain is suggestive descriptions/self-reports from the patient, as recorded and extracted from the pain drawing. However, according to our previous discussion, self-report is considered to be subjective by definition: thus, this method is subsequently also considered to be subjective in nature for the purpose of assessing pain.

To this end, the need for a reliable objective pain measurement method has been identified, which would ideally complement the pain drawing in the assessment of pain in the back and after a SCI.

3.1 Existing Limitations

Notwithstanding its proven popularity in the assessment of pain, the pain drawing has its limitations, as the paper-based, limited 2-dimensional representation of the medical information does not capture the 3-dimensional nature of the human body. Thus, patients are unable to express the pain that they are experiencing visually, as statements of the form *“I have a pain on the inside of my thigh”* are not easily captured in a 2-D pain drawing. Although the development of 3-D imaging is being extensively used in clinical imaging, it has not yet been ported across to the world of pain drawings. Therefore, keeping in mind concerns regarding the pain drawing’s subjectivity, the focus of our current work has been the augmentation of the traditional 2-D pain drawing with novel, computer-based methods that would exploit 3-D techniques in the anticipation that this approach would overcome the issue of limited 2-D pain visualization, as well as the need for objective assessments.

4. Using 3-D in the Assessment Process

In computer technology, the concept of 3-D is intimately associated with that of virtual reality. This is the simulation of a real or imagined environment that can be experienced visually in the 3-D of width, height, and depth, and that may additionally provide an interactive experience. Thus, by being able to interact with the environment, anomalies caused by 2-D depth perception can be removed, potentially allowing for more accurate and consistent data collection.

In the case of pain visualization it was felt, after consultations with clinicians and patients alike, that a patient would be able to map the pain that they were experiencing better onto a 3-D model of themselves rather than a 2-D one. Using a front and rear 2-D projection of a human torso makes it difficult to map pain that is occurring at the edges of the representation. A 3-D model provides a continuous body surface, which allows a practitioner, or indeed a patient, to record the pain accurately.

In terms of back pain and pain resulting from SCI, Frank and De Souza (2001), in an experimental study for reconstructing spinal cord injuries, constructed 3-D virtual images from performing computerized medical scans. In this case 3-D images were extremely beneficial because the models could be observed from many different viewpoints. Rotation and zooming features were combined to allow observer navigation within the tissue. The same feature benefit was anticipated from devising a 3-D adaptation of pain drawings combined with a 3-D approach for objective pain assessment.

4.1 3-D Pain Drawings

Based on the above discussion, it seems natural to implement digitized 3-D pain drawings, since such an approach provides an attractive opportunity for enhancing interaction between the practitioner and the patient in a more perceivable way to the natural environment. The design of the 3-D pain drawing was conducted in collaboration with a team of clinicians from the Rheumatology Department of Northwick Park Hospital, London, with invaluable help from the U.K. National Forum of Wheelchair User Groups.

The developed solution consists of a 3-D representation of a pain drawing with the possibility for the user to navigate directly and select the location of pain (Fig. 2) as well as its type from a choice of four different colour-coded types that the user can select – numbness, pain, pins and needles, and ache – based on the earlier work of Parker et al (1995) and Prkatchin et al (2002).

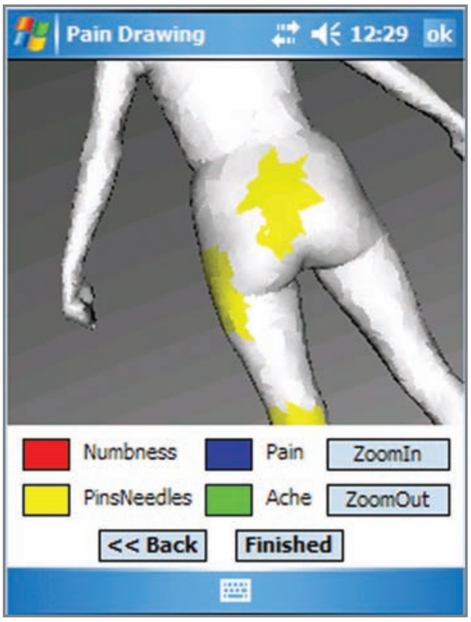

Fig. 2 3-D Pain Drawing

In order to input the type of pain, the user first selects the pain type, after which s/he manipulates the 3-D drawing to the desired level of detail, and finally indicates the particular region of the body that is affected, which is then colour-coded based on the pain type selected. After consultation with the medical staff in our research, the 3-D mannequin's surface was segmented into clinically appropriate regions. The developed 3-D drawing, as well as its design and implementation, are described in more detail in previous work of ours (Ghinea et al, 2008).

4.2 3-D Objective Pain Assessment

So far in the clinical literature many methods have been used to acquire objective measurements of pain, in order to provide a solution to the recurring issue of pain subjectivity. Unfortunately, these often tend to be less reliable (Haefeli and Elfering, 2006) even compared with patient-reported subjective measures (e.g. pain drawings).

To both authors' knowledge, to date there are no reliable methods that can be used to measure pain objectively. Thus, considering the need for more objective measurements (Harcourt et al, 2003; Kendal et al, 1996), the approach that the authors of this study have decided to take is based on advancements that have occurred in the field of pressure mapping – a system of assessing the pressure distribution between a person's thighs and buttocks, and the seating surface (Stinson et al, 2008) as shown in Fig 3.

Such a pressure mapping system consists of a pressure sensing mat that is directly connected via an interface module to a computer, an example of which is the commercially available FSA (VistaMed, Canada) device, which consists of a sensor mat (16x16 array of sensors), a computer interface module, and sophisticated software to record the information from the pressure sensors. This is also the pressure mapping system used in these studies. Data computed from the sensors is recorded and displayed on a computer screen in various forms, including a 3-D grid (Stinson et al, 2003) as shown in Fig.3.

To this end, various studies (Stinson et al, 2008; Tanimoto et al, 1999) have used pressure mapping on patients suffering from several medical conditions, such

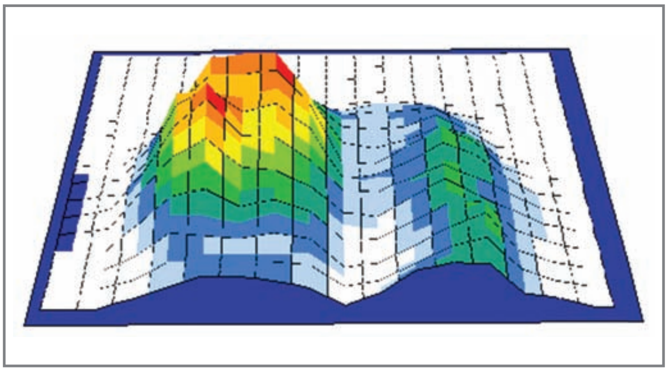

Fig. 3 3-D Pressure Mapping Technique

as multiple sclerosis and SCI, with the results of these being very promising in terms of the usefulness of visual pressure maps, and their practicality for the wheelchair and elderly population.

5. Concluding Discussion

The usefulness of pain drawings and pressure mapping as communication tools for characterizing pain is well established. However, they're both being used separately, and most of the time each for a different medical purpose. To the best of our knowledge no study currently exists in the literature which explores the combined use of pain drawings and pressure mapping's ability to communicate pain more efficiently, for the purpose of assessing pain in the back and after a SCI.

Also in this study, taking into consideration the limited, 2-D visualization ability of the current pain drawings, together with the well-established fact of pain subjectivity, we have proposed the development of an innovative method that encompasses a combination of subjective and objective measures, through the use of a 3-D pain drawing and 3-D pressure mapping respectively.

The innovation in our work lies in the fact that, compared to other studies in the literature that have used pressure mapping in order to mainly reduce the consequences of pain (e.g. pressure sores, inappropriate cushioning), our intended purpose is the combined use of 3-D drawings and pressure mapping to identify any existing pain so as to prevent any possible consequences that might arise. To this end, preliminary analysis of the results has revealed that a direct association exists between our proposed methods, showing that high pressure is a possible direct indication of the existence of pain. On the other hand, an indirect association was also found, which exposes that high pressure might not necessarily be a possible direct indication of pain, but it can reveal further information for its existence.

We strongly believe that by using our 3-D pain drawing for pain information collection, in combination with pressure mapping technique's ability to visualize patterns in a 3-D perception, it would have many benefits to the pain assessment process, as also described by Harcourt et al (2003) an opinion embraced by both authors of these studies.

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A Guide to Safer Wheelchair Use: Creating an On-line E-learning Course for Carers

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Abstract: *If a client has multiple carers, it is likely that not all of them will be present when the wheelchair is issued. As a result some carers may not have the necessary knowledge to ensure safe use of the wheelchair. An on-line training course aimed at carers has been constructed to cover the basic aspects of wheelchair use, with the aim of encouraging safe practice. This is now in use by the Isle of Wight (IoW) Primary Healthcare Trust (PCT).*

Keywords: *Training, E-learning, users, carers, safety, wheelchair*

Assessment for basic or standard wheelchairs usually takes place with the client and one or, at most, two carers present. The same situation occurs when the chair is issued. At the client's home many different family members or visiting carers may be involved who were not present at the assessment and the delivery of the chair.

Consequently they will not have been in a position to gain basic knowledge of the wheelchair and the client's specific needs relating to it. A similar situation can arise in residential or nursing homes or on a hospital ward where there may be numerous carers, all with different levels of knowledge concerning wheelchairs. I have had many encounters with carers who are unable to operate what I consider to be basic aspects of wheelchairs, for example footrest mechanisms. Other common examples are of carers misusing cushions, chairs being unfolded incorrectly, or clients sitting in the wrong chairs. This is not necessarily the carer's fault. It may be that they were not present when the chair was issued or they are not aware of the importance of reading the user guide.

I discussed this with my colleagues in the Isle of Wight wheelchair service. We agreed that this was a common experience and that it posed a safety risk to wheelchair users. But we also agreed that it was something that could and should be addressed with proper training. We held a meeting to 'brainstorm' what the problems and potential risks were to wheelchair users and carers.

The IoW PCT uses E-learning, a system where employees complete training courses on-line. These courses vary in length but consist of a number of pages, or slides, containing information on the subject matter. These are illustrated with photos, diagrams, and charts. A test at the end based on the contents of the course has to be successfully completed for the candidate to pass. Members of the wheelchair service had all experienced this way of learning, and we agreed that it was ideal for imparting basic facts of wheelchair use to carers.

We agreed that the course should cover these basic themes:

- Preventing injury by using equipment in the correct way
- Reducing the risk of cross infection and/or injury by not using equipment issued to others
- Using the appropriate equipment
- Preventing loss of equipment

I then contacted the Development and Training Department of the IoW PCT who agreed in principle to the idea of making a new E-learning course. As I put the course together they gave me useful advice and support throughout. At a further wheelchair service meeting I presented the basic initial content of the course with ideas about illustrations. I had initially hoped illustrations could be sourced from the internet, but these turned out to be of limited value and in the end I took most of the photos myself. Some of these are of equipment but others are of staff representing wheelchair users or carers. Several attempts were trialled with colleagues until a final draft was agreed upon. This was 'tweaked' by the training department and it ultimately went 'live' to all IoW PCT staff two years ago. It consists of 16 'slides' and takes about 30 minutes to complete. The course has already been taken and passed by over 300 members of staff. It has since been put on a CD ROM for sale to nursing and residential homes and day centres.

Content Of The Course

After a brief introduction, a series of 'golden rules' on the safe use of wheelchairs is given. These are very much 'back to basics' but firstly cover preparing the chair for use, how the chair is folded/unfolded, ensuring the chair is fully opened, and getting in and out of the chair safely. This is followed by a section aimed at those pushing the wheelchair with advice on communicating with the user, back care, and taking hills and kerbs. Also included is advice on finding the safest place to cross the road.

A section on wheelchairs and vehicles follows. Advice is given on lifting chairs in and out of cars and then there are illustrated instructions and advice on securing chairs when they are used as vehicle seats.

I'm sure that all therapists reading this will have horror stories of cushions not used, used upside down, being sat on by the wrong person, or in a filthy condition so, with this in mind, it was decided to give wheelchair cushions a section of their own! With accompanying warnings on the need for pressure relief and correct postural support, advice on cushion weight limits and correct positioning is included with illustrations. The risks of cross infection are pointed out, and therefore the importance of identifying the cushion and the ways of doing this are shown.

Further aspects of wheelchairs are then covered: weight limits, tyres (including maintaining correct pressures for pneumatic tyres), use of footrests and the importance of their correct position, use of armrests, and use of brakes.

The aim of the next section is to help ensure that the client is using the wheelchair that he/she was actually issued, again with warnings of the risk of cross infection or injury. So this part shows the ways of identifying the chair from the labels used by the various sources of wheelchairs locally (apart from the privately purchased chairs): the IoW wheelchair service, the Red Cross, the hospital, and the hospice. Phone numbers are given for all of these.

The course ends with two pieces of general advice to all those who are not wheelchair users themselves: to remember to communicate with the wheelchair user, not just the carer, and to consider how they would want to be treated if they were the one sitting in the chair.

Conclusion

The course is entitled 'A Guide to Safer Wheelchair Use' and, in its introduction, is described as being 'aimed at anyone who cares for someone who uses a wheelchair.' It is not aimed at the wheelchair user and does not emphasise the responsibility the user themselves should take if they are able to do so.

Criticism could be made of the content of the course in that no survey was done of wheelchair users and carers to discover what their experiences were of wheelchair use, whether they had any difficulties, what these difficulties were, and indeed whether such information as they were given was adequate. This would have been a whole separate piece of work on its own and would have led to a considerable delay in the production of the course. The use of such a survey, if carefully carried out, would be to highlight any changes needed in service provision, with consequent changes in the training course, the contents and structure of which should be reviewed regularly.

Residential and nursing homes have requested and been given copies on CD-ROM, but the course has not been offered to members of the public – a situation that could change in the future.

I would like to thank the staff at the Isle of Wight PCT Development and Training Department, the Wheelchair Service, and the Occupational Therapy Department for all their help and encouragement in putting the course together.

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PAMIS: Supporting People with Profound and Multiple Learning Disabilities and Their Families for a Better Life

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Abstract: *PAMIS (acronym for "Promoting a More Inclusive Society") is a unique organisation in Scotland, based within the University of Dundee. It was established in 1992 by Professor James Hogg and Loretto Lambe to support people with profound and multiple learning disabilities (PMLD), their families, and carers. It has offices in five areas of Scotland: Tayside, Grampian, Fife, Glasgow, and South Lanarkshire, and a Family Support Service (FSS) providing training workshops and involvement in a number of projects. All these services are available free of charge to families and professionals supporting individuals with PMLD. PAMIS is also a founder member of the Scottish Consortium for Learning Disabilities.*

Keywords: *Learning disability, profound and multiple learning disability, PMLD, family support, support services*

Jenny and her son Craig

My family involvement with PAMIS

I became involved with PAMIS in 1993 when, as the mother of a little boy with profound and multiple learning disabilities (PMLD), I was contacted by the newly appointed co-ordinator for PAMIS in Tayside. She made a home visit and asked me what support I needed; she didn't leave for 3 hours! There was so little support available to me in my local area at that time, and there was so much I needed to learn around the very complex health needs of my son who had digestive issues, epilepsy, respiratory problems, and a deteriorating scoliosis.

Family Carers at a PAMIS Workshop

Workshop Programme

Shortly following the home visit to me, the PAMIS training workshop programme began with a workshop on support and equipment in the home. Over the years PAMIS has followed on with many training workshops on topics that family carers have raised themselves such as: respiratory issues, nutrition and feeding, oral healthcare, continence, moving and handling awareness, vision, and epilepsy. The PAMIS workshop format is one that suits the caring commitments of family carers, for example they are held one day a week for a 2 or 3 day workshop, and between the hours of 10 am and 3 pm to allow the family carer to get their relative off to school or day centre, and then to be there for their return. The workshops are led by local professionals from the health or social work teams, because PAMIS recognises the importance of the partnership between family carers and the professionals involved with the individual with PMLD. If a local professional cannot be identified to lead the workshop, PAMIS will find the best professional available. Additionally, PAMIS has trained family carers to lead a workshop on recognising poor mental wellbeing in people with PMLD (Phillip et al 2005), as we recognise that their caring role has given them the knowledge and skills to do this. The need for this topic was identified as a direct outcome of the PAMIS research project, The Wellbeing Project: identifying and meeting the needs of young people with PMLD and their carers (Phillip et al 2005a).

Over the years of my son's life, the PAMIS workshop programme gave me and other family carers the knowledge we needed to work more effectively in partnership with the many professionals involved in our children's care. The workshop programme also had a great influence on me in my professional work which includes ensuring that an effective workshop programme for family carers continues to be delivered in the Grampian area.

Campaigning

As a result of the opportunity for family carers to come together, either at the PAMIS workshops or at special interest group meetings, issues were raised by family carers that PAMIS then took up as campaigns, such as the *Changing Places Campaign* (adult sized changing facilities) that has now gone UK wide and is led by the *Changing Places Consortium* (see www.changing-places.org).

Changing Places Toilet

My son and I were involved at the start of this campaign with other PAMIS family carers and I see his continuing involvement, through his story (Craig's Story) on the web site, as part of his legacy. The campaign has become so successful that it has influenced British Standards, which now include a standard (and guidance) for adult changing facilities in BS 8300:2009 (design of buildings and their approaches to meet the needs of disabled people).

Currently PAMIS is involved with the UK-wide campaign to reinstate applications by people with PMLD to the Independent Living Fund (ILF), following the cancellation of all new applications to the ILF in March 2010. This funding stream is vital to people with PMLD as they transition into adult services, to support a more independent lifestyle and to access the care and support they need. I found it an essential part of my son's adult life, supporting him to have a good quality of life, and it enabled me to go back to work.

Projects

PAMIS has developed a number of very important projects over the years that have either resulted from, or been combined with, research, or were cultivated from issues highlighted by family carers. They have all been very successful with ongoing benefits to people with PMLD, their families, and professionals. Some of these initiatives are described below.

The Futures Project (2003-) and *Transition Pathways Project* (2009-2011) offer support to families whose youngsters with PMLD are approaching or going through the transition from child to adult services. Often families describe this time as "falling into the black hole of transition" because many services supporting a child with PMLD appear to fall away as the young person moves into adult services. The project worker will now assist the family in the development of a *Personal Communication Passport* for the young person, and offers the use of the *Transition Planner* (2010) which helps the family to plan the young person's life after school. These important documents are completed in partnership with the young person's family and the education, health, and social work professionals supporting the young person.

The *Healthy Lifestyles Project* (2006-2009) took place in all of the five regions of Scotland where PAMIS has a family support service. The first part of the project involved a programme of nine workshops over the three years on the main health difficulties experienced by people with PMLD. The second part was aimed at improving the health and wellbeing of people with PMLD through opening up opportunities for them to participate in community and sporting activities in which historically they have had very little opportunity to take part. This project was extremely successful and promoted very close working relationships between PAMIS, health professionals, social work teams, and many other professionals such as disability sports personnel. Allied health professionals led and supported the workshops and activity programmes introduced by the healthy lifestyles project workers. Many of the benefits of this project have been sustained with various community-based leisure activities available for people with PMLD, such as Sporting Opportunities for Motor Activities (SOMA) groups, wheelchair ice skating, adapted bike riding, boccia sessions, rebound sessions, and drama & dance groups.

Oliver and his Dad on a bike ride

The *Freestyles Project* resulted from the *Healthy Lifestyles Project*, and has developed an awareness training pack and accompanying DVD to support professionals and care staff in developing community based leisure activities that are accessible to people with PMLD.

Library and Information Service

PAMIS has a dedicated information officer, Julie Taylor, based at the head office in the University of Dundee, and the PAMIS library holds the largest collection of books and journals on the subject of PMLD in Scotland. Books are free to loan out and the information officer will seek out information that is not already available through the PAMIS library.

Multi-sensitive and Sensory Stories (MSS) were two projects that used the bag books model (see www.bagbooks.org.uk), created by Chris Fuller, and were developed and continued with her blessing by PAMIS. The projects involved the development of a library of personal stories, research into the impact of the story on the individual, and assessment of whether certain learning targets were being met. The projects were hugely successful and PAMIS now has a library of over 50 MSS stories that are loaned free of charge to families and professionals. The stories are enjoyable, can support specific learning targets such as increasing attention span, reaching, or looking at objects, and can help families and professionals tackle difficult subjects such as epilepsy, going to the dentist, or issues around puberty.

I now teach professional staff and family carers how to use MSS as a means of communication, having learned firsthand through my son what a powerful communicative tool it is.

PAMIS in Grampian

I became the Grampian co-ordinator in 2005, following a campaign by parents of children with PMLD to establish the services of PAMIS in the region. I had previously been the co-ordinator in Tayside since 2002. Over the past five years I have built up a database of over 250 family carers and individuals with PMLD across Aberdeen City and Aberdeenshire. I work at a strategic level, ensuring that the needs of people with PMLD are kept on the agenda with Social Work and NHS Grampian. I also support those living in supported accommodation through the providers strategic groups.

The most important aspect of my work, and that of any PAMIS Co-ordinator, is the *Family Support Service*. We offer one to one support to families, usually through an initial home visit, where families are given the opportunity to discuss issues freely. They may need information on a range of issues, or support at a specific meeting, case review, etc. I may attend meetings on their behalf, or set up a meeting with relevant professionals to discuss a particular issue. I appreciate and recognise the importance of this service, because some families go through periods of extreme stress when caring for an individual with PMLD and very complex health issues.

Presently I am involved in a number of exciting areas of work involving both adults and children with PMLD and their families and carers. I have been raising awareness of communication skills in special schools, day centres, and care provider organisations using the PAMIS MSS stories, and it is very satisfying to see how well those involved have responded to the sessions.

I am in the process of holding moving and handling awareness workshops in partnership with Voluntary Service Aberdeen and NHS Grampian, funded through the NHS Carer Information Strategy Funding. This approach of partnership working with other voluntary agencies or partners is one I welcome, and hope to continue to develop so that the maximum number of people can benefit from the workshops and the best use of resources is ensured.

Recently I have worked in partnership with NHS Education for Scotland and Robert Gordon University in Aberdeen on a pilot project for student radiographers to give them an experience of "24 hours in the life of…". This project was developed as a result of recognising that improved communication, positive changes in attitudes, and greater mutual understanding between families, service users, and health professionals may be built from family carers and service users taking part in the training of health professionals. Working very closely with the university radiography tutor, we linked a number of 1st year radiography students to families caring for children and adults with PMLD. The students made a number of visits to the family where they learned what it is like to care on a daily basis for someone with PMLD and very complex health issues. They also had the opportunity to visit the school or day service that the young person with PMLD attended and accompanied the family to any clinic or hospital appointments that took place during the time of the pilot project. Following these pilot project visits, the family carers completed a questionnaire to assess the students' abilities to communicate with the family, and the students also assessed their experience.

The university tutor and I are now in the process of preparing a report, so that PAMIS, NHS Education for Scotland, and Robert Gordon University can assess the ongoing benefits to the students taking part in the pilot, with the goals of developing this experience for other health professionals and opening up the service user and family carer involvement to other groups.

Protection of Body Shape

This has been a developing area of importance for professionals and families in recent years. It is certainly important to me, as very poor body shape contributed to my son's early death; his severe scoliosis and hip rotation had a serious detrimental impact on his health and wellbeing. Bed systems and 24 hour protection of body shape are not systematically available in my region nor in many other areas in Scotland. I, therefore, did not have any information on the benefits of these systems until my son was almost an adult; I would have gladly met the cost of such a system had I only known about it earlier. Additionally, I did not have the skills required to protect my son's body shape until I had accessed training offered by John and Liz Goldsmith (Postural Care Skills) when my son had reached adulthood. This training and information did, however, help to maintain my son's comfort and quality of life during his final years, but I wish I had been given all the vital information on how to protect his body shape much sooner. Postural Care Skills have developed a national focus group that I attend on behalf of PAMIS. I am very proud that they have named a document on protection of body shape after my son – *Craig's Consensus for a Mainstream Future*.

Last year I held two awareness days on protection of body shape for family carers and professionals. Both days were very well attended with over fifty family carers and professionals participating. The evaluations from both events highlighted the need for further information and training, and I am currently collaborating with NHS Education for Scotland, Robert Gordon University Health Science Department, and Postural Care Skills to look into the accreditation of postural care training courses in Scotland. I firmly believe the future results of continuing improvement in this area of work in Scotland and elsewhere will have an immense impact on the overall health and wellbeing of individuals with body shape problems.

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Useful websites

www.bagbooks.org.uk
www.pamis.org.uk
www.changing-places.org

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PAS 900: 2010 Code of Practice for Wheelchair Passport Schemes

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Introduction: *In 2007 PMG and BHTA, represented by Barend ter Haar, joined forces with Bob Appleyard, chair of BSI Rehab Equipment committee, and Donald MacDonald of the Department of Transport, to host the event* Achieving Mobility for Life*, which was kindly sponsored by Volvo at their UK HQ in Warwick. At the meeting, wheelchair users highlighted the need for an effective national wheelchair passport scheme. After 3 years of hard work and the involvement of several individuals and organisations, a Publicly Available Specification (PAS) has now been awarded for Wheelchair Passports by the British Standards Institute. This is PAS 900 which will initially take the form of a Code of Practice.*

In consultation with Bob Appleyard, PMG Committee member Alison Johnston writes here about PAS 900

Abstract: *The PAS 900 was published through BSI on 22nd July 2010, after approximately a year of input from a number of organisations plus financial sponsorship from Essex and Lincolnshire County Councils. Technical authorship was supported by Unwin Safety Systems. It is intended to be a UK-wide document providing information to transport commissioners and transport operators on how to implement a wheelchair passport scheme in their area.*

Keywords: *Passport scheme, risk assessment, wheelchair seated passenger, safety, transport, stakeholder identity.*

This PAS (Publicly Available Specification) has been developed through BSI (British Standards Institute) with input from:

- Essex County Council
- Lincolnshire County Council
- Unwin Safety Systems
- British Healthcare Trades Association (BHTA)
- British Red Cross
- Chartered Society of Physiotherapy
- Community Transport Association (CTA)
- Department for Transport
- Dial-a-Ride
- Empower
- RED Kings College Hospital Foundation Trust.

It has been published to offer guidance and recommendations for setting up and implementing a passport scheme for safer transportation of wheelchair seated passengers in transport.

Fig 1

A passport will contain essential information relating to the securement of a wheelchair, such as tie-down points and mechanical settings, but also information regarding the achievement of effective occupant restraint, plus any other relevant details that may affect occupant safety in transport.

It has been developed to assist in the introduction of the scheme throughout the UK. At present schemes operate in isolated pockets, and passports from one county are not always accepted in a neighbouring one. By adopting a uniform structure, the passport can become accepted throughout the UK.

PAS 900 sets out an operational framework around the supply of information and responsibilities of all those involved, e.g. the wheelchair user, prescriber, manufacturer, and driver. It does not shy away from allocating final responsibility to the driver who must do everything in his/her power to ensure the safety of his/her passengers.

Risk assessment is at the heart of this document and provides a general (although not exhaustive) risk assessment framework. Risk assessment should be carried out throughout the prescription and provision process, involving the user and carers, prescriber, and manufacturer, with a hazard checklist being completed by the transport provider to ensure all aspects of travel are covered.

There is also a suggested layout for the passport. It is intended for it to be A6 or A7 in size and carried in a high-visibility wallet attached to the wheelchair. It should also contain photos of key points of attachment and routing of the wheelchair tie-downs and occupant restraint system in order to help speed securement and enhance safety in the vehicle when travelling on unfamiliar transport.

Fig 2

The Code of Practice document costs £65 and is available for purchase via http://shop.bsigroup.com/en/SearchResults/?q=PAS%20900

As a specification that has been developed through BSI and written by reputable and knowledgeable organisations, this is a document that should be used as a point of reference for all local transport providers and commissioners. Unfortunately, I feel the price may put off some local authorities from purchasing it.

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Please ensure that your PMG membership details are up-to-date!

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Society for Research in Rehabilitation Summer Meeting – 7th July 2010

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***Abstract:** In July 2010 I was very generously given the opportunity, by the Posture and Mobility Group (PMG), to attend the Society for Research in Rehabilitation's (SRR) Summer Meeting at Sheffield Hallam University. This is a multi-disciplinary group, focusing on encouraging healthcare professionals to carry out and disseminate high quality research within the field of rehabilitation, to inform and challenge practices and to improve the quality of services offered to people with acute and chronic disabling conditions.*

The following report is a summary of my personal reflections on the most relevant research presented at the symposium, and my perceptions of the importance and significance of this research to the members of PMG.

The focus of the majority of the day was on the role of exercise therapy in the management of multiple sclerosis (MS). This is a particularly relevant area for PMG as over 100,000 people in the UK have MS (Fricker 2009), and it is a condition that can place high demands on wheelchair and seating services resources. Jane Petty (programme lead for physiotherapy with the MS society) commenced with an overview of the changing perspectives on exercise for people with MS by physiotherapists and healthcare professionals. Over the past few years there has been a significant shift from the traditional advice given to people with MS, which was to avoid strenuous activities and exercise therapy due to the potential effect of triggering an exacerbation or worsening disease activity and fatigue. The current thinking is that exercise and increased activity can actually have a positive impact on decreasing the effects of disease progression and assist with managing symptoms such as fatigue, muscle stiffness, balance difficulties, anxiety, depression, and bladder and bowel problems (Reitberg et al 2004). Additionally, as with the general population, increased activity and exercise is responsible for improved general health and reduces the risk of conditions such as heart disease, therefore positively influencing life expectancy for people with MS.

Jane went on to discuss some of the strategies that the MS society is employing to overcome the reluctance and anxieties surrounding exercising for individuals with MS. It is acknowledged that people with MS may face several barriers to exercise that need to be addressed at the first stage, such as confidence, body image, balance and co-ordination, concerns about getting on/off exercise equipment, as well as numerous social and environment barriers such as knowledge of sport centre staff and physical access to sports and leisure centres, pools etc.

The MS Society has been working alongside a number of different agencies, including day centres and the private fitness industry, to develop exercise opportunities for people affected by MS in the community. These initiatives include running introductory activity days all around the country (available to any person with a neurological condition), liaising with a chain of nationwide fitness centres to introduce discounted membership rates for people with MS, introducing specific classes such as Pilates, and providing staff with the knowledge and skills required to assist people with MS in how to optimally exercise. Furthermore a very interesting and relevant pilot study is currently under way looking at the impact of a Pilates programme on posture, pain, and function in people with MS who use wheelchairs. I have invited Jane to present this at PMG NTE 2011, as it is important that, as professionals in frequent contact with this client group, we are aware of these developments and can support and encourage our clients to become as active as possible and reap the rewards that an active lifestyle can offer.

Two current research projects relating to different aspects of exercise for people with MS were then presented. Anouska McConnell (senior sport and exercise science officer at Sheffield Hallam University) presented an ongoing large randomised control trial (RCT) involving 120 people with MS, randomised into either a control group who were offered a usual care programme, or an exercise group using an interval training style combined with cognitive behavioural therapy (CBT) strategies to promote motivation and confidence. Preliminary results show that the interval training style appears to have had a positive impact on fatigue levels as well as self esteem, but longer term results looking at the impact on physical activity, strength, functional ability and overall health are not yet known.

Dr Helen Dawes (senior lecturer in exercise physiology, School of Life Sciences, University of Oxford) then continued this theme with comments that exercise could be seen as a treatment for this client group and that, if a medication existed which had a similar effect on so many aspects of health, it would be regarded as a wonder drug! She therefore suggests that exercise can be considered in terms of dosage, and her team at Oxford have been exploring dose-response issues to exercise for people with MS. They found no real differences between groups using 3 different intensities and regimes of cycle ergometer training; however all showed improvements in terms of specific activity performance and power. The team found one interesting issue with regards to adequate hydration of people with MS: they discovered that 42% of participants were dehydrated even before undertaking exercise. This is something that needs addressing for the individual prior to commencing an exercise programme as dehydration can affect balance, cognition, endurance, and fatigue, the very things that people with MS are already susceptible to. Additionally they found that many participants with MS displayed a delay in elevating heart rate during the first two minutes of exercise, and highlighted that this could be a key factor in putting people with MS off exercise, as activity and exercise will feel harder until the raised heart rate increases oxygen circulation around the body.

This symposium raises a number of pertinent questions for therapists involved in providing wheelchairs for people with MS, in particular around the timing and type of wheelchair provision. With exercise therapy being actively encouraged, might it be that people with MS will be more active for longer with wheelchair services consequently becoming involved further down the line, rather than the current fatigue management approach of early wheelchair provision?

Further research is needed to explore these ideas and issues and to ensure that service provision meets the needs of people with MS based on the current evidence. It highlighted for me that greater links are needed between professionals involved with people with MS and that, as wheelchair and seating therapists, we are not always aware of the research going on in other areas such as rehabilitation, and the potential impact of the resulting evidence on the area of mobility provision and fatigue management.

I would recommend that professionals working with this client group read the MS Society's excellent information leaflet on Exercise and Physiotherapy for people with MS (Bailey 2009), and pass this information on to their clients.

References:

Bailey, J. 2009. *MS Essentials 21: Exercise and Physiotherapy*. MS Society, London (available online at: www.mssociety.org.uk)

Fricker, J. 2009. *A guide to MS for GPs and primary care professionals*. 2nd Edition. MS Society, London (available online at: www.mssociety.org.uk)

Rietberg, M.B. Brooks, D. Uitdehaag, B.M.J. Kwakkel, G. 2004. Exercise therapy for multiple sclerosis. *Cochrane Database of Systematic Reviews*. Issue 3.

PMG Small Research Study Fund

The PMG R&D sub-committee will find out shortly what funds will be available to offer as grants for small research studies in 2011. If you are considering applying to PMG for a grant, you can submit an outline proposal for your research project up to **31st December 2010**.

For further information and to submit an outline proposal, click on
www.pmguk.co.uk/Research/Information

Applicants will be informed about the funding situation as soon as possible.

Whistle-stop Tour of Rehacare, 21st International Trade Fair and Congress

**Joanne McConnell, Business Manager Mobility, Otto Bock Healthcare Plc,
32 Parsonage Road, Englefield Green, Egham, Surrey, TW20 0LD**

Abstract: *On October 6th and 7th this year I had my first experience of Rehacare, when I visited as an employee of Otto Bock. I was in Düsseldorf for two days prior to the exhibition for the international briefing on new product updates and for training with Otto Bock colleagues from around the world. By the end of my 5 days in Düsseldorf I felt I had a much better international perspective of the world of mobility. After many informal discussions with my colleagues I could see that, even within one manufacturer's range, there are hugely differing needs from country to country. I offered to write a brief review of my experiences for those of you who haven't had the opportunity to visit Rehacare.*

Keywords: *aching feet, beer.*

On arrival at the exhibition, it struck me almost immediately that this was going to make Naidex look like a table top sale in a village hall! The exhibition halls were vast and numerous – not really that different from the N.E.C., except that the exhibition takes up the majority of the space and the whole area was alive with wheelchair users.

Another difference is that you pay to go to the exhibition: the cost was 6 euros for a day's entry and nobody seemed to have a problem with this. There were some free entry tickets available from various exhibitors, but the vast majority of visitors were happily paying their entrance fee. From observing the wheelchair users at the exhibition over my two days visit, what I found on the whole was that most of them were there with a real purpose to find a specific product and compare the market. Lots of detailed assessments were taking place on the various manufacturers' vast stands, and I saw several people leaving with a quote. This is very different from exhibitions in the UK, where many visitors see it as a free day out and a place to stock up on a year's supply of pens! So maybe the fact that a charge is being made to enter means the audience are more focussed, and value the experience as a real opportunity to compare products that they are looking to trial or purchase?

Another observation was that the wheelchair users were mostly in very high end light weight wheelchairs, and many manual chair users were using add-on power drives. These were more prominent on the whole than powered chairs, and this again is a big difference from the UK market. I didn't see people in basic steel chairs, and the kids were mostly in active chairs propelling around, or in high end special needs buggies. This is quite different from observations made at Naidex and various kids' exhibitions in the UK.

Joanne at the show

The equipment was split roughly into product areas within halls, but wheelchairs featured within every hall. There were 4 main exhibition halls, each one large enough to spend almost a day in for the serious industry addicts. The main wheelchair manufacturers were all showcasing their biggest, brightest, lightest, cheapest and most expensive products, so to the untrained eye it could be quite a confusing visit. You could also be forgiven for getting the show mixed up with a food show because you could not pass by the stands of Handicare, Invacare, Otto Bock, Permobil or Sunrise without being fed and watered – from a latte to a beer, from a plate of chocolates to an elaborate selection of smoked salmon canapés. (It would be really rude to pass them by when they had gone to so much trouble plus my feet were killing me by day two.)

There were many companies from Taiwan and, if you were not paying enough attention, you could be forgiven for thinking you had just seen that very same chair on a Taiwanese stand round the corner on one of the "big five" manufacturers' stands. That's because you most certainly had – well, their version of it anyway!

I felt very patriotic when I searched out the UK area of the exhibition, and I went to look around the smaller stands of companies like Dycem, South West Seating, and somehow the UK branch of Dynamics sneaked in too. It felt really good standing amongst them.

It was also reassuring to bump into fellow PMG sub-committee colleagues Julianna Arva and Barend, and managing to chat briefly. I saw many familiar faces from the UK mostly from mobility dealerships. It was a good reflection on their interest in the industry to have flown over, many of them just for the day, so they could see the latest trends in mobility and take this knowledge back to the UK market place along with their aching feet!

I would urge all of you who haven't visited Rehacare to go if you have the chance. It was a really interesting comparison to how we run our exhibitions in the UK; it was also an eye opener in terms of the differences in the level of equipment being used in the main in Germany.

There is also a detailed three day programme of seminars in a hall designated for seminars and workshops.

One of the biggest wows for me was the wheelchair repair service areas provided by Otto Bock and Sunrise. These areas were there to repair chairs for free! A real service to the community of wheelchair users who attended, offering a repair service and advice regardless of the make of the chair.

The Otto Bock stand at the show

I could write the same amount again about the night time scene in Düsseldorf and how the city comes alive with mobility dealers, but I have probably run out of space, and there is only so much you can say about beer, excellent food and cobbled streets. I look forward to visiting again.

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Scottish Posture and Mobility Network 21st Annual Conference

19th and 20th May 2011 Glasgow

Day One: ***Postural management strategies and positional issues***
Day Two: ***Enabling mobility***

More details coming soon at www.spmn.org.uk

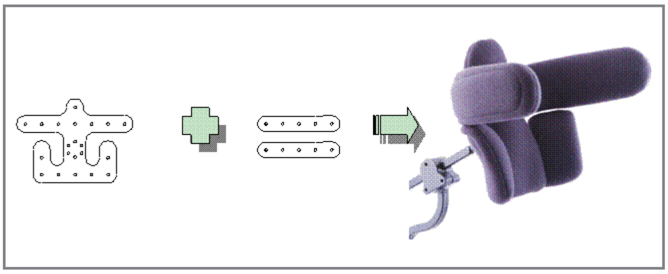
Product Reports

Heads First – Matrix Seating Ltd

Sylvia Cousins, Director, 28 Greville Park Avenue, Ashtead, Surrey, KT21 2QS

Introducing Heads First, a totally new concept in head support.

Matrix Seating is a company focusing on new and innovative products. We are pleased to announce our new head support range, the Heads First. There are three standard head shapes which, with simple add-ons, allow for numerous combinations to achieve the *optimal* fit for every client. After R&D with a range of clients we believe this product should be considered by anyone supplying head supports. Not every option is shown on our website; however in our 'off-the-shelf' range there is a choice of 24 variations. Alternatively frames and extensions can be bought separately to produce customised versions as required. Each frame is malleable allowing even further adjustments. We have received extremely good feedback from our first sales; a parent of a child fitted recently commented 'this is the first time he has received something that works for him – if you can meet his needs it will work for anyone'.



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Vixen Scamp – Newton Products Ltd

Fred Allen, Director, 111-116 Great Bridge Street, West Bromwich, B70 0DA

The Scamp is a newly designed paediatric powered wheelchair from Newton Products Ltd.

Building on the success of the Vixen Cub, the Scamp has the same manoeuvrability and versatility with the addition of modern styling. It also has the benefit of having been successfully crash tested.

The Scamp is offered in three versions:

- The Scamp Driver has a seat to ground height of 393mm. This is an economical chair which allows the child to be on a level with peers. With a tight turning circle and the Vixen manoeuvrability, in this chair the child will feel 'one of the gang'!
- The Scamp TIS has the same seat to ground height and manoeuvrability as the Driver with the additional tilt in space facility for various clinical needs.
- The Scamp Riser allows the child to reach bookshelves, tabletops, and desks, but still allows peer interaction.

As with all Newton's products, the Scamp can be adapted to enable the fitting of special seating, the chair can grow with the child by fitting larger seat units to the original chassis, ensuring this chair provides good value for money.

There will be an introductory offer of a 10% discount on any of the models, available until 31st March 2011. Please contact Newton's sales office for further information.

Newtons are happy to bring any chair from the Vixen range to an assessment, at a client's home or in clinic, with a qualified healthcare worker, following which an individual quote can be made available.

The New Bodypoint Push-Button Buckle

The most common buckle on hip belts is the push button buckle. However, all the push button buckles available to date have emanated from the motor industry, and have been big and clunky, and designed for other purposes.

Following a number of years of research with clinicians and users, Bodypoint has engineered a push button buckle where its good looks match its performance: the new Bodypoint Push Button Buckle is slimmer and lighter weight (one third less) than the old style buckles, and has a sleek low-profile design for attractive looks, comfort, and reduced risk of snagging on clothes. Within the buckle is an integral antislip mechanism to avoid the adjustable belt slipping once set in place – essential for proper positioning.

There is a spring-assisted release, with the buckle resistance set from Bodypoint's clinical research for the optimal pressure needed. The patented construction allows for the removal of the buckle cover for easy cleaning, and to allow changing the cover to another of the three optional covers with a choice of a 6, 14, or 22 mm hole for different levels of ease or difficulty of access to the push button.

Bodypoint pioneered the custom design of posture support buckles a few years ago with their rehab latch buckle replacement for the aircraft latch buckle. The new Bodypoint push button buckle continues this trend.

3-D Modular Seat – Specialised Orthotic Services

Gordon McQuilton MBE, Managing Director, Unit 127-128, Fauld Industrial Park,
Fauld Lane, Tutbury, Staffordshire, DE13 9HR

Specialised Orthotic Services has been designing and manufacturing specialised seating for over 30 years. A recent development from SOS is the '3-D Modular Seat' – modular seating developed for clients with complex seating needs who have some fixed postural asymmetry and who struggle to achieve postural balance when using conventional linear based modular seating.

Postural asymmetry (imbalance) is a common problem when seating the disabled and has a significant influence on overall postural balance when sitting. For many years SOS has supplied clients with custom modular seating, but the 3-D Modular Seat is able to accommodate a significant degree of postural asymmetry very accurately by combining custom moulded and standard seat components to establish better postural balance.

Research shows the younger a user is positioned in a supportive and corrective position the better their health outcomes. Postural asymmetry can arise at a very early age and the sooner this is controlled the more effective seating is at managing the overall problem and assisting functional and health needs.

Using a technique designed and developed by SOS it is now possible to provide modular seating with bespoke custom moulded elements to accommodate and support complex spinal and pelvic problems such as scoliosis and pelvic obliquity.

3-D Modular Seat Systems are configured to interface into appropriate mobility bases and are suitable for use with most standard wheelchairs and buggies.

The improvements in postural balance achieved using 3-D Modular Seats are a significant improvement on conventional modular seating and can stabilise significant levels of fixed postural asymmetry.

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4th International Interdisciplinary Conference on Posture and Wheeled Mobility

Best Practice Guidelines: Harmonizing the Way

Julianna Arva, Manager of Education, Europe, TiLite,
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Abstract: *The International Conference in Glasgow this year has seen the smartest initiation: the conference was built around the theme of Best Practice Guidelines in a variety of topics covering seating and mobility. Groups worked hard for one or two years prior to the conference to complete their draft papers, and participants at the conference had a chance to review, comment, and discuss during and after the presentations. The result will likely be a few widely accepted and used Best Practice Guidelines, which brings together a consensus of many peoples' differing perspectives and views.*

Keywords: *Best practice guideline, posture, mobility, rehabilitation engineering, assistive technology.*

Consistency in our industry – clinical methodology, seating and mobility solutions, and assessment outcomes – is scarce. The same client evaluated by a number of professionals may end up with differing solutions, depending on the assessor, place, time, availability of equipment, etc. Students often learn on the job – their knowledge and skills in seating and mobility grow with years of experience. Clinical solutions are at times hard to get approved by funding sources due to the lack of conclusive evidence.

These and other related issues led to the realization that a form of cohesive document (clinical guideline, position statement), issued by professional organizations, written and agreed upon by a panel of experts, would be needed in a variety of topics. The international effort in Glasgow follows a North American example, dating back a few years.

The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) started working on its first Position Papers in 2004, issuing the first one in 2005. Since then 3 more have been issued by the organization, with groups working on additional topics. A few of these papers have also been published in the organization's Medline referenced journal, Assistive Technology. RESNA's finalized and board approved Position Papers cover the following topics: Seat elevators (2005), Wheelchair standers (2007), Paediatric powered mobility (2008), and Seat functions such as tilt, recline, and elevating legrests (2008).

The purpose of RESNA's Position Papers was similar to those of the International Best Practice Guidelines:

- Collect and reference available and applicable research up to date
- Add clinical opinion, agreed upon by a panel of experts
- Comprehensively describe the benefits and contraindications of certain seating and mobility interventions.

A Position Paper or Best Practice Guideline as a format allows for much-valued clinical opinion to be added. Unlike a journal published methodological literature review, this type of paper has the freedom to include things we have learned from practice, and issues that make common sense. As the papers are written by a group of experts, opened for public feedback during and after conferences, and finally reviewed and approved by the board of the organization, there are enough checks and balances in the process to make the clinical opinions of these papers acceptable industry-wide. When issues arise in which the panel cannot find consensus or lacks information, there will simply not be conclusive advice in the paper.

The intended uses of these documents are:

- Guidance for practitioners in the development and provision of assistive technology interventions
- Teaching tools in educational and clinical settings
- Additional support for justifying a positive funding decision, whether on the individual or strategic level
- Resource to search for scientific references

The longevity of such documents is typically five years. Beyond that the papers are considered outdated, primarily due to the lack of inclusion of the latest research. As a group of expert volunteers is needed to write the original papers, so is a group of dedicated volunteers needed to complete the five-yearly updates, so the papers remain relevant and valid. The experts on these panels are highly commended on their efforts, as it does take time and energy to bring these documents to life.

The RESNA papers are of North American relevance. While clinically they apply worldwide, the approving and issuing organization is based in North America. The goal for the International Best Practice Guidelines was to ensure their worldwide relevance and validity. The groups working on these papers were from a variety of countries and continents, including Australia, North America, and various European countries. This allowed standards, rules, issues, methods, and requirements of different environments to be included. Alternatively, some items that were too country-specific could be excluded to ensure higher overall relevance.

Some groups were chosen to base their work on the existing RESNA papers by reviewing, commenting, modifying, adding, or subtracting. Other groups started their work from scratch. By the time of the conference in Glasgow, we saw some nearly final drafts, nearly complete papers, while others were still relatively at the beginning of the work. None of the papers was complete, as the purpose of the session was to collect feedback for inclusion in the papers.

Topics covered by the International Best Practice Guidelines currently in the works are:

- Empowering children and adults with cognitive disabilities to learn skills for powered mobility (lead: Rosalie Wang)
- Preservation of upper limb function following spinal cord injury (lead: Tina Roesler)
- Supported lying (lead: Joyce McDonald)
- Early powered mobility for children (lead: Josephine Durkin)
- Transfer training for transferring in the home (lead: Jean Minkel)
- Wheelchair standing devices (lead: Ginny Paleg)
- Clinical guidance on use of pressure mapping systems (lead: Pat Meeker)
- Early interventions – best practice before the patient reaches the rehabilitation unit (lead: Laura Graham)
- Vehicular transportation for users occupying their wheelchairs (lead: John Tiernan)
- Seat-elevating devices for wheelchair users (lead: Lisa Møldrup)
- Tilt, recline and elevating leg rests for wheelchairs (lead: Helle Dreier)

For anyone interested in the papers and possibly making a comment, the discussion drafts can be found in the proceedings of the Glasgow conference. Some copies still available from PMG as we go to press: contact olwen.ellis@pmguk.co.uk for details of prices.

Email contact for all group leaders can be found on the website of the International Conference, www.mobility2010.org.

Many thanks to Barend ter Haar who initiated this effort, and to his fellow conference committee chairs David Long and Bart Van der Heyden; to the group leaders and all the group members who continue to volunteer their time to this important work. More volunteers will be needed, both to complete the papers and, further down the road, to keep them up to date.

References:

RESNA Position on the Application of Seat Elevating Devices For Wheelchair Users, 2005. Available from: www.rstce.pitt.edu/RSTCE_Resources/RSTCE_Resources.html

RESNA Position on the Application of Wheelchair Standing Devices, 2007. Available from: www.rstce.pitt.edu/RSTCE_Resources/RSTCE_Resources.html

RESNA Position on the Application of Power Wheelchairs for Paediatric Users, 2008. Available from: www.rstce.pitt.edu/RSTCE_Resources/RSTCE_Resources.html

RESNA Position on the Application of Tilt, Recline and Elevating Legrests for Wheelchairs, 2008. Available from: www.rstce.pitt.edu/RSTCE_Resources/RSTCE_Resources.html

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There were several more bursars in 2010 than ever before, so that the editorial team gave them a variety of tasks to complete, not just the usual bursar report, of which we have 12 for you to read here. The accompanying photographs, except for those in the exhibition reports, were taken by bursar Kit Tzu Tang who is a Specialist Rehabilitation Engineer at Leeds Teaching Hospital.

Bursar Report: The Exhibition at the International Conference in Glasgow, June 2010

Reporting Bursars: Dan Adams & Pippa Sprinz, Clinical Technologist Trainees, Nuffield Orthopaedic Centre NHS Trust, Oxford, OX3 7LD

Abstract: *We were very privileged to be awarded bursaries to attend the 2010 International Conference to aid our training as Clinical Technologists. This is a brief report and overview of a very small selection of the many new, innovative, and interesting products on display in the conference exhibition. It is a summary of what we found to be relevant to our field of work and does not reflect the quality and full range of other products on view.*

G-code Technology Ltd: MediCarve System

Due to its relevance and potential within custom and specialist seating, one of the first products that stood out for us was the MediCarve System from G-code Technology Ltd. (Fig 1).

This system offers time-saving and additional options when carving foam for custom seating. By using the handheld laser scanner to scan a cast or an existing seat, you can have a 3-D image ready for editing or construction, using Computer Aided Design (CAD), in minutes. This data can be stored indefinitely and accessed on demand. It can then be passed directly to the Computed Numerically Controlled (CNC) carving machine to produce the contours of the seating. This system has the potential to cut down production time, as engineers can work on other aspects of the seating while the foam is being carved. Additionally, as the data is stored indefinitely, an exact duplicate can be produced in the future without the need for additional appointments.

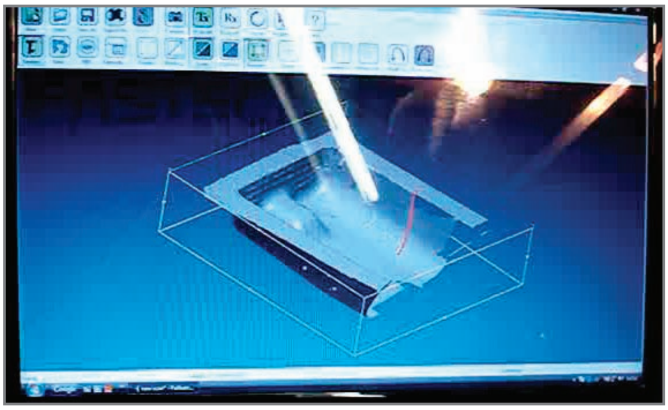

Fig 1 – MediCarve System

Gel Ovations: SynerGel Dynamic Floatation Polymer

Pressure distribution is a key issue in custom made seating. On display at Gel Ovations' stand was the Synergel Dynamic Floatation Polymer pressure pad (Fig 2). These pads are designed specifically to have the same physical characteristics as human fat tissue.

Fig 2 – Synergel Dynamic Floatation Polymer pressure pad

Unlike many gel or foam pressure relieving pads, the softness of the gel will stay unchanged at any temperature. This is useful for both transport and storage. As the silicone polymer used is a solid, it will not leak if trimmed or punctured, and will not dry out. Its cellular design offers good air circulation, minimizing heat and moisture build up, which are factors impacting on the rate at which a pressure sore develops. All things considered, the features of the pad help to improve comfort and reduce pressure.

South West Seating & Rehab Ltd: Neo Wheelbase

Being already familiar with the Neo wheelbase from South West Seating and Rehab, we were interested in visiting their display. On show were the Neo footrest hanger brace kit (Fig 3), which we had not seen before.

Fig 3 – Footrest Hanger Brace Kit

We have had issues with loose hangers in the past, and this kit will support and add strength to the footplate hangers for the heavier user. Another feature of the Neo that we hadn't been aware of was that self propelling wheels are now available (Fig 4). This offers another option for the more active user.

Fig 4 – Self Propelling Neo

Matrix Seating Ltd: Second Generation Matrix Seating

We were interested in the Matrix stand at the exhibition, as we are more familiar with Lynx and were keen to learn about other specialised systems which provide custom contoured seating. We were especially interested in the flexible matrix system as this is a feature which is not currently available with the Lynx system.

Fig 5 shows a flexible 4-ball unit of matrix compressing to allow movement of the structure. Different grades of flexible matrix are available permitting different degrees of movement. Fig 6 shows the three grades, with red being most flexible, followed by green, and blue being least flexible.

Fig 5 – Flexible Matrix

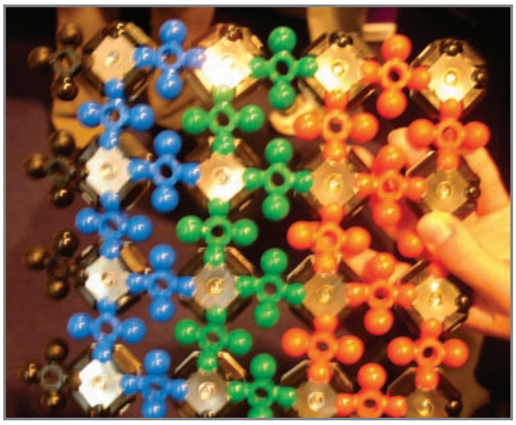

Fig 6 – Grades of flexible matrix

A row of units can be used as a hinge, for example Fig 7 shows a corrective spinal support with the thoracic supports containing a hinge to allow easy fitting, and the remaining matrix being non-flexible to provide sufficient support.

Fig 7 – Corrective Spinal Support

It can also be used for dynamic seating, where areas are allowed to bend when extensor force is applied and then return to their original position afterwards, or to soften the edges of the non-flexible matrix prone to pressure, for example under the thighs behind the knees.

Leckey: Kit Seating System

We found Leckey's Kit seating system interesting (Fig 8), as it has been designed with the aim of bridging the gap between modular and moulded seating systems for teens and adults. It has a three part backrest which has interchangeable components so the chair can be tailored to meet the person's needs. They are mounted on ball and socket joints so that the parts can be moved in multiple planes to gain an optimal position.

It also has the ability to accommodate lower limb windsweeping, a postural need which is often difficult to overcome in non-customised seating. It uses multi-positional leg guides and foot supports so that the head and shoulder girdle can remain in neutral alignment and face the direction of travel (Fig 9).

Fig 8 – Leckey Kit Seating System

We felt that a possible disadvantage of this system, as with many other similar seating systems, was the weight of the seat, which could cause difficulties for parents and carers who have to transfer and manoeuvre the chair.

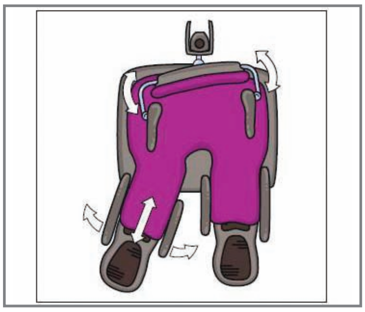

Fig 9 – Kit Windsweeping Accommodation (multi-adjustable leg and foot supports)

Fig 10 – Pelvic Cradle

We felt that the Pelvic Cradle (Fig 10), was an interesting new product which comes with the Kit system, but has the potential to be used with many other seating options. It is intended to help people with complex postures to obtain a stable pelvic position.

Conclusion

We found the event very interesting and beneficial, helping us to learn about companies that we are less familiar with, and new products that would soon be available. It will no doubt help us in our future careers in this field. Overall, the conference was a success; however it would have been beneficial to have more time between the range of seminars, to take full advantage of the high quality of information and knowledge available at the exhibition.

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Bursar Report: A Programme for Prevention of Hip Dislocation and Severe Muscle Contracture in Cerebral Palsy

Presenter: Gunnar Hägglund MD PhD, Dept of Orthopaedics, Lund University Hospital, Sweden

Reporting Bursar: Augustine Adu-Amankwah, Wheelchair Therapist,
Bowley Close Rehabilitation Centre, Farquhar Road, London SE19 1SZ

First of all, I would like to express my sincere appreciation to PMG for sponsoring me to attend this international interdisciplinary conference.

Cerebral palsy (CP) is a common paediatric disorder occurring in about 2 to 2.5 per 1000 live births (Hägglund et el 2007 and Jan, M. 2006). Often it results from an injury to the developing brain. It is clear that children with CP suffer from multiple problems and potential disabilities. Therefore such children are best cared for through specialist family centres, with a multidisciplinary team approach.

According to Edwards, S. (2002) “dislocation of the hip in children with cerebral palsy is not an infrequent complication”. Having worked as a paediatric community physiotherapist for over one and a half years prior to undertaking my current role as a wheelchair therapist, I was aware of the importance of positioning to improve daily function and to minimise secondary complications.

Now imagine a world or health system in which shocking images of children locked in severely contracted postures are completely eradicated. One may ask how this could be. I believe this is possible through a system that involves setting up a structured CP programme – a national register. This is what the presenter, Gunnar Hägglund, was proposing. Hence the Health Care Programme for Children with Cerebral Palsy (CPUP) was initiated in Sweden as shown in Fig 1.

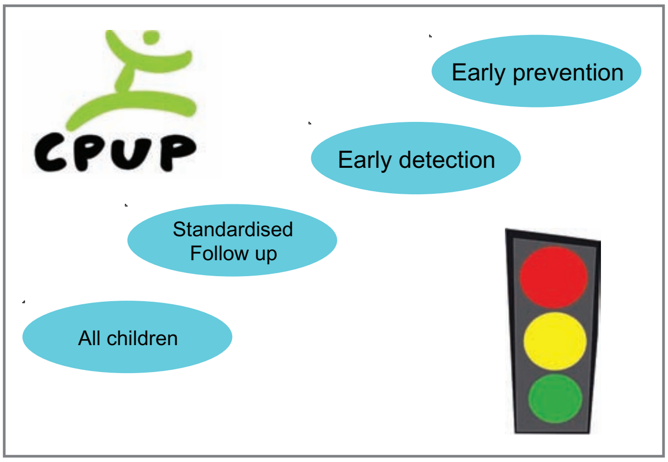

Fig 1

The benefits of having a national CP register, in terms of standardised follow-up, early detection of hip migration, and fewer operations, with related economic benefits for the health service should, I believe, be considered for the UK.

In my previous role as a paediatric physiotherapist, I experienced working with a similar register known as the hip protocol, but this was only applicable to children diagnosed with diplegic or quadriplegic cerebral palsy. It was not open to all children diagnosed with cerebral palsy but was selective.

According to an annual report on the CPUP website (2007) it states that CPUP differs from most other registers in that it can be used “simultaneously as a clinical instrument to monitor an individual, a structured patient record, and as a general monitoring of all children with CP”.

Since the introduction of the CPUP programme, the percentage of the incidence of hip displacement has reduced, as shown in Fig 2.

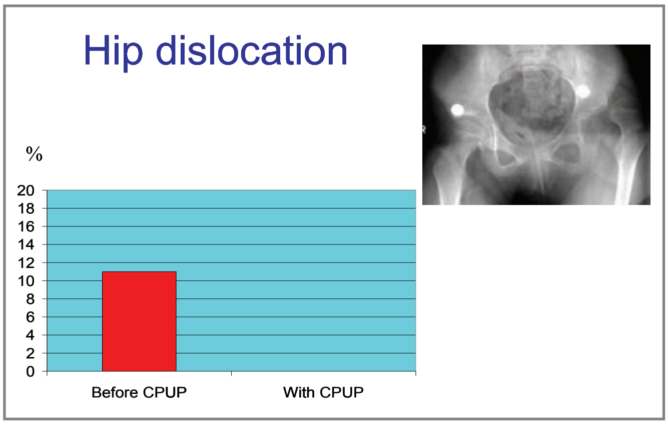

Fig 2

What was interesting for me was the fact that the risk of displacement was directly related to the level of gross motor function. As emphasized by Soo et al. (2006) “the frequency of hip displacement classified as GMFCS level I was 0% and 90% for those with GMFCS level V”. Since attending this session, I have used the GMFCS as an assessment tool and this has impacted my practice significantly in providing specific intervention.

In summary, we as clinicians need to work jointly as a team, share information, communicate more, and share resources. In my opinion, implementation of a national register for monitoring every child diagnosed with cerebral palsy would enable health professionals to monitor the children through early warning systems, and to identify children who are at risk of secondary complications. It is time we consider such a national database.

References:

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Gunnar Hägglund's presentation can be viewed on the webcast programme from the conference, which PMG members can access via the PMG website NTE (conference) section.

Bursar Report: Dance Can Be An Option

Performers: Caroline Bowditch, Scottish Dance Theatre's Dance Agent,
Dundee Rep Theatre, Tay Square, Dundee, DD1 1PB
Marc Brew, Associate Director of the Scottish Dance Theatre
Reporting Bursar: Anne Munn, Chief Executive, Mobility Trust,
17b Reading Road, Pangbourne, Berkshire, RG8 7PR

I am the CEO of a small national charity providing powered wheelchairs to people who cannot obtain statutory help or afford to purchase one. As well as fundraising, more than 50% of our time is spent organising medical assessments, arranging purchase and delivery, and following up problems. We aim to reach and help disabled people who have nowhere else to turn.

So why did I apply for a bursary? It is my priority to learn about postural management, specialist seating, clinical conditions, and prescribing the correct equipment for each person's needs, and then convey it to my colleagues. We must understand these subjects in order to discuss them with medical professionals. The Glasgow International Conference was the occasion to meet and learn from the best.

The first plenary session was about dance. Many people did not know quite what to expect. This was not just moving around in formation but a truly emotional experience of classical dance. Where were the wheelchairs? We only had eyes for Caroline and Marc. If only it was like that for everyone who uses a wheelchair.

Caroline Bowditch was born with osteogenesis imperfecta and by the age of eight had 250 fractures. Dance did not seem an option then, but she has been the Scottish Theatre's Dance Agent for Change since 2008. In partnership with other organizations, she is tackling some ambitious aims – breaking new ground for dance and disability, with inclusion at the forefront to increase the number of disabled people involved in dance. She continues to develop and co-ordinate an integrated creative programme which educates, inspires, informs and expands horizons.

While in his first professional job after training in ballet, Marc Brew was involved in a car accident and broke his back. Within two years he started dancing again and has been dancing in his wheelchair or using the floor ever since. He has worked in the UK and internationally for the past twelve years as a dancer, choreographer and teacher. This included working at Sadler's Wells with an integrated cast of professional and disabled dancers.

Caroline and Marc have trained hard to become the talented dancers they are today, and are now encouraging other people that they can do the same.

They also demonstrated that dance is great exercise, and could be for people with only upper body movement. If, with medical approval, they can extend their body and arms to their own personal limits to maintain strength and flexibility, their whole being could be enhanced by the chance to be physically creative. When you see professional ballet, note how much expression and movement is in the head, body, arms and hands.

People often resist artistic pursuits thinking they will not be any good. They shouldn't worry about that, but splash a paint brush around, move to music or follow any other artistic pursuit and just enjoy being creative for their own pleasure and self esteem.

I'll let you into a secret: I always wanted to go to dancing lessons but did not have the chance. Now when I am on my own, I dance around my kitchen and feel great.

Dance is my passion and working to enable people with disabilities become mobile is a privilege. This plenary session was inspirational.

Note from Caroline Bowditch: *I really hope that many of the people that were at the conference do see dance as being an option. We are pursuing many exciting things here in Dundee in connection with Ninewells Hospital, which is a great outcome for us as a result of being at the conference.*

References:

Further information: www.scottishdancetheatre.com
Videos available through www.danceagentforchange.co.uk

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The bagpipers preparing to lead the assembled delegates across the river Clyde to the Science Museum for the welcome reception

Bursar Report: Plenary 3 – Tissue Integrity and Support Surfaces: Where Are We ....Where Should We Go?

Presenters: David Brienza, Department of Rehabilitation Science and Technology,
University of Pittsburgh, Pittsburgh, PA, USA
Makoto Takahashi, Japan
Michael Clark, Welsh Wound Network, 237 Capella House, Cardiff CF10 4RE
Evan Call, Weber State University, 2506 University Circle, Ogden, UT 84408-2506, USA
David McCausland, ROHO Inc, 100 North Florida Avenue, Belleville, IL 62221, USA

Reporting Bursar: Dominique Bacon, Occupational Therapist, Wheelchair Assessment Service,
St Martin's Hospital, Littlebourne Road, Canterbury, CT1 1AZ

Abstract: *Plenary 3 consisted of three sessions, chaired by Bart van der Hayden, Belgium. The European Pressure Advisory Panel (EPUAP) and the National Pressure Ulcer Advisory Panel (NPUAP) Pressure Ulcer Prevention and Treatment Clinical Practice Guidelines (2009) are the result of impressive international collaboration based on the strongest available research. For clinicians working in seating, new recommendations on support surfaces now exist which will help guide the care of those with or at risk of developing pressure ulcers. Testing the effects of pressure and shear remains a significant challenge due to the many variables affecting an individual, and laboratory testing remains the norm for most manufacturers of pressure relieving products. The ultimate goal remains the ability to prescribe a specific cushion via an objective means of evaluating and comparing the support surfaces available on the market.*

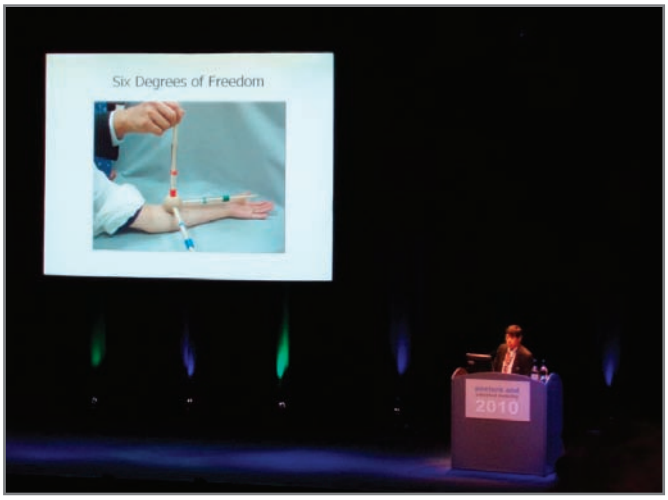
Keywords: *Pressure ulcer, pressure, shear, ischaemia-reperfusion injury, evidence based guidelines, support surface, laboratory testing, variables, funding, cost*

Introduction

The subject of tissue viability usually provokes mixed reactions. It is one of the potentially 'yuk-but-interesting' aspects of working in the wheelchair service. Other professionals often want advice about therapeutic cushions for their clients to use which will aid, or at least not disrupt, the healing process. There is always uncertainty over what to recommend due to the lack of research evidence that is reflected in the vague wording contained in the manufacturer's instruction leaflet. The subject of what to sit on and for how long often provokes a collision between what the professional sees as good practice and what the patient sees as interference in their often fast diminishing control over their life. I was eager to see whether there would be some cogent argument I could present to the wheelchair user with pressure ulcers who sits all day on a very expensive cushion topped by a home made cover and several towels.

Tissue Damage And Its Cause

The EPUAP-NPUAP Prevention and treatment of pressure ulcers: quick reference guide (2009) defines a pressure ulcer as "localised injury to the skin and/or underlying tissue usually over a bony prominence, as a result of pressure, or pressure in combination with shear. A number of contributing or confounding factors are also associated with pressure ulcers; the significance of these factors is yet to be elucidated". Aside from a number of primary diagnoses, skin condition and nutritional factors, many extrinsic contributing factors exist, such as: sitting or lying too long, poor manual handling, no footplates or poorly adjusted footplates. This makes the task of researching the reasons why pressure ulcers develop very challenging. Makoto Takahashi is currently researching how pressure on the skin surface contributes to more severe shear damage, resulting in excessive deformation to cells in the deeper



Makoto Takahashi speaking

layers of tissue and restricted blood flow in the deep arteries, especially near bony prominences. He has found that when loading and subsequent relief take place repeatedly and over long periods, ischaemia-reperfusion injury takes place when oxygen is re-introduced and free radicals form and attack other cells. Mr Takahashi explained that pressure ulcer injury occurs as a result of a combination of 3 linear forces and 3 rotational forces known as *the six degrees of freedom*. He uses skin sensors which aim to show the level of pressure being experienced by the individual but admits this is very hard to measure.

EPUAP-NPUAP Pressure Ulcer Prevention Guidelines

Dr Evan Call and Michael Clark gave an overview of the new guidelines, which represent a truly international collaboration. Post-1995 studies were used from a wide variety of scientific designs using 10 or more people with, or at risk of, pressure ulcers. Much is still based on expert opinion rather than scientific evidence. US and European terminologies have been aligned and some guidelines have been improved and new ones added. Important recommendations for wheelchair users state that a pressure redistributing cushion should be used for those with reduced mobility. Time seated should be reduced for those at risk who have no pressure relief, and for those with ulcers in the ischial or sacral/coccyx area, sitting should be limited to three times a day for periods of not longer than one hour. Those with ischial ulcers should not be seated in a fully erect position. Taking into account individual environment and microclimate, posture should be frequently re-evaluated. These guidelines give clinicians strong backing for the advice they give to patients, carers and care homes especially in view of the difficult balance between best practice and allowing for personal choice.

Support Surface Laboratory Testing and its Clinical Significance

David McCausland defined a support surface as a specialised device for redistribution of pressure. Numerous high cost products are available. Manufacturer information does not usually include testing data nor is there always specific advice on use for clients with pressure ulcers. Given the myriad factors which can affect one individual, the issuer has little information on which to base an informed choice. Funding bodies are cutting costs and are demanding evidence as proof for funding, and there are ever more costly regulations to comply with. Mr McCausland showed slides of the indenters, mannequins and skeletons that are used in the laboratory to test the effects of pressure and shear and how they might affect living skin and tissue. Some models appeared to have strayed from a Damien Hirst exhibition, but they cannot hope to replace the real human backside in all its infinite variety. In reality, few randomised controlled trials are carried out due to time and cost and there is a real difficulty with comparison of results and repeatability given different wheelchairs, backrest and footrest positions, individual anatomy and numerous other variables. Mr McCausland painted a bleak future where price will be the deciding factor. He called on clinicians to carry out more research and on manufacturers to share research data to avoid repeating mistakes. The pressure on manufacturers to provide evidence of efficacy in order to secure sales may prove an incentive to share data and pool the cost of research, perhaps leaving us with less choice, but with cushions which are designed and tested to provide specific therapeutic benefits.

Can we look forward to a future with cushions which are manufactured and tested for the specific pressure needs of the user? Maybe. However, I do feel that, although the new guidelines don’t really tell us anything we didn’t already know, we do have some more power to our elbow. We can put the new guidelines on the table and say ‘this is the best advice based on the most recent research’ and then complete a risk assessment detailing the risks and benefits to the patient of continuing to sit all day on the very expensive cushion with the hand-made cover and several towels.

References:

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Bursar Report: The Physical Assessment

Presenters: Jean Minkel (Physical Therapist, New York)
and Dorte Støvring (Physiotherapist, Denmark)

Reporting Bursar: Craig Adam Evans, Occupational Therapist, Artificial Limb and Appliance Service, Rookwood Hospital, Fairwater Road, Llandaff, Cardiff, CF5 2YN

The reason for my interest in attending this course was that, as a newly qualified band 5 occupational therapist in the posture and mobility service in Cardiff, I have had little clinical experience compared to most others. Over the past twelve months the clinical team has tried to ground my knowledge and understanding in terms of what is a good seating position. By attending this session I was able to compare the practice that I have learnt with the practice described by Jean and Dorte.

The strongest take-home message for me was the importance of carrying out an assessment on a plinth, which Jean and Dorte commonly referred to as a 'mat assessment'. I was already aware of the importance of an assessment on a plinth, because it allows gravity to show a client's true posture away from a supported sitting position. The other message that I took away from this session was that everyone has a different sitting position where they feel comfortable and functional.

On reflection, the main point that was raised that was new to me, and that I felt was controversial, is the positioning of the head in sitting and lying. Jean explained that a client's head position should always remain in their neutral position. If a client has visual midline shift syndrome, possibly as a result of a cerebral vascular accident, their 'neutral' head position could be offset out of midline, and could therefore result in swallowing problems.

Another issue which was new to me again related to head positioning when carrying out the assessment on the plinth. Jean and Dorte recommended that initially the client's head should not be supported with pillows etc, as this may influence the client's true head position.

Overall, what I took from this session was that the members of the team I work with have taught me well. It helped to reinforce my understanding of good sitting, and I now feel more confident in carrying out the correct techniques in the clinical environment.

Due to my only having twelve months clinical experience, I feel my biggest learning need is more clinical experience, so that I can continue to see new things when clients present themselves and learn to understand more the challenges facing them. Only then do I feel it would be appropriate to advance my theoretical knowledge and application to the next level.

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Posture and Mobility Seminar

24th January 2011

The *Irish Posture and Mobility Network* (IPMN), together with the *Engineers Ireland Seating and Mobility Interest Group* (SMIG), will be co-hosting a third day of seminars on Monday 24th January. The group is seeking to collaborate with the UK and hoping to set up videoconference links. There remain some 15min slots, and it is hoped that up to four UK presenters will be able to share their knowledge, experience, projects and skills with the other seminar delegates.

If any persons, groups or services feel they would like to join the seminar, and can assist in connecting to Ireland and contributing to this exciting opportunity, please contact jtiernan@enableireland.ie

Bursar Report: Invasive Methods of Treating Spasticity

Presenters: Alastair Cozens, Woodend Hospital, Aberdeen
Chris Roy, Southern General Hospital, Glasgow
Jane Lough, Southern General Hospital, Glasgow
Patricia Littlechild, Woodend Hospital, Aberdeen

Reporting Bursar: Tanya Gibson, Head of Therapy, Dame Hannah Rogers Trust,
Woodland Road, Ivybridge, Devon, PL21 9HQ

The aim of this workshop was to present and discuss the invasive methods of treating spasticity using peripheral and intrathecal medication. This presentation was of particular interest to me as I work in the field of complex disability and manage children, predominantly with cerebral palsy, who benefit from botox injections, and I see an increasing number of children using intrathecal baclofen.

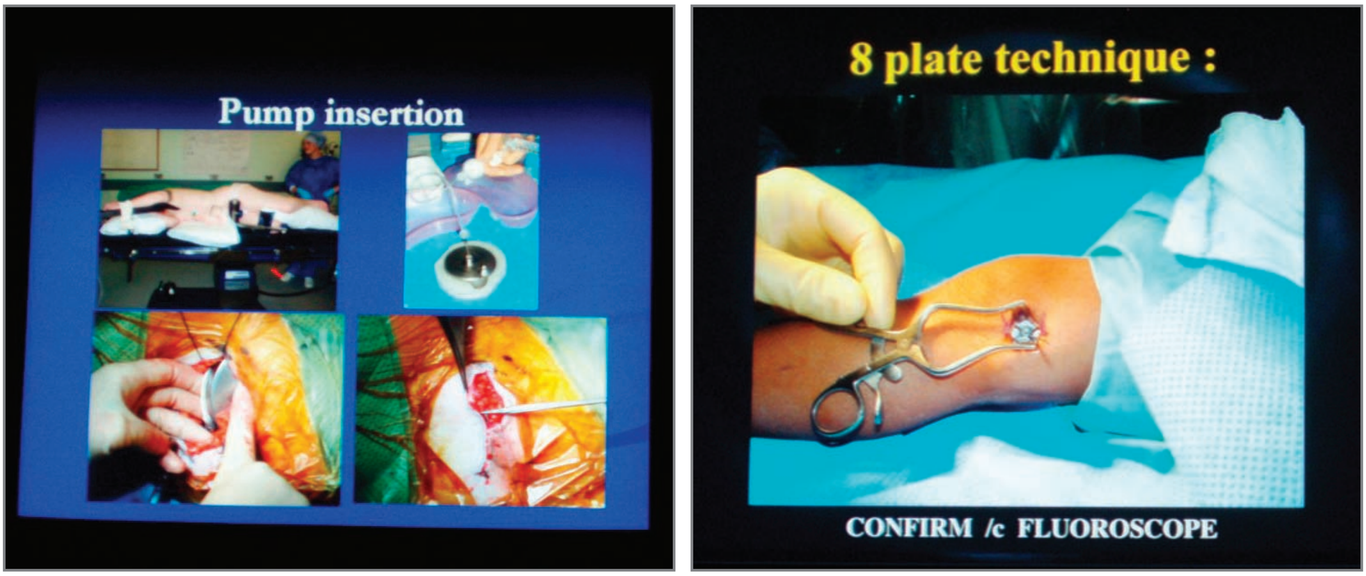
Alistair Cozens began the presentation by outlining the principles of managing spasticity and the role of botulinum toxin for reducing spasticity. Chris Roy then described his experiences with using localised phenol and included a very clear video of the procedure to demonstrate the injection technique using a stimulating needle. Chris also compared and contrasted localised phenol with botox and discussed some of the adverse effects associated with phenol. Jane Lough then explained her role in coordinating the pathway for individuals with MS requiring intrathecal baclofen, by taking the audience on a journey through the stages from clinical assessment to implant and follow up. This led into the final presentation by Patricia Littlechild who covered the types of intrathecal baclofen pumps – constant flow and programmable pumps – precautions, and her experiences of complications associated with pump management.

Key Themes

Throughout the presentations there were several key themes. Firstly, that the use of medication to reduce spasticity is only a small part of the overall management of any individual with an upper motor neurone disorder. Secondly, the need for a multidisciplinary approach in assessing, delivering and reviewing any treatment where the intervention needs to be coordinated with other management strategies. This requires effective communication between members of the MDT. Finally, there need to be realistic functional goals decided collaboratively with the patient, prior to the intervention, as part of the decision-making process, and to assess the outcome of the intervention. These goals could also be linked into an outcome measure such as the goal attainment scale.

Personal Reflection

Having attended this presentation, it has highlighted the importance of a number of key themes as outlined above. In addition, I would like to go on to explore the potential of reflecting the outcome measures in terms of the domains outlined in the International Classification of Functioning, Health and Disability (WHO, 2001). This could not only reflect the impact on function but also on level of activity and participation rather than



Pump insertion

8 plate technique :

CONFIRM /c FLUOROSCOPE

Two of the treatments covered in the workshop being limited to showing a reduction in body impairment alone. During the presentations, details of a website were given by Jane Lough (www.medtronic.com). I found this a very informative website which has numerous downloadable presentations for healthcare professionals. The presentation has also extended my knowledge of phenol, and has emphasised the need for collaborative functional goal setting when considering any intervention.

References:

World Health Organization. *International Classification of Functioning, Health and Disability (ICF)*. Geneva: World Health Organization, 2001.
www.medtronic.com Accessed: 12/06/2010

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Bursar Report: Medical Problems Affecting Posture and Movement

Presenter: Margaret Phillips, Division of Rehabilitation Medicine, University of Nottingham
Reporting Bursar: Ramakrishna Gundapudi, Specialist Physiotherapist,
Holy Cross Hospital, Haslemere, Surrey, GU27 1LJ

Margaret Phillips' lecture focused on the role of medicine in promoting function in posture, seating and movement with the examples of various medical conditions affecting balance and posture.

The lecture was of interest to me as I share some of the concerns raised. I work in a 40 bedded hospital where rehabilitation and long term care is provided for people with complex neurodisability. The majority of our patients require a 24 hour posture management regime with some requiring specialised seating and sleep systems. We have a multi-disciplinary team led by a consultant in rehabilitation medicine to review and monitor patients' overall progress including medical, physical and psychosocial aspects. Due to the nature of their condition, patients require timely medical intervention to address the acute medical problems (e.g. chest & urinary tract infections). Failing to address these issues would have an impact on patients' posture due to these problems causing an increase in muscle tone compounded by the inability to sit in the wheelchair that provides good postural support.

Margaret described the basic classification of medical condition in relation to posture and movements into four categories:

1. **Upper Motor Neurone (UMN) impairments** with associated spasticity, spasms, contractures, and specific movement & posture patterns
2. **Extrapyramidal impairments** exemplified by rigidity, poverty of movement, and involuntary movements
3. **Movement disorders** where movement leads to various postural patterns
4. **Lower Motor Neurone (LMN) or muscle impairment** with issues of weakness and associated contractures.

She described how the primary underlying pathology, and its interaction with secondary effects of the pathology, result in a wide variety of effects on seating and posture. It is important for the health care professionals to have a deep understanding of the pathology of various conditions, progression, secondary complications, and also similarities and differences between conditions. For example, Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) and Gullian Barre Syndrome (GBS) have similar pathologies, but symptoms tend to come on more slowly and progress for a longer period of time in CIDP.

Margaret explained that health professionals occasionally seem to get carried away with the assessment of disability within the framework of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) at the expense of a multidimensional approach, including the original diagnosis and nature of disease progression. A multidimensional approach gives clues to providing timely intervention, thus preventing the secondary complications. For example, we can prevent or minimise the contractures by providing intervention proactively if we are aware that contractures in LMN lesions are going to develop in the direction of more active/normal muscle groups rather than the paralysed (flaccid) muscle groups, unlike UMN lesions, where contractures are in the direction of paralysed (spastic) muscle groups.

Margaret then went on to talk about the situations where there are conflicts between medical problems and seating. She cited an example of some patients with muscular dystrophy who require a lying position for better breathing and coughing. At the same time, the postural needs are compromised as the patient is not seated in the chair that meets his/her postural needs.

At Holy Cross Hospital we are sometimes confronted by similar conflicts when patients have acute illness; they tend to stay in bed for longer periods which compromises their posture. Due to their acute illness patients may lose weight, which makes their seating system too big leading to the patient leaning to one side with a resulting scoliotic posture. Such situations do require timely input in the form of multidisciplinary team working – the consultant to assess the medical condition, dietician to improve the weight, OT/physiotherapist, in liaison with wheelchair services, to adapt the equipment to the changing needs of the patients.

I think the strong 'take-home' message Margaret conveyed in the lecture was that the health care professionals caring for disabled people need to have an in-depth understanding of the various medical conditions that affect our service users, in order for us to provide timely interventions.

Although we have a multi disciplinary team to address various issues in a timely fashion, accessing some resources is often beyond our control. For example, intervention by special seating services can take a long time.

This lecture has helped inform my practice by making me think through various medical problems affecting posture and movement in a logical way. It emphasised the paramount importance of understanding the disease pathology and progression, in order to provide 'timely intervention' for our patients.

References:

World Health Organisation (WHO, 2001). Available from: www.who.int/classifications/icf/en/ Accessed: 05/08/2010

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Bursar Report: Difficult Decisions in Multi-Disciplinary Rehabilitation: How to Reduce the Pain

Presenter: Professor Chris Ward, Division of Rehabilitation Medicine, University of Nottingham, School of Graduate Entry Medicine and Health, Derby Hospitals Foundation Trust

Reporting Bursar: Chantal Hamon, Wheelchair Therapist (Occupational Therapist), Wirral Wheelchair Service and Independent Living Centre, Hind Street, Birkenhead, Wirral, CH41 5DA

I have been working for Wirral and West Cheshire Wheelchair Service since October 2009 and previously at Treloar College (for students with physical disabilities), where I developed my interest in wheelchairs, posture and seating.

We all have to make many difficult and/or complex decisions in our working lives. Difficult decisions within a wheelchair service context can involve resource allocation, powered wheelchair provision, removal of equipment, referrals and discharges. These can involve many different people from many different backgrounds coming together.

The aim of Professor Chris Ward's session was to provide 'guidelines on how professionals can help decision-making processes to be as effective and just as they can be'. This was done by exploring how we can facilitate this by looking at individuals' personal and professional qualities and experience by using a 'systems approach', which looks at how people function in their system and the relationship between those systems. See Fig 1.

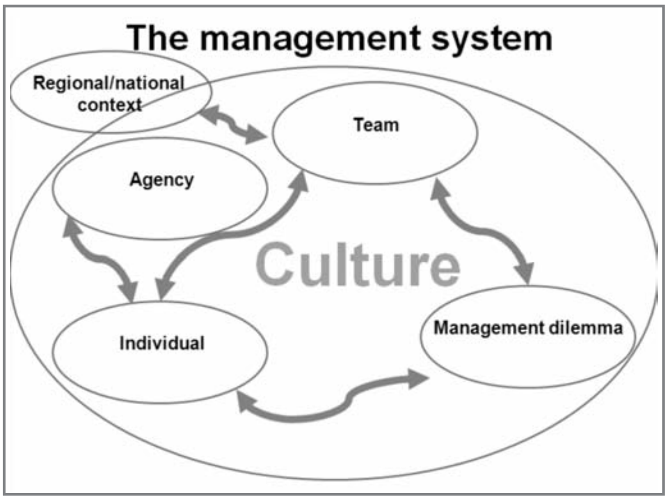

Fig 1

Professor Ward draws on ideas from Family Therapy, in particular the work of Sallyann Roth (Portilla 2003) – specific reference was made to her idea of a *focussed pause* – and group dynamics, which reminded me of some of the group work training I did when studying to be an occupational therapist.

When looking at making decisions in a group situation, Professor Ward suggests taking into consideration simple but important aspects such as seating arrangements and rituals of empowerment and disempowerment (e.g. chatting with other professionals before the start of the meeting, therefore creating a 'them and us' situation) as well as behaviours like awkward silences, people hogging the limelight, interruptions, dismissive behaviour, non-verbal communication, and motives, such as who is worried about 'losing face', and who wants to impress. Also noticing introvert/extrovert personalities with reference to The Myers-Briggs Type Indicator, MBTI (Briggs-Myers et al 1998) – a psychometric assessment questionnaire designed to measure psychological preferences in how people perceive the world and make decisions.

Professor Ward explored ideas separated from the content of the interview or appointment (see exercise: Appendix 2) by discussing:

- **Power** – finding out in the group who has the power i.e. who holds the key to a positive outcome. This could be a manager who has access to something, or an influential family member.
- **Language** – Being aware of any jargon used or terms which mean different things to different people. Therefore descriptions need to be clarified as one persons' description of what happened can be very different from another's. This includes a client's language and agenda.
- **Responsibility** – Feelings linked into this, e.g. blame.
- **Problem Solving Experience** – Considering the past efforts of those involved towards solutions, methods used and the effects for whom and why.
- **Relationships** – Clash of ideologies, clinical v moral, trust, understanding, respect, family dynamics (linking back to power and emotions such as anger). Carer v professional dynamics, including acknowledging the effects on both parties. Maintaining objectivity.

In writing this report, I found myself exploring further some of the interesting ideas discussed, specifically Sallyann Roth's *Focused Pause* (See: Appendix 1) and *Authoritative Doubt* (Hardham, 2006).

In summary, the session increased our awareness of being focussed on more than the clinical and managerial decisions. Other important things to consider are context and process i.e. people's motives, experiences, and steps leading up to the situation that needs a decision or, as Professor Ward puts it, 'clinical and managerial decisions are given meaning by their context. As well as facts we must consider the feelings, beliefs and attitudes of the professionals and users'.

Appendix 1:

Quote taken from 'The Conflict Resolution Information Source' (Portilla 2003):

One is we rely very heavily on what I call the "Focused Pause", which occurs when a question is asked and then giving people an opportunity to reflect quietly before anyone speaks. It may seem like a tiny little thing but in American culture, and some other cultures, it is unusual to pause and reflect before speaking and then notice what they've said. This has a few really important effects. It gets people to think about what's really important for me here. It gets people to be succinct in their speaking, which means it is easier for people to listen. When everybody thinks before anyone speaks and is committed to speaking what they have thought of, as opposed to reacting to what somebody else has just said, they are able to stay centred in themselves and notice what they care about. They are able to notice what they want and listen. In other kinds of conversations, people become reactive, and then look back later and say 'I *wish I had done this and instead I spoke of something that wasn't important to me.'*

Appendix 2:

Exercise taken from handout given at conference session:

Getting away from the content: Interview someone about a dilemma where a decision must be made (clinical or managerial), WITHOUT THE PROBLEM ITSELF BEING NAMED. Ask questions such as:

a. When did the problem come into your life? Is it a new kind of problem, or a familiar one?
b. Is there sufficient understanding, respect and trust among those involved in the decision? If not, how can the conditions for good outcomes be created?
c. Who says there is a problem? How is it named? Is there someone who might name it differently, or even describe a problem as a solution?
d. What kind of power does the client have? Who else holds power in this situation? What are the effects of power?
e. Who has responsibility through a position of power?
f. Who else (client, family or professional) feels responsible? Where do these feelings come from and what are their effects? Who in this situation has no responsibilities? Who might feel blamed?
g. What methods have been tried to resolve problems like this in the past?
h. What effects did these efforts have on the problem? What effects on people?
i. When has this problem or one like it improved? Why? For whom? What were the effects on people involved?
j. Who and what can help the same favourable conditions occur again?
k. When has this problem or one like it got worse? For whom? Why? What effects?

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Drinks before Gala dinner at the Crowne Plaza

Bursar Report: Using Reflexes for Better Seating

Presenter: Leslie Fitzsimmons, Physical Therapist, New Jersey, USA

Reporting Bursar: Amie James, Physiotherapist, Wheelchair Services, Artificial Limb & Appliance Centre, Rookwood Hospital, Fairwater Road, Llandaff, Cardiff, CF5 2YN

I am a state registered physiotherapist working for a wheelchair service based in South Wales. Prior to taking this static post I have worked in general rotational posts in the UK and Australia, as well as a specialist neurological rotation. During this time I developed a specific interest in neurological rehabilitation, and this area continues to be highly relevant in my clinical practice. I was keen to attend Leslie's presentation as I assess many clients who present with abnormal muscle tone and reflex activity. This can often present a significant challenge to effective seating and mobility solutions.

I found Leslie Fitzsimmons's presentation to be very thorough and detailed with a strong knowledge base. A sound introductory framework covering normal child development, primitive reflex activity, and anatomical structure/function of the central nervous system were outlined, before progressing to a detailed account of abnormal reflex activity and movement patterns. This theoretical base reinforced a strong "take-home" message that it is essential to conduct a thorough assessment of clients in order to identify primitive reflex patterns and understand potential triggers. It is through this process that causal factors can be minimised, resulting in the prevention of secondary complications.

Another key point was to consider the functional needs of the client as well as postural needs. This was clearly illustrated through case studies where head position was affected by altered muscle tone and abnormal reflexes causing postural misalignment/asymmetry. This in turn had a dramatic impact on functional activities such as those requiring an effective swallow, eye contact, or use of upper limbs.

The presenter proposed that reflexes become stronger when repeated. The optimal seating position should therefore focus upon reducing the opportunity for reflexes to be initiated. This view could be regarded as controversial when considering the use of dynamic seating systems, which are specifically designed to tolerate and accommodate strong reflex activity. This query was raised during question time, but it was not possible to discuss it in depth due to time limitations.

The presentation offered possible strategies to assist with the management of undesirable reflex activity. It is perhaps this part of the workshop that will be most influential to my current and future practice. A strong emphasis on the importance of supporting and stabilising specific key points of control within the body, limbs and head reminded me that muscle tone and reflex activity can be altered significantly. Principles were discussed rather than specific equipment, allowing for greater flexibility during practical application. The presenter encouraged the listener to actively think and create solutions to challenges, rather than settling for equipment which may not be resolving the problem.

Reflecting on the presentation, I feel that I would benefit from consolidation of the recent knowledge gained, rather than identifying further learning needs. I also feel it is imperative to share this knowledge with my colleagues as we all assess and treat a variety of clients with complex postural needs. The presentation has inspired me to raise awareness amongst my colleagues of abnormal reflex activity and possible solutions within seating. In conclusion I found the presentation to be highly relevant to my clinical practice and I am keen to apply and share the knowledge gained with fellow therapists in order to improve outcomes for clients.

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Bursar Report: Spinal Cord Injury and Manual Wheelchair Propulsion: Free Paper Session

Presenters: (Presentation 1) Lone Rose from the National Spinal Injuries Centre, Stoke Mandeville

(Presentations 2 & 3) Bonita Sawatzky from Dept of Orthopaedics, University of British Columbia, Vancouver

Reporting Bursar: Gillian Taylor, Research Occupational Therapist, Oxford Brookes University School of Health and Social Care, Jack Straw's Lane, Marston, Oxford, OX3 0FL

This free paper session consisted of three 15 minute presentations around the subject of spinal cord injury and wheelchair propulsion.

Additional authors for these presentations were: 1. Ferguson-Pell, M.
2. Boutilier, G. Denison, I. Finlayson, H.
3. MacGillivray, M. and Lam, T.

Presentation 1: Prevalence of shoulder pain in people with spinal cord injury less than 10 years post onset

The Wheelchair Users Shoulder Pain Index (WUSPI) was used for this survey of 610 full-time manual wheelchair users. Results showed that pain was higher in the younger age-group and it was suggested that this may be due to this group being more active. Pain was also high in the tetraplegic group, which was reported to be in line with other literature. The activities that caused most pain were pushing > 10 minutes, pushing up ramps/slopes, and sleeping. The presenter focussed on the pushing > 10 minutes and the pushing up ramps/slopes categories and reported there was higher pain linked to folding wheelchairs compared to rigid ones (high statistical significance p=0.000).

This presentation suggested that existing evidence supports the supply of lightweight and appropriately adjustable wheelchairs to minimise the risk of overuse injuries, and it highlighted the need for practitioners to continue working towards a high standard of wheelchair provision. In addition, other shoulder pain risk factors can be affected by interventions (e.g. posture, strength, wheelchair skills training, body weight management, earlier use of powered chairs) and these should also be taken into account.

Presentation 2: Spasticity reduction using the Segway personal transporter in people with SCI

This presentation reported investigation into the use of Segways for people with spinal cord injury in Canada. The Segway was described as a two-wheeled, self balancing electric vehicle. See Fig 1.

Fig 1

Previous work by the presenter had suggested that:

- a Segway can be used by people with virtually any condition provided they have the ability to stand (with or without bracing or support) and adequate hand grip.
- Segway use may result in psychological benefits of standing and increased access to off-road terrain.

The pilot study being reported looked more closely at the physiological effects of Segway use, particularly on spasticity. Eight subjects showed reduced spasticity immediately after using a Segway for 30 minutes, but the benefit did not persist over time. The presenter questioned what was causing the reduction in spasticity and referred to previous studies reporting a similar effect in people with SCI following hippotherapy (horseriding) sessions. The presenter believes it may be linked to the vestibular system, although vibration and involvement of the vestibulospinal tract may be alternative explanations.

This paper highlighted the need for further research to explore long-term physiological and psychological effects of Segway use. It also challenged the audience to think imaginatively about alternative mobility options for wheelchair users.

Presentation 3: The biomechanics of manual wheeling in able-bodied subjects and experienced manual wheelchair users

This study compared biomechanical characteristics of manual wheeling between able-bodied subjects and experienced manual wheelchair users. The results were complex and impossible to report in detail, but suggested that wheeling strategy was found to be dependent on manual wheeling experience. Inexperienced able-bodied participants did not automatically use the most efficient propulsion method, which suggests a need to teach the most efficient way to propel, rather than leaving wheelchair users to acquire their technique over time.

In summary, this free paper session reminded the audience that a high proportion of manual wheelchair users experience over-use injuries that lead to pain. It challenged practitioners to reflect on their intervention and to think imaginatively about how the needs of people with spinal cord injury can be met. It also reinforced the individuality of wheelchair users and the challenges this poses to both practitioners and researchers working with this client group.

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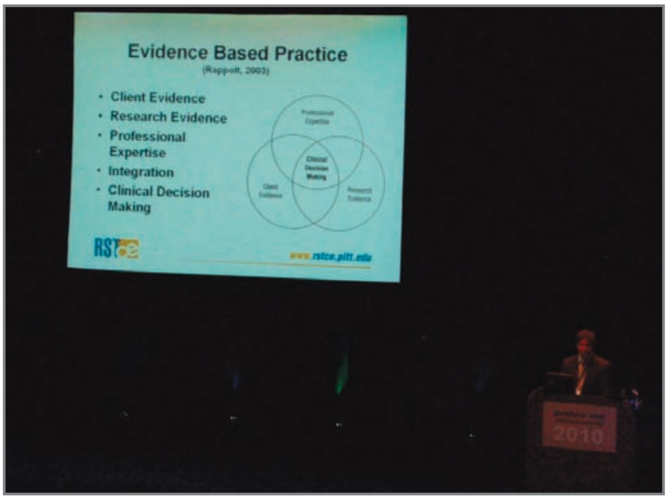
Bursar Report: Plenary 2, Outcome Measures: What Can I Use In My Clinic

Presenter: Mark Schmeler, USA.

Reporting Bursar: Rachel Watts, Band 6 Occupational Therapist,
Paediatric Wheelchair Services, Artificial Limb and Appliance Centre,
Rookwood Hospital, Fairwater Road, Cardiff, CF5 2YN

I have been working in wheelchair services for two years now as both a paediatric and an adult wheelchair therapist. Throughout this time I have become aware that wheelchair provision can draw higher media and political attention than other therapy healthcare areas and this is forcing us to have a high level of accountability and justification for our prescriptions.



Evidence Based Practice
(Rappolt, 2003)

- Client Evidence
- Research Evidence
- Professional Expertise
- Integration
- Clinical Decision Making

Mark Schmeler speaking

However we find it difficult to provide this justification due to lack of research, usable outcome measures and their perceived threats to the quantity and quality of our clinical practice.

Mark Schmeler talked about the usability of existing outcome measures and the limitations of the many global functional tests such as the Functional Independence Measure (FIM) which he gave as an example of a scoring method. Instead of being sensitive to levels of function within assistive technologies, the results show a ceiling effect for our clients' function. Thus these global functional tests do not provide the evidence we require to back up our practice.

When looking at choosing an outcome measure, Mark Schmeler highlighted that the following issues needed to be considered:

Administrative burden – meaning the length of therapist or clerk time taken to complete an outcome measure and how this impacts on clinical routine.

Apparatus required – taking into account a wheelchair therapist's need to be flexible, working within clinics and community settings, and its impact on any standardised assessment.

Mark discussed the possibility of a self reporting tool to be completed by the client which could thus have a decreased administrative burden, with the possibility of completion over the telephone by experienced administrative staff. However it was discussed that this may present evidence with decreased validity or reliability. Thus there is potential to gather information without discernable results being highlighted. Interest was raised by Mark Schmeler's description of his Functioning Everyday in a Wheelchair (FEW) with the pre-assessment questionnaire being able to be worked into present clinical practice, and the possibility of the post-assessment questionnaire being completed by experienced clinical support staff.

The other possibility was the Performance or Capacity observations carried out by the therapist. These would provide more valid and reliable results, but depend heavily on the expertise and clinical timing of the therapist.

Overall, the audience stressed the need to work the use of any outcome measures seamlessly into clinical practice with minimal administrative burden. However it was also raised that any results collected had to show clear relevance to practice, and thus that the expertise of clinical therapists was essential to ensure validity and reliability of setting of any SMART goals and any outcome results gathered.

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Bursar Report: Plenary 4 – The Challenge of Independent Living

Presenters: Dr Chris Ward, Consultant in Rehab Medicine, Derby
Dr Andrew Hanrahan, Consultant in Rehab Medicine, National Rehab Hospital, Ireland
Alan Carson, Consultant Neuropsychiatrist
Reporting Bursar: Christina Birkby, Occupational Therapist,
Leicestershire and Rutland wheelchair service,
Gwendolen Road, Leicester, LE5 4PW

As an occupational therapist I have a strong interest in independent living.

This plenary session included three separate presentations relating to the topic.

1.Community and culture in rehabilitation: a UK perspective

Dr Ward works in a neurology and rehabilitation team which also comprises of a specialist nurse and specialist occupational therapist. In Leicester we have a multicultural population similar to that in Derby, so I was interested to learn about his experiences. He outlined three case studies to demonstrate the importance of including the client's social context within their rehabilitation programmes. Dr Ward also explained how vital it is to have an understanding of the relationship of the individual with others in the family unit and with other professionals involved. His team have found that improved interagency working and liaison has reduced the number of hospital admissions.

He used diagrams to illustrate the relationships each individual had with different health professionals and family members and how this can impact on our intervention.

I feel it is an important lesson for all of us working within postural management where so much of our work interlinks with other professionals. It is vital that we have an awareness of cultural needs and establish links with appropriate agencies in order to ensure that our intervention is meaningful for that individual.

2. Decision making in rehabilitation

Dr Hanrahan explained that decisions can be simple or complex and that we must, as clinicians, be aware of the power we have within the clinical setting and be careful that we don't become too paternalistic, i.e. that we don't impart our opinions too strongly to the patient. A challenging question that was raised was whether or not we are ever really independent. Or are we just co-dependent or interdependent?

3. Capacity and cognition

Alan Carson emphasised that capacity varies according to the decision which is to be made, for example "would you like a cup of tea?" requires a different level of cognition compared to " do you consent to surgery?"

His presentation illustrated visually how the different parts of the brain have different functions. He then described how different medical conditions can have an effect on, for example, executive functions such as self awareness, planning and organisation.

His closing comment was that it is important in our assessment and intervention that we follow a logical progression of thought, and also that we should not get too lost in minutiae but instead ensure that we use common sense.

Alan Carson speaking

References:

WHO International Classification of Functioning, Disability and Health, Interaction of concepts – ICF 2001 Available from: www.who.int/classifications/icf/en

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Associate Parliamentary Limb Loss Group

for the Promotion of the Prevention of Limb Loss and of the Provision of Prosthetic, Orthotic, Wheelchair/Special Seating, Medical and other vital Rehabilitation Services to persons of all ages suffering Limb Loss and associated Complex Physical Disabilities in the United Kingdom and Internationally

The Associate Parliamentary Limb Loss Group, more commonly known as the APLLG (www.apllg.eu), is an all-party group of MPs working for the promotion, within Parliament and Whitehall, of the prevention of limb loss and the provision of prosthetic and other rehabilitation services to all persons suffering limb loss in the UK and Internationally. The group is also supported by a wider group of Associate Members (www.apllg.eu/associates.html). The APLLG therefore involves itself in many areas of service and equipment provision, for instance with its patient-led charters.

Wheelchair Charter

The All-Party Group has published collaboratively a *Patient Led Wheelchair & Special Seating Services Charter* (www.apllg.eu/charters.html) which illuminates the hope of APLLG member Baroness Wilkins that "Together we can move towards a modern wheelchair service which better meets the needs of its users and supports them in leading more independent lives."

APLLG is also supporting the introduction, at the London South Bank University, of Foundation Degrees for Clinical Technologists working in Special Seating and Prosthetics and Orthotics.

For more information please visit www.apllg.eu or www.em-pow-er.org **Email:** feedback@apllg.eu

PMG
POSTURE & MOBILITY GROUP

Executive Committee Vacancies April 2011

Time to get involved?

There will be 5 vacancies on the PMG committee at the AGM in 2011.

The committee meets four times a year and provides the chance for members to meet others in the field, and to become involved in organising the activities of PMG. It also provides CPD for individuals.
Please encourage your colleagues to stand for election, or suggest that they nominate you for membership of the committee. It is extremely important that the committee is fully staffed so that the work of the group can be progressed. Please note that we continue to be under-represented from the North of England and from the medical profession.

Further details in the terms of reference for the executive committee which are on the PMG website:
www.pmguk.co.uk/Home/About/Terms+of+Reference

As well as the quarterly committee meetings, which discuss the broader issues, as a member of the PMG executive you would join one or more of the lively sub-committees, where so much of the group's creative work arises…

Education & Training, which planned the pre-conference training day at the NTE in 2009, and collaborated with BSRM and SPMN to host the pre-conference training day at the Glasgow International Conference in June 2010;

NTE, which plans the group's annual conference;

Publications & Marketing, which produces the twice-yearly journal and keeps the membership informed;

R&D, which has funded 16 research studies since 2006;

Website, which will be bringing you the new website in Spring 2011, and produces and monitors the library of conference webcasts.

If you would like to have an informal chat with a current PMG committee member before making any commitment, please contact Olwen who will put you in touch. olwen.ellis@pmguk.co.uk

Nominations close on 4th March 2011 and the nomination form will be available to download from the PMG website members' section.

ANNUAL GENERAL MEETING
POSTURE & MOBILITY GROUP
12.40pm, April 15TH 2011
UNIVERSITY OF WARWICK

The PMG National Training Event 2010
University of Warwick, Coventry, CV4 7AL
April 13th to 15th 2011

So much of the 2011 National Training Event programme has now been confirmed that we are giving members a sneak preview ahead of bookings opening in January. There are still a few speakers to be confirmed and, as ever, the programme will be enriched by exciting free paper presentations and posters. Also, in response to delegate requests for more time to visit the exhibition, we have, for the first time, added a parallel session for exhibition viewing. Bookings will open on 4th January 2010: check the PMG website for updates nearer the time.

13th April 2011		**Presenter(s)**
2pm - 9pm	*Registration & Exhibition*	
7pm - 10pm	**Ice Breaker**	
14th April 2011		
8am - 9.15am	*Registration and Exhibition*	
9.30am – 9.45am	**Opening Address by PMG Chair**	Clare Wright
9.45am – 10.15am	**Plenary Session 1** Human rights, the Disability Discrimination Act and the provision of assistive technology: do they fly in the face of health & safety / risk management?	Diego F. Soto-Miranda
10.15am – 10.55am	**Free Papers and Research**	tbc
10.55am – 11.55am	*Break and Exhibition*	
11.55am – 1pm	**Free Papers and Research**	tbc
1pm – 2.15pm	*Lunch and Exhibition*	
2.15pm – 3.15pm AND 4pm – 5pm	**Parallel Sessions**	
PS1	Transportation of people seated in wheelchairs	John Tiernan
PS2	Service provision – positioning beyond the wheelchair	Lisa Ledger & Gail Russell
PS3	Advanced powered wheelchair control systems: a whistle-stop tour	
PS4	Exhibition viewing	
PS5	Fundamentals of research	David Porter & Marie Kelly
PS6	What does lying mean for sitting and how can I help?	Pat Postill & Claire Finch
PS7	Normal movement development and neuroplasticity	Marion May & Peter Lane (tbc)
3.15pm – 4pm	*Break and Exhibition*	
5pm – 6pm	FREE TIME	
6pm – 7.15pm	**Drinks in Exhibition Halls**	
7.30pm	*Conference Dinner & Entertainment*	
15th April 2011		
8am – 9.15am	*Registration*	
8.30am	**Exhibition Opens**	
8.30am – 9.15am	**Wake – Up Sessions**	tbc
9.30am – 10.45am	**Free Papers and Research**	tbc
10.45am – 11.45am	*Break and Exhibition*	
11.45am – 12noon	**Launching the new PMG website**	James Hollington
12.00 – 12.40pm	**The Aldersea Lecture:** The chapters so far……	Ros Ham
12.40pm – 1.20pm	**PMG AGM**	Clare Wright (Chair) Rakesh Shukla (Treasurer) James Hollington (Vice-chair)
1.20pm – 2.30pm	*Lunch and Exhibition*	
2.30pm – 4.15pm	**Plenary Session 2** 1. MS Society funded research on symptom management 2. The evolving nature of multiple sclerosis: solutions for mobility and positioning	Jane Petty Marc Defour (tbc)
4.15pm	**Prize Giving and Close**	Clare Wright
4.30pm	*Refreshments*	

We look forward to seeing you in Warwick in April!
Kirsty-Ann Cutler, Chair, NTE Sub-committee

PMG accepts no responsibility for any inconvenience caused by changes made to the programme

PMG
POSTURE & MOBILITY GROUP

2nd Announcement & Final Call for Papers

National Training Event
14th and 15th April 2011
Warwick Arts Centre, University of Warwick, Coventry

We wish to invite you to participate in PMG's next annual NTE being held again at Warwick Arts Centre, University of Warwick in April 2011

The abstract submission form for free paper and platform presentations is available to download via

www.pmguk.co.uk/NTE+(Conference)/Speaker+Abstracts/Guidelines

Deadline for submissions is *31st December 2010*

Further information on the NTE will be notified via ebulletins,
or contact olwen.ellis@pmguk.co.uk
tel/fax: 0845 1301 764

See over for latest programme details

www.pmguk.co.uk

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