PMG
POSTURE & MOBILITY GROUP

POSTURE & MOBILITY
Volume 26:1 • July 2009 • ISSN 1752-1629

this issue...

Meeting the Needs of People with Neuro-Degenerative Disorders

Front Cover: PMG member Gordon McQuilton outside Buckingham Palace after receiving his MBE award (see page 34).

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Posture & Mobility is published by the Posture and Mobility Group, **Registered Charity Number 1098297**.

ISSN 1752-1629

Editorial

This feels very strange writing my editorial for the last time. When I took on the job as editor back in 2005 I had no idea it would last this long, and would never have predicted enjoying it quite so much. It would be really hard to step down if I weren't handing over to such a capable replacement. I am particularly pleased with the news that Carolyn Nichols will be taking the reins from now on, not only because she is so experienced and will bring some new ideas to the journal, but because I was the clever person who talked her into joining the editorial team and becoming a co-opted member of the Publications and Marketing sub-committee! I am not too sad to be moving aside as I have agreed to remain a member of the editorial team for another year, and so will get to work with the team for a while longer, and see how Carolyn can move the journal forward even further.

Looking down the contents page for this edition is yet again very satisfying, as I hope you will agree. There are some great articles, from both experienced and new writers, which is what we aim to provide. We want to deliver varied and thought-provoking articles written from as many different perspectives as possible. It is wonderful to see a piece on holidaying with wheelchairs – a must-read from a carer's perspective. See Holiday Crush by Jane Muir.

There is also some useful feedback on a couple of study days; these give us a snapshot of what training is going on, and might tempt some of us to go next time round. As always we hope there is something in this issue for everyone; we work in such a specialist field that we really do need to celebrate good practice and share our knowledge with each other.

I can't really write an editorial after NTE without congratulating Kirsty-Ann, Olwen, Simon and the rest of the fabulous NTE sub-committee. I had a very enjoyable time and especially valued the networking and the excellent exhibition from a very dedicated group of exhibitors; I always find the informal discussions with them during coffee and lunch breaks as important as attending the various lectures.

For those of you who attended the AGM, you will know that PMG needs to look carefully at their expenditure in this difficult financial time, so my last plea to you regards the journal, which is costly and time consuming to produce. If you value it and want to keep it, please read it, tell others to read it, and most of all tell others to consider joining PMG. And, last but not least, make 2009/2010 your year to write a piece for it!

My final thanks go to Olwen again for holding the journal together and to everyone in the editorial team for working so hard, with big thanks to Carolyn for taking over from me. I look forward to reading the next issue.

Joanne McConnell, Editor

Carolyn Nichols and Joanne McConnell

It wasn't until Jo mentioned that the PMG Publications & Marketing sub-committee needed more members that I started thinking that I might as well put my natural compulsion for correcting spelling and punctuation to good use. I didn't realise how much I would enjoy it! And then, Jo somehow talked me into taking over as Editor. She will be a hard act to follow, as she is a great networker (translation: "chatter"), and is therefore very good at encouraging others to contribute to the Journal. And she somehow manages it without making them feel overly pressured. Many, many thanks to Jo for all her hard work. I'm very pleased that she will be there to assist with my first year.

With all the changes taking place within PMG – webcasting from the NTE, increasing international links, the international conference here next year, the beginning of SIGs – I look forward to receiving some interesting articles.

Carolyn Nichols, Editor-elect

Letter from the Chair

There are several big items I would like to talk about in this brief note.

First of all a huge thank you to all of you who participated in PMG NTE 2009 – that goes for attendees and participants, Kirsty-Ann Cutler and her team, Olwen Ellis and Simon Hukku, our many volunteers, Jo Jex and Monica Young for handling the pre-NTE Training Day and to our major sponsors – Day's Medical, Invacare and Specialised Orthotic Seating. The whole event was a great success, both as a learning venture and in providing funding for future PMG activities.

This issue of the Journal looks great. I have had the pleasure of a preview of the articles, and hope you get as much out of them as I have – terrific content. This says a lot for our editorial team and reflects very well on the years of work Joanne McConnell has spent building the Journal into what it is today. Again an opportunity to say a heartfelt thank you, this time to Jo. This is her last issue – what an act for follow for our new editor, Carolyn Nichols.

Special Interest Groups have kicked off with a lively opening discussion event at the NTE – please look out for email announcements about participation in the SIGs. This is your opportunity to participate more in PMG activities and to influence how we work for you. My thanks go to Clare Wright for leading this new PMG venture.

In another first, PMG members will very shortly have access to webcasts of the PMG 2009 NTE presentations. For this I would like to sincerely thank Paul Hewett; additionally I wish to thank Active Design for sponsorship of the webcasts. The webcasts will give you an opportunity to catch up on parallel sessions which you could not attend or for a good overview of the conference presentations for those of you who were unable to attend the NTE. Again look out for email announcements of how to view the webcasts on the PMG website.

Nigel Shapcott

Those of you who were able to attend the NTE saw a changing of the guard within the PMG Executive committee. Barend ter Haar, Martin Moore and Monica Young now have their chance to relax in the sun (to some extent), whilst we welcome our new committee members Alison Johnston, Carolyn Nichols and Clare Wright.

Participate, participate, participate.

That's it for now.

Nigel Shapcott, PMG Chair

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Production Editor: Olwen Ellis

Design: Nicholas Smith

Printer: SPS Communications, Ilford, Essex.

Journal Advertising costs:

Full Page:	£600
Inside Front Cover, Inside Back Cover or Outside Back Cover:	£750
Half Page:	£360
Quarter page:	£200
Loose inserts:	£200

The main theme of the next issue will be **Best Practice: Lessons from the Field**. Please consider sharing your case studies with the rest of the membership: **Deadline for copy is 30th September 2009**.
Articles submitted can be between 500 and 2,000 words. For details on the format, or if you need to write a longer article, please contact **Olwen Ellis** at **olwen.ellis@pmguk.co.uk** or **Telephone: 0845 1301 764** or **PMG, 29 Myrtle Close, Alphington, Exeter EX2 8UX**.

Meeting the Needs of People with Neuro-Degenerative Disorders

Starting to Understand the Politics?

**Dr Linda J Marks, Consultant in Rehabilitation Medicine and Director, Stanmore DSC,
Royal National Orthopaedic Hospital, Brockley Hill, Stanmore, Middx HA7 4LP**

Abstract: *As an organisation, PMG is trying to become more influential, particularly in political spheres. In order to facilitate this, we have engaged the services of Mark Oaten MP. He has suggested that attending All-Party Parliamentary Group hearings (APPGs) is one way of learning about affairs of 'the House'and starting to get PMG recognised. Linda Marks attended two sessions of the APPG Enquiry into Muscular Dystrophy (MD) and reports back on the experience.*

One of the parliamentary mechanisms for collecting information is to hold a national enquiry via an APPG, which stands for All-Party Parliamentary Group. An APPG is made up of a cross-party group of MPs and Peers, and chaired by a specific named MP. In December 2008 the APPG for the Muscular Dystrophy National Inquiry into "Access to Specialist Care" was launched at the Houses of Parliament.

The background to this enquiry is that in the past year or two there have been a number of high profile reports by the Muscular Dystrophy Campaign, which have highlighted distinct differences in the quality of service provision for people with Muscular Dystrophy across the UK. It was also noted that there are no NICE guidelines for Muscular Dystrophy and related neuromuscular conditions, and additionally these conditions do not appear in the National Definition Set for Specialised Commissioning.

The formal terms of Reference for the Enquiry are: "To determine the current provision and quality of specialist services for people with Muscular Dystrophy and related neuromuscular conditions: to highlight areas of best practice and recommend possible solutions where improvements are necessary".

I attended the launch on December 10th 2008, and the first evidence session in January 2009. Further evidence sessions, approximately monthly, have been held between then and June with a report anticipated in the autumn.

The sessions are held in the Houses of Parliament so that interested MPs and Peers can attend in between other activities. Access to the session is open throughout, both to MPs and members of the public. Essentially each session has a number of invited people selected to answer the MPs' questions around a particular theme. At the launch, the invited panel included two Professors (Newcastle and Oxford) and a Specialist Nurse from Newcastle, and the session was primarily about 'setting the scene' – i.e. the diagnosis and incidence of MD and how services are currently arranged. At the second session the panel was composed of three people, two with MD and the mother of a boy with MD – this session focused on their particular personal experiences of living with MD. It was also very evident that the MPs were well briefed, and the questions were wide ranging. The session lasted about 1.5 hours, and the 'audience' could also make comments/ask questions if time permitted at the end.

None of the information that I heard was new; however it was an interesting exposure to Parliamentary activities. Clearly the bulk of the work on such enquiries is done behind the scenes, and the evidence sessions serve to test out theories and verify information. There is limited opportunity for interaction (although one can submit evidence to the Enquiry at any time), so as for raising the profile of PMG, it will take a long time by this route…!

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Do you like the Journal's new look?
Email your comments to olwen.ellis@pmguk.co.uk

Motor Neurone Disease – A Protocol for Practice

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Abstract: *Motor Neurone Disease (MND) is a rapidly progressive neurological illness. Although relatively rare, MND presents a particular challenge to wheelchair services due to the rapid deterioration that can occur and the need to respond quickly to constantly changing postural and mobility needs. This article briefly describes the development of a protocol to guide Wheelchair Therapists, and a short case study illustrates its use in practice.*

Background

Motor Neurone Disease (MND) is a progressive neurological disease with an average life expectancy following diagnosis of 1-5 years. The presentation depends on the type of MND with symptoms varying according to the motor neurones affected.

The King's Lynn Wheelchair Service covers West Norfolk and parts of Cambridgeshire, serving a population of 220,000 and with approximately 3,000 wheelchair users. The service is staffed by Occupational Therapists, a Wheelchair Technician and administrators.

The incidence of MND nationally is 1:50,000 but locally the incidence has been higher. Even though numbers encountered by the Wheelchair Service are still small, MND presents a particular challenge due to the rapid deterioration that can occur and the need to respond quickly to constantly changing postural and mobility needs.

Development of the Protocol

In order to meet these challenges we decided to develop a protocol for the provision of services to people with MND. This not only guides the therapists within the service but also enables clear communication with other professionals about the role of the service. A literature search was performed to identify evidence to inform the protocol but although the effects of MND are widely documented, there was no evidence specific to the use of Wheelchairs with people with MND.

The MND Association and other wheelchair services were also contacted but there did not appear to be anything similar in existence. The protocol was therefore developed through discussion with colleagues and general evidence regarding wheelchair provision and pressure care. Some of the issues we considered were as follows:

- Flexibility and speed
  The MND Association's key principles to underpin the care of people with MND include flexibility and speed in response to referral, and regular monitoring and review (MND Association).

  It is also important that criteria are used flexibly, for example issuing Electrically Powered Indoor/Outdoor wheelchairs (EPIOCs) to clients with MND while they are still able to walk – to use outdoors only initially – if this is appropriate for the client.

  The challenge for therapists is to balance the anticipation of a client's needs with sensitivity to the client's and/or carer's emotional adjustment to the disease. For example, it may not be appropriate to suggest an EPIOC to a client who is still walking and has only just been diagnosed. However if you wait until the client is unable to walk to broach the subject, there may not be enough time to order a chair to issue while they are still able to use it.

- Occupational function and client involvement
  As an Occupational Therapist it is important to ensure that, as far as possible, the occupational performance of the individual is maximised within the constraints of this rapidly progressing disease. Evidence suggests that the participation in valued occupations contributes significantly to the perceived wellbeing of the person with MND (Brott, Hocking and Paddy 2007). Assessment of client needs should therefore include consideration of their roles and activities. Although it would be the intention of therapists to involve clients in the decision-making regarding their equipment needs, people with MND do not often have the opportunity to become "expert patients" as the disease progresses too rapidly. They will therefore look to professionals to predict their needs (MNDA 2003).

The Protocol

First Assessment

- MND clients will be seen within 4 weeks of referral. More urgent requests will be seen sooner as requested by referrer.

- Clients will be seen at home on request.
- Clients will be issued with a manual wheelchair within 10 days of assessment.
- The therapist will initiate the preparation of a suitable electric indoor/outdoor wheelchair following their first assessment. (They may choose not to discuss it with the client and carer at this time.)
- The therapist will ensure that the client has contact details of the MNDA.

Re-assessment

- Clients and carers have direct access to the service and can request reassessment at any time.
- The therapist will review clients regularly – at least 2 monthly – to ensure needs are anticipated.
- The therapist will undertake a pressure sore risk assessment and issue a suitable pressure-relieving cushion.
- The therapist will address the issue of an EPIC/EPIOC with the client at a suitable time.

Equipment

The type of equipment that might be issued includes:

- Lightweight manual wheelchair
- Indoor electric wheelchair (EPIC) or Indoor/outdoor electric wheelchair (EPIOC)
- Pressure reducing cushion
- Accessories to assist postural control
- Manual tilt-in-space wheelchair
- Electric tilt-in-space wheelchair

Alternative controls for EPIOCs

If a client is unable to manage the standard right or left hand controls on their EPIOC, they will be given the opportunity to try alternative controls, e.g. tray control or chin control.

Case Study

The following is a brief case study to illustrate the implementation of the protocol.

Mr Plumb was diagnosed in 2004 with amyotrophic lateral sclerosis. He was referred on 19th November and seen on 2nd December. At that time he had bilateral foot-drop and was walking short distances with crutches. A pressure-reducing cushion was issued at the assessment (Qbitus Sun-mate), and the next day a lightweight wheelchair (Action 2000) was delivered to the client's home. At the same time an order was made for an EPIOC to be prepared from stock. Unfortunately Mr Plumb did not have good access at his address and was waiting to be re-housed. The EPIOC (Phoenix) was issued the day he moved to his new home. At this time he was still walking indoors.

Over the following year his condition deteriorated and he was reviewed regularly – at least every two months. Various changes were made to his equipment to accommodate his changing postural needs, including provision of a headrest and a Jay Back for his manual and electric wheelchairs, and various positions for the controls for his EPIOC (fig 1). His pressure care needs were also regularly reassessed and his cushion was changed, most recently to a ROHO.

Fig 1

In 2006 Mr Plumb was issued with an Invacare Spectra with powered tilt, recline and elevating leg supports (fig 2). (This was purchased under the partnership voucher scheme as the Spectra was not on NHS contract at that time). The Wheelchair Technician has since made numerous adaptations to the controls and arm supports to enable maximum function as his condition has changed (fig 3).

Fig 2

In 2007, following discussions with the MNDA Regional Care Advisor and local MND Association

Fig 3

branch, an Invacare Rea Assist was purchased by the branch for the wheelchair service to issue to MND clients while waiting for their chair to be ordered (fig 4). This chair was issued to Mr Plumb for use when he is taken out, as his ability to drive the Spectra had deteriorated and his partner found the attendant controls difficult. A replacement was ordered for MNDA stock and Mr Plumb continues to use the Rea Assist.

Fig 4

In March 2007 Mr Plumb got married and his condition has since stabilised. Over the last year, the position of the controls has been changed according to Mr Plumb's ability and the Wheelchair Technician has also adapted the chair to be able to carry his NIPPY ventilator.

The Wheelchair Service continues to review his needs and respond as required.

Conclusion

The process of developing the protocol was a useful way of evaluating the service we provide to clients with MND and agreeing good practice. The case study shows that it is possible to keep to the standards set in the protocol. Reflecting on the service we provide – especially to those with particularly challenging conditions – may seem a luxury in the midst of waiting lists and targets, but is necessary to ensure we are providing the best service we can to our clients.

This protocol has been a valuable tool in communication with other professionals and MND Association visitors, and has given us a benchmark to ensure best practice.

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A Wheelchair Loans Service for People Living with Motor Neurone Disease (MND)

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Abstract: *The Oxford MND Care Centre has developed a wheelchair loans service for people living with MND through additional charitable funding. This article describes the service, how it has developed and the aims for the future. The charitable funding includes provision of an Occupational Therapist, who completes a postural assessment for the person living with MND and also the provision of seating equipment. The aim of this service is to provide equipment quickly to people with MND and without eligibility criteria. Therefore it is not intended to replace the NHS wheelchair service, but to complement it, working to see people quickly and providing equipment to those who might not be eligible for it through the NHS.*

Charitable funds have enabled the development of a wheelchair loans service from the Oxford MND Care Centre. This service includes an Occupational Therapist (OT) to complete postural assessments for people living with MND and the timely provision of appropriate seating. This service was set up intending to complement existing NHS wheelchair services, who under their resource restraints are not always able to provide a timely service and can be limited on the type of wheelchairs which they can provide. The MND wheelchair loans service does not have any criteria (other than being seen in the Oxford MND Care Centre), for example: ability to walk, where the wheelchair will be used, for how long, and for what purpose. Any person seen in the weekly clinic can be assessed for seating and have an appropriate chair provided to meet their postural and life style needs. This aims to help maximise the quality of life for people living with MND and their carers.

Although this service operates without the tight resource limitations normally experienced in the NHS wheelchair service there are challenges, highlighting that money alone cannot solve all the problems of service delivery. One of the first challenges experienced was establishing a fleet of chairs which could be accessed quickly for people living with MND. In the first instance this was not a problem, until all the chairs had been issued and more were required. This encountered the issue of ordering time scales. The order time for a new wheelchair can be up to eight weeks and longer if there is a "delivery problem". This is too long for anyone with a rapidly progressing condition and created another challenge for the service. In order to have a steady supply of wheelchairs storage facilities for the equipment were needed. The local wheelchair service kindly provided a corner in their wheelchair stores where the MND chairs can be stored.

Another challenge faced by the loans service was the maintenance and upkeep of the equipment. Initially the local wheelchair service agreed to provide this service for the chairs. However a change of contractor meant they were no longer able to maintain the chairs as they are not owned by the wheelchair service. The MND loans service now funds a maintenance contract for the chairs.

One of the final challenges was the available time of the OT. This service currently runs with an OT funded for two days a week (increased from one day). This limits how timely the provision of assessment and equipment can be, with increasing waiting times for OT assessment, equipment issue, and provision of necessary follow up. Future plans include expanding the service by employing a full time OT, which will allow more assessments and more time to follow people up and manage the service.

The service is a valuable addition to the NHS wheelchair service and working closely with them has enabled both services to provide a better quality of service to people living with MND and their families. The challenges of ordering equipment continue, as a transient caseload can be difficult to predict stock requirements. With additional time for the OT and the development of a maintenance contract with a reliable contractor, it is hoped that the stock can be managed more effectively and efficiently to provide equipment quickly.

The wheelchair loans service is currently available to clients seen within the Oxford MND Care Centre, but with the expansion of the service it is aimed to open it to a wider area.

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Proof of Principle and Hope for Patients with Early Active Relapsing-remitting Multiple Sclerosis

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***Note:** CAMMS223 was published in New England Journal of Medicine (2008) 359, 1786–1801 and was funded by Genzyme and Bayer Schering Pharma AG. A closely related version of this article was published as 'New hopes for the nervous system' in Research Horizons (University of Cambridge) 2009: 8; 24.*

Multiple sclerosis affects almost 100,000 people in the United Kingdom and several million worldwide. At first, individuals experience episodes that transiently disturb functions that healthy people take for granted: seeing, walking, feeling, thinking and emptying the bladder. Later, these episodes fail to recover fully and are then replaced by secondary progression. Disabilities affecting many aspects of daily living accumulate thereafter. Most affected individuals develop multiple sclerosis between the ages of 20 and 40; the diagnosis is therefore threatening but also a major burden on young people at the most active professional and domestic stages of their lives.

The illness results from the development of an autoimmune attack on elements of the nervous system – the inflammatory process targeting the myelin sheath that envelops axons, interfering with passage of the nerve impulse through the spinal cord and brain, and directly damaging the underlying nerve fibres themselves. The pivotal event in the cascade of events that leads to tissue damage in multiple sclerosis is migration of activated T lymphocytes across the blood brain barrier and their accumulation around blood vessels in the central nervous system; demyelination, axonal loss, reactive overgrowth of astrocytes and limited repair due to remyelination all ensue. But why the characteristic relapsing–remitting pattern is followed by secondary progressive disease, and both when and how best to treat the illness have, until recently, remained elusive.

The results of a recent drug trial raise new hopes for patients with multiple sclerosis and establish that – at least over a period of some years – effective suppression of the inflammatory process early in the course and before significant disabilities are established significantly modifies the natural history of the disease. A three-year, phase 2 clinical trial with Campath-1H (now known as alemtuzumab), in which over 300 patients were treated, shows that not only is disease activity halted but many patients get better, perhaps due to brain repair. Alastair Compston and Alasdair Coles from the Department of Clinical Neurosciences at the University of Cambridge led the study showing that Campath-1H reduces the relapse rate by an additional 74% compared with the best treatment for multiple sclerosis available at the time the study was designed (high dose beta interferon [Rebif]), and the risk of sustained accumulation of disability also fell by 71%.

These results provide a new instalment in what has been a long history for a monoclonal antibody made in Cambridge by Herman Waldmann in the Department of Pathology in 1979; and, with Greg Winter, turned into a medicine by the process of 'humanisation' that builds on the Nobel prize winning research of César Milstein in the Medical Research Council Laboratory for Molecular Biology who introduced the technology for making monoclonal antibodies. Campath-1H was the first such antibody to be 'humanised', a technique that largely disguises the injected foreign protein from the host immune response and so minimises the risk of the drug being neutralised following repeated administration. Because the drug destroys all lymphocytes, Campath-1H has principally been used to treat drug-refractory chronic lymphocytic leukaemia but the lymphocyte-depleting property has now been exploited also to remove the cells that perpetrate tissue injury in multiple sclerosis. Surprisingly, given that Campath-1H effectively destroys immune cells for a prolonged period following a short pulse of treatment lasting only 5 days, infections are only slightly more common after treatment in treated patients. Rather – and as previously noted in open-label studies leading up to the CAMMS223 trial – the development of another autoimmune disease, usually affecting the thyroid gland, has proved to be the major complication.

Although the potential of Campath-1H as a treatment for multiple sclerosis was first considered in Cambridge 18 years ago, early attempts at treating patients who had already entered the secondary progressive stage failed to influence their disabilities. Conversely the results of CAMMS223 show very different outcomes when immunological treatments that effectively suppress the inflammatory response are given before acute injury and destruction of the myelin sheath have advanced to the point that secondary damage to the underlying axons has acquired a momentum of its own, leading to progressive disability. It seems that not only does this strategy suspend the sustained accumulation of disability for the duration, to date, of follow-up (now 10 years in some patients), it also allows existing damage to improve, an event not previously seen in a clinical trial but now confirmed using other aggressive strategies for immunosuppression in early active multiple sclerosis. Expectations are high that the Phase 3 trials, now in progress, will confirm these results and lead to drug registration within a few years.

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Are you nearing retirement?

Do you want to stay involved in some way in the posture and mobility field? Then why not consider becoming a co-opted member of a PMG sub-committee and share your knowledge and skills...

Please contact Olwen (olwen.ellis@pmguk.co.uk) who will put you in touch with the relevant committee member(s) to discuss your particular interests.

The Management of Spasticity Affecting the Seating of Patients with Multiple Sclerosis

Dr. Alison Hatfield, Consultant in Rehabilitation Medicine, Portsmouth Hospitals NHS Trust, St. Mary's Hospital, Milton Road, Portsmouth PO3 6BR

Abstract: *Multiple Sclerosis (MS) is a common progressive neurological condition that often affects younger adults. While progression can be slow over many years, some patients can progress very rapidly to become fully wheelchair dependent. Spasticity is a frequent problem for these patients affecting comfort, positioning in sitting or lying and the management of personal care.*

A search should be made for underlying medical problems that may exacerbate spasticity. A review of 24-hour posture management should also be undertaken. Oral antispasticity agents can be considered. Botulinum toxin can be helpful for localised spasticity.

Introduction

Multiple Sclerosis (MS) is the most commonly diagnosed disabling neurological disorder of young to middle aged adults and the third leading cause of disability after trauma and arthritis. The pathophysiology of MS consists of inflammatory white matter lesions which continuously appear, resolve and recur even during periods of apparent quiescence. Myelin is stripped away and axons are eventually left bare. There is also axonal loss. By 15 years after onset of symptoms, approximately 15% of individuals will require a unilateral aid to walk. The relapsing, remitting nature of multiple sclerosis presents a complex moving target for the rehabilitation team.

Problems caused include reduction in strength, mobility, cognition, language ability, bladder and bowel function impacting on ability to self care, social roles and self image.

Rehabilitation aims at functional training, facilitation of new compensatory behaviours and symptomatic management of various complications of the disease. Most individuals with longstanding Multiple Sclerosis know their disease well and should be actively involved in goal setting.

Spasticity

This is a motor disorder characterized by a velocity–dependent increase in the tonic stretch reflexes. It occurs in conditions where there has been an upper motor neuron lesion as in multiple sclerosis. Initially after injury there is disruption of the neural pathways involved in execution of voluntary muscles. Muscles become flaccid. Subsequently new fibres sprout and abnormal excessive reflex responses occur to peripheral inputs such as muscle stretch. The most effective treatment is a combination of physical therapy and medication. However, spasticity may be useful to some patients for a more stable stance and gait. In these patients treatment of spasticity may increase the effect of existing weakness.

Effects on seating

Spasticity can cause problems in seating with reduced stability, tendency to slide forward, tight hip adduction or windsweeping of the lower limbs. Foot positioning can be problematic. Spasticity affects transfer ability, either standing or using a hoist. It can be painful and lead to the development of pressure ulcers and contractures.

Treatment of spasticity

General principles

Treatment of spasticity should be multidisciplinary and be part of a 24-hour posture management programme. There are a number of medical problems which can exacerbate spasticity, for example urinary tract infection or a pressure ulcer. Medical treatments range from oral medication and intramuscular botulinum toxin to more invasive surgical treatments (Sheean, 1998). Spasticity may be associated with poor trunk control. Posture can be improved by good support in sitting, for example with use of tilt-in-space seating.

Oral treatment

Baclofen is the most widely used oral antispasticity agent. It can be very effective but has significant side effects of drowsiness and weakness which limit the dose which can be used. Alternatives are tizanidine and dantrolene (Paisley et al, 2002; Kamen et al, 2008). Diazepam is sometimes used but is also limited by drowsiness and risk of dependence.

Botulinum toxin

This is a potent neurotoxin which blocks neuromuscular transmission. It is used for focal spasticity management.

It is generally well tolerated. In seating it can be very useful for reducing hip adductor or hamstring spasticity and also ease personal care (Hyman et al, 2008).

Invasive procedures

Intrathecal baclofen, delivered via a pump, can be very beneficial in patients with severe generalised spasticity. This maximises delivery to the spinal cord and much lower doses of baclofen can be used. Intrathecal phenol is sometimes used in patients with severe spasticity that have completely lost lower limb sensation and are doubly incontinent.

Conclusions

Spasticity can severely affect ability to seat patients with multiple sclerosis. Treatment is multidisciplinary, exploring underlying exacerbating medical problems initially, then commencement of oral medication. A regular review of the management of spasticity is required because of the changing underlying condition. If very persistent or severe and generalised then more invasive treatment may need to be considered.

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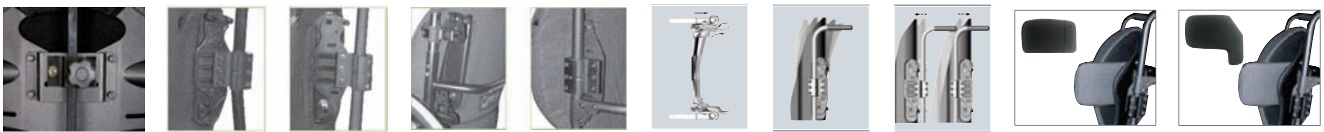

Seating for Huntington's Disease at the Royal Hospital for Neuro-disability

Prina Patel, Senior II Physiotherapist and Adrienne Scott, Senior I Occupational Therapist,
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Abstract: *The Huntington's Disease (HD) service, at the Royal Hospital for Neuro-disability (RHN), is one of the largest dedicated units in the country, enabling us to gain experience in the physical and postural management of the condition.*

Due to the complex nature of HD, seating this client group continues to pose many challenges. This article aims to highlight the RHN's approach to seating this client group. Seating needs are monitored by the whole Multi-Disciplinary Team (MDT) and reviewed by the Physiotherapist and Occupational Therapist due to the progressive nature of the disease impacting on their postural needs and thus all aspects of their daily life.

Huntington's Disease (HD) is an autosomal neurological degenerative disease which presents as a triad of major features of movement, psychiatric and cognitive problems. Characteristics of HD are uncoordinated, jerky body movements collectively known as chorea. As the disease progresses there is a steady decline both physically and cognitively, resulting in the need for a 24 hour postural management approach. There are numerous challenges to consider/overcome when prescribing seating for this client group due to the complex nature of the disease. The HD service at the Royal Hospital for Neuro-disability (RHN) is one of the largest dedicated units in the country, enabling us to gain experience in the physical and postural management of the condition.

Posture is the basis on which movements are organised (Massion 1998). With emphasis on postural control as background to selective movement, seating should pay careful attention to the interplay between optimal positioning and alignment in order to provide a stable base to allow active movement to occur. However, some abnormal postures/alignment may need to be accommodated in order to enable function.

MDT therapy assessments are carried out to assess key areas such as range of movement, tone, alignment and correctability of head, trunk and pelvis. In order to accommodate the postural changes customised seating systems (matrix, foam carve) with tilt in space wheelbases are used in the unit as well as comfort seating. The extent of choreic movements is also considered to maintain safety and reduce the risk of injury from entrapment. Padding is therefore applied to accessible structures on the wheelchairs.

Seating can impact on an individual's ability to transfer, mobilise and interact with their immediate environment. As functional ability declines, at the RHN, we recommend the use of two seating systems. A comfort chair can provide minimal postural support enabling clients to carry out activities of daily living. A wheelchair with similar adaptations designed for transportation/mobility both in the internal environment and the wider community is also provided. Inevitably with the progression of HD these systems will no longer meet the demand in postural needs and/or large choreic movements, resulting in the need for custom seating. Foam carve seating systems have been successful in reducing choreic movements evident in the casting stage. A possible reason is that the seating is moulded to accommodate/correct posture, providing a larger base of support and sensory feedback. These systems provide a more stable base to allow more selective movements of the upper limbs.

As you can see from the photo the foam carve seating is contoured allowing alignment of the hips using an integral pommel and lateral supports for the trunk. Large padded trays allow for optimal upper limb positioning and function. From the picture you can also see the padding used on the footboard and footrest stems to reduce the risk of injury secondary to choreic movements. Head straps are occasionally used to assist in maintaining alignment of the head for meal times.

Often trunk alignment is correctable but not sustainable resulting in a kyphotic position being adopted impacting on respiration, swallow and social interaction. Therefore at the RHN, we have explored the use of dynamic chest and shoulder harnesses with the aim of providing more stability. We have found that active head extension has improved as a direct result of optimised trunk positioning and stability through the use of dynamic harnesses.

Summary

There are a number of factors which need to be taken into consideration when it comes to correct seating and positioning. Each person has their own specific needs and requirement and it is important to remember this when dealing with each individual. Therefore a dynamic, creative, MDT approach to postural management and seating is essential when working with Huntington's disease.

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Dynamic Seating vs Rigid Seating: A Quantitative Comparison Using 3D Movement Analysis in People with Cerebral Palsy

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Introduction: *High-tone extensor thrust or involuntary muscle contractions experienced by many children with Cerebral Palsy with severe dystonia can cause a host of problems for them relating to the seating system. Since most existing chairs are rigid the occupant must be constrained in the seat, sometimes by means of seatbelts, such that he/she could not fall out of the chair during extensor thrust. Once strapped in, however, the occupant is able to exert very large forces on the seatback, headrest and footrest of the seating system, producing significant risk of skin breakdown even though the seat is well padded. In addition, from a biomechanical point of view, during these involuntary movements, children have great difficulty in postural maintenance due mainly to destabilization of the pelvic joint: and most have the same difficulty returning the pelvis to the original position. From the 80s the concept of a dynamic seat which moves with respect to the seat system frame during an extensor thrust event, was suggested as a potential solution*[1]*. However literature is poor on this topic and no quantitative evaluations on this kind of seat system exist. In light of these considerations the main objective of this study is to make quantitative comparison of a dynamic seat system versus a rigid seat system for dystonic patients with Cerebral Palsy, using quantitative analysis of movement (3D kinematics and pressure distribution).*

Materials and Methods

10 clients with Cerebral Palsy (CP) (range: 6-19 years), in particular with spastic and dystonic tetraparesis of type V according to Palisano's classification[2], were evaluated quantitatively during sitting on a seat system (X-PANDA). The system allows the seatback to pivot backwards when the seat is in a dynamic configuration while remaining rigid when the seatback rigidizer is engaged. The clients were evaluated using an optoelectronic system with passive markers (ELITE,

BTS, Italy) for kinematic data acquisition, a synchronic Video system (BTS, Italy) and a system placed on the seatback (Tekscan, USA) for acquisition of pressure distribution data. Passive markers were positioned at specific points of reference on the client's body to represent the head, the torso, the upper extremities and the lower limbs. Data collection was performed with the patient sitting in the seating system in two sessions: first with the seat system in the dynamic configuration and then in the rigid configuration. In both sessions at least 3 external perturbations were performed to produce dystonic movements. Some parameters from 3D kinematics (Range of Motion, Average Jerk index[3]) and from pressure distribution on the seatback (peak force) were identified and analysed in order to make the comparison between the two configurations of the seating system.

Results

The main results of this study may be summarised as follows:

- during the extensor thrust, most clients (70%) showed a larger excursion of trunk in the anterior-posterior direction in the dynamic configuration than in the rigid one: this means that the rigid configuration locks the movement during the thrust phase with high resistance;
- the dynamic configuration means that clients are not forced to move down in the seat; on the other hand, 60% of the clients' trunks rolled down in the rigid configuration, so showing low trunk and pelvic stability in this configuration;
- in some clients (40%) the lower value of Average Jerk index of the upper limbs in the dynamic configuration revealed improved smoothness of the limb movement in comparison to the rigid one;
- some clients showed a lower peak force on the seatback in the dynamic configuration than in the rigid one: the force reduction is an indicator that the occupant is exposed to weaker compressive loads.

In rigid configuration most of clients' upper limbs evaluated (70%) showed a larger movement excursion in all directions: it seemed that in dynamic configuration the "irradiation" (an inappropriate diffusion of hypertone in muscles far away from the main spastic muscle) decreased. It will be interesting to develop and continue the research on this focus point.

Conclusions

The results obtained in this study demonstrate that the seating system in the dynamic configuration improves overall occupant conditions during an extensor thrust. It is able to reduce the forces experienced by the patients as well as to increase the range of motion in the anterior-posterior direction, limiting rolling down of the trunk and the pelvis and showing better upper limb smoothness during extensor thrust. This can lead to an increase in occupant comfort and quality of life.

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Material Choice in Custom Moulded Seating for People with Neuro-Degenerative Disorders

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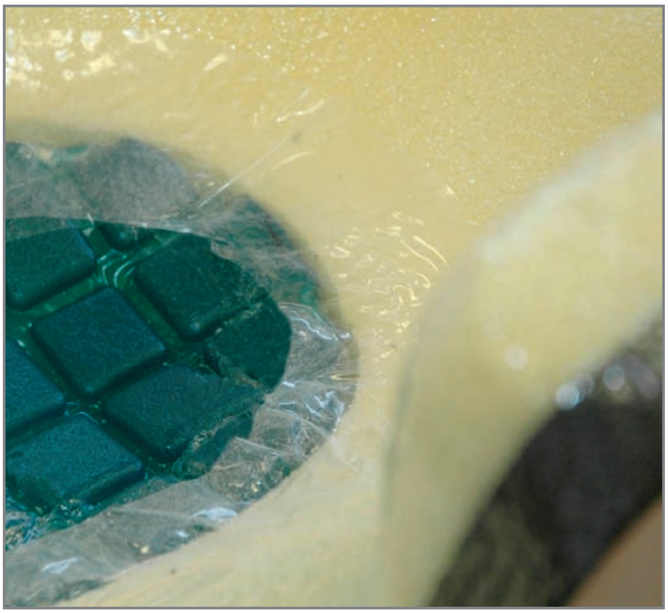
Abstract: *This article describes commonly used seating materials and goes on to propose a comparison table, which can be used as a clinical tool for choosing materials for the client. This will enable clinicians to make material decisions led by client need and consider the long-term implications of material choice. A case study will demonstrate how this can be used in practice.*

Various materials are available for custom-moulded seating: Carved Foam, Foam in Place, Matrix, New Matrix, Lynx and Thermoplastics. Each has different clinical, functional and technical attributes. The difficulty is choosing which material best meets the aims established during the assessment of the client. The material can influence how the seating works clinically and how it performs long-term. Knowledge of the materials available can assist clinicians to make an informed decision and choose the most appropriate material for the client with a neuro-degenerative disorder.

Clients with neuro-degenerative disorders present with some similar problems. These include muscle weakness, spasticity, postural deformity, contractures and the need for pressure relief (Ham R et al, 1998, pp 117). Each condition also has its own unique problems. Clients with multiple sclerosis (MS) have a "high incidence of pressure sores" (Ham R et al, 1998, pp 127) and have a tendency to overheat. With muscular dystrophy (MD) "many boys adopt a position with an exaggerated lumbar lordosis" (Ham R et al, 1998, pp 119) this is to maintain functional capabilities through building a stable sitting base. Clients with neuromuscular conditions may experience "possible shoulder girdle weakness, which may make it difficult to self propel" (Muscular Dystrophy Campaign, 2006, 46). Clients with cerebral palsy present common "complications *relating* to involuntary movements" (Ham R et al, 1998, pp 117). All of these factors will have implications on the type of material used, with consideration being given to clinical and functional needs in addition to technical considerations. These needs continually change, which means the material chosen has to be adaptable.

Carved Foam

The shape of the moulding bags is carved out of the foam. This can be done electronically or manually. Electronically, the person moulding takes a digital map of the cast, which is sent to a computer aided machine, which in turn carves the 3D cushion. Manually, the process is similar to that used in key cutting; the cutter in the profile machine follows the movements of the person tracing around the shape of the mould. During the manual process, tweaks can be made while carving if errors were made during moulding. In the electronic process this can be done on the computer prior to carving.


Carved foam

Advantages:

- Varying densities of foam can be used to increase durability and support.
- Foam is softer and more forgiving than the other materials.
- The moulded shape can be accurately reproduced in foam facilitating very acute angles and large drops in height. It can be modified for growth and some degree of postural change.
- The seat and back can be made in two separate sections to enable more adjustment.
- Pressure relieving materials such as gel, visco foam or Roho can be inserted so that they are flush with the top surface of the seat. Localised pressure relief can be given, ensuring support is retained where needed.
- Functional aids, such as swing away thoracic supports, can be added.

Disadvantages:

- Foam is an insulator and therefore can get too warm: this can be minimised by cutting holes through the foam and shell to enhance heat transfer.
- The perception of foam is that it is bulky and whilst it can be shaped to look slim-line, it is not as slim-line as other possible materials.
- Most foam seats are supplied with a protective layer to stop the ingress of fluids. However, some of these layers can deteriorate over time. Protective fabric covers can be made to stop fluids reaching the foam surface.
- Foam can deteriorate and bottom out through heavy use.

Clients who self propel find Carved Foam can be bulky under their axillae when propelling. They also find that it is quite heavy, especially when using a custom-made, lightweight wheelchair. Foam inserts without shells can be used for some clients. Foam can also provide good comfort and pressure relief. Foam can also be more forgiving for those clients who are quite thin with bony prominences. Foam has the ability to form acute angles and small radii; for example, this could be of use when making seating for clients with MD who have lumbar lordosis.

Matrix

Plastic interlocking clamping components, circular in shape with four ball and socket connecting stems. The ball-jointed connections provide the adjustment. This is made from flat sheets, which are loosened and tightened around a plaster cast of the moulded shape. It can also be formed live, suspended within a frame and tightened around the client. The finished seat is then framed using aluminium tube to keep the structure rigid.

Advantages:

- Good air flow between the components.
- Simple to adjust, as individual components can be added for growth, although it requires large areas to be loosened off to make small modifications.
- Can check the clients' conformity to the seat through the gaps in the Matrix.
- Retains shape well, due to the secure connections between the components and rigid framing.
- Fairly slim-line: components are 17mm in thickness. The framing can make the overall system more bulky when allowing for future adjustment.
- Matrix can be kept clean, by washing and scrubbing to remove any dirt from the crevices.

Matrix

Disadvantages:

- Can be heavy when made as a full seat due to material and framing, furthermore the system can be awkward to lift.
- Some clients find the material feels hard.
- Difficult to introduce localised areas of pressure relief.
- Without splitting the matrix can achieve a diameter of 40mm plus the cover thickness on top.
- Full Matrix systems are usually made as one, and, therefore, major work is needed if the backrest angle needs modification.
- Maintenance checks are required to ensure components have not loosened.

Matrix's good airflow is ideal for clients that overheat, such as those with MS. The overall system is heavy and may not be suitable for some when having to transfer it from a power chair to a manual chair on a regular basis. For clients with strong athetoid tone it is less likely to lose shape than the other materials. For MD clients with an acute angle at their lumbar curve, accurate representation of the mould at this point may not be possible. It would need to be considered at the time of assessment for the mould whether support into the lumbar curve is crucial.

New Matrix

New Matrix is similar to Matrix but thinner in profile and made of a different plastic composite, and formed from a sheet of interlocking segments, which are then loosened and tightened over a plaster cast of the moulded shape. The suggested framing method for New Matrix is to use flat aluminium cladding, although tube can be used.

Advantages:

- Good air flow between the components.
- Lighter than Carved Foam, Matrix and Lynx when framed.
- Have components, which consist of one stem and a ball joint at either end. These can be set up to allow 3D expansion of an area. This results in fewer units needing to be loosened off than Matrix when making modifications.
- Thinner in profile than Matrix, 12mm at its thickest point and is clad with flat framing, which maintains the thin profile all over the seat.
- Can check conformity through the gaps in the New Matrix.
- The flexible components can be used to make swing away anterior supports. They can also be used in areas which are susceptible to pressure.
- Cleaned using the same process as Matrix.

Disadvantages:

- Can be quite hard in comparison to foam.
- Individually the components are stronger than Matrix, but care needs to be taken when framing as there can be flex in the overall system.
- Does not conform closely to shapes with tight angles or radius under 38mm.
- Longer to adjust than Matrix due to cladding strips used for framing.

New Matrix

Consideration of the appropriate framing technique should be made when using this material for strong athetoid clients, or those who exert a lot of force through one particular area. The cladding has been found to bend away in some cases. For those with postural deformity such as scoliosis and corresponding rib prominence, the flexible components are good for accommodating and relieving pressure. Where there is expected to be postural change the two ball units can be used compressed initially and then gradually extended out to allow for change. This material also lends itself to clients who self propel, as it is slim-line, lightweight and can be easily modified and adjusted unlike thermoplastics.

Lynx

Interlocking plastic cross shaped components, which have been slotted to facilitate extension or compression. Formed from a sheet of interlocking segments, which are then loosened and tightened over a plaster cast of the mould. The final seat is then framed using aluminium tube to give it rigidity.

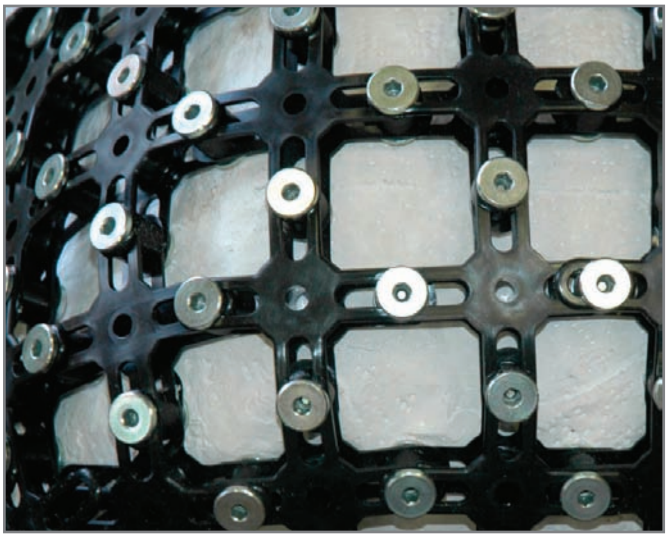
Advantages

- Good air flow between the components.
- Reasonably thin in profile, but can be bulky due to framing.
- Can check conformity through the gaps in the Lynx.
- Easy to modify: small areas can be loosened and adjusted by sliding the components over each other.
- Can be pulled out and expanded to create more room within the mould. Whereas with Matrix, additional components would need to be added.
- Cleaned using the same process as Matrix.

Disadvantages:

- Reasonably strong, but due to their flexibility and clamping Lynx components can loosen and give, especially if the client has strong athetoid tone.
- Both the material and framing can be heavy.
- Can be hard if the components are fully extended. Can get localised pressure areas on the components themselves due to large gaps between them.
- Difficult to introduce localised areas of pressure relief.

For clients expecting weight gain or where there are likely to be postural changes Lynx offers the most adjustment. This is due to its ability to grow in width and length within each component. It is also simpler to modify than Matrix and New Matrix as a smaller area can be loosened off. However over time the plastic work hardens, which makes adjustments more difficult. Lynx has more flex within the components than Matrix, but less flex in the overall structure than New Matrix due to the framing method used. This can be an advantage for clients where some give in the seating would be of benefit, but not as suitable for those clients with strong



Lynx

tonal patterns, as the Lynx gradually loosens and gives with the movements.

Thermoplastics

The shape is created by vacuum-forming plastic, generally ABS, around the mould of the client.

Advantages:

- The most lightweight in comparison to the other materials.
- Slim line, 6mm or 8mm plastic shell and then one or two 10mm inner foam linings.
- High strength in thin sections and rigid with no loss of shape over time.

Disadvantages

- Difficult to modify either for postural change or growth, large areas of the mould have to be heated to make small corrections. This process can be inaccurate.
- The final seat is made with the seat and back as one. The angle of the backrest section is therefore unable to be altered. It can however be manufactured as two separate parts with a hinge point between the two.
- The manufacturing process will not allow for the material to have a large drop in height and contour: instead it may hammock across. This will vary depending on the manufacturer. Also, with each forming process, the contours are smoothed, thereby losing definition.
- Limited airflow as the plastic shell and foam lining insulates. Holes can be drilled in the shell but this should be done with caution as it weakens the material.
- High rigidity, although pressure relieving material can be added flush to the seat surface.

Where weight is an issue, for instance those who self propel and have a lightweight chair, thermoplastics offer best strength to weight ratio. But this benefit has to be weighed up against the disadvantages. The client will ideally have been stable in weight for the past couple of years and not likely to change significantly in posture. Clients with MS may find thermoplastics too hot. If holes are drilled in the plastic for airflow, their spasms may cause the plastic to crack around the holes. For clients with fixed deformities such as very limited flexion in one hip, the material may not form properly due to the drop in height from one leg to another.

Foam in Place

This consists of a bag divided up into compartments, each containing a different chemical. These are mixed together and the solution poured out into a bag. The chemicals then start to react with the air and expand. The shape is moulded directly to the client. The client will need to be covered to protect them from the expanding foam and the heat generated during the reaction. The foam is then trimmed and then sent off to have a cover made. Another technique is to use moulding bags, from which a plaster cast is taken and then the foam is formed around the cast.

Advantages:

- Relatively quick in manufacturing time compared to the other materials.
- Fairly inexpensive compared to the other materials.
- No loss of accuracy between mould and final product.
- Good for providing basic support

Disadvantages:

- Not able to form stable lateral support to the torso or pelvis. This limits the degree of support that can be achieved and its ability to arrest the progression of deformity.
- The client has to remain completely still in the desired position while the seat sets, which is difficult to achieve.
- The process can be very messy and hot, which may distress the client.
- The results are not always accurate due to limited moulding time.

When looking at which material is suitable for the client the following areas should be addressed:
Clinical – comfort, pressure relief, posture, tone.
Functional – weight of the system, cleaning, size of the system, transport and manoeuvrability.

Aesthetics – is the proposed solution acceptable to the client?
Technical – growth, adaptability, strength.

The clinical and functional aims are established following the initial assessment. The aesthetics can be discussed if the clinician has examples of moulded seating, or using examples given at the moulding by the engineer. The importance of a good mould cannot be underestimated, but the material and technique in which the mould is then reproduced can add to the success of the final mould. Technical considerations should be discussed with the engineer prior to moulding.

Case Study

The following case study will show the areas considered when comparing materials. A comparison table, as described by Stuart Pugh (Pugh, 1991), is used as a tool to assist the clinician when making the final decision.

In this case study the client is a 15 yr old male with muscular dystrophy with severe postural deformities. Due to muscle weakness head control is maintained by precise balance of the body segments over the base of support.

The key issues affecting the material choice were identified to be:

- Tendency to overheat.
- A scoliosis that is likely to progress and therefore ability to modify the support would be beneficial.
- Need for adjustment within the backrest area behind the left shoulder to facilitate movement, which is used to relieve pain.
- Thin profile around the axilla to facilitate arm function.
- Strength to ensure the material holds the moulded shape, in order to limit deterioration of posture.
- Low profile and rigid material needed at the transition of the backrest to the seat, where the back cups under the ribs.
- Allowance for future modification around rib fullness where change in shape may be expected.

The materials considered were New Matrix, Matrix, Lynx, Carved Foam and Thermoplastics. A material selection chart was used to assess the importance of the key criteria against how well each material meets that need.

Material requirements to meet the key issues were defined and given a weighting specific to this client.

	Weighting	Matrix	New Matrix	Lynx	Carved Foam	Moulded Seat Insert
Heat	1 Client tends to overheat however low area of contact therefore heat retention low	3 Increased air flow	3 Increased air flow	3 Increased air flow	1 Insulative	1 Limited air flow
Future modification of concavity	3 Shape likely to change in this area with increase in rib fullness, likely need to pull out	2 Requires large area to be loosened and disconnected to make adjustments pulling out an area	3 Use of 2-ball components to pull out easily	2 Pulled out easily providing radius is not very small	1 Area can be scraped out, must be done with user out of seat and difficult to push in an area	0 Limited adjustment for pulling out
Modification around shoulder	3 May need to adjust to compromise support with ability to perform stretch	3 Easy to reshape relatively flat areas	3 Easy to reshape relatively flat areas	3 Easy to reshape relatively flat areas	2 Easy to scrape back relatively flat areas but adding foam less accurate	1 Adjustments can be made to flat areas but low accuracy and difficult to achieve in clinic
Thin profile	3 Thin around axilla for arm function	2 High strength and rigidity with thin profile but thicker than other materials	3 As Matrix, but slightly thinner	2 As Matrix	2 Difficult to give firm support to thin areas	3 High strength and rigidity at thin sections
Strength	3 Losing shape over time is likely to lead to conforming to that shape and potential deterioration of posture	3 Holds shape well and rigid	3 Holds shape well and rigid	3 Holds shape well and rigid problems with slippage resolved with framing	2 Compression of foam over time	3 Rigid with no loss of shape over time
Transition	3 Needs to flow onto seat cushion under ribs	2 Thicker than New Matrix and no modifications to thin edges	3 Thinner than Lynx and Matrix	3 Can be made thinner with edging	3 Can be tapered to a thin edge	3 Thinnest of all materials whilst maintaining strength

Fig 1

Each material was assessed as to how well it meets each material requirement and given a rating. Comments were documented to justify these ratings. Multiplying the ratings by the weightings and summing for each material, a numerical indication of how well each material meets the requirements can be identified. The higher the number, the better the material meets the stated requirements. This can be used to aid the decision of which material to use along with the expertise of the clinician and engineer involved.

The most appropriate material for this client was found to be New Matrix. The case study demonstrates a method used for a particular client, however in general practice the process can be utilised informally with full documentation not necessary.

The conclusions raised in this article may vary dependent on the engineer involved in the moulding of the seating and the specific circumstances of the clients. Each contractor has their own method of moulding and production and their own experiences of each material. With new technologies being developed, there are going to be more advances in the materials and technology available in this field. Each new development will have its own pros and cons which are evaluated when assessing a client for moulded seating. By maintaining their knowledge of the materials available, the therapist will be able to assess which is best for their client.

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Key for Figs 1 & 2: **Weighting:** 0 – negligible benefit, 1 – some benefit, 2 – significant benefit, 3 – essential.
Rating: 0 – does not meet requirements, 1 – meets some aspects of requirements, 2 – meets most aspects of requirements, 3 – meets all aspects of requirements.

	Weighting	Matrix	New Matrix	Lynx	Carved Foam	Moulded Seat Insert
Heat	1	3 x 1	3 x 1	3 x 1	1 x 1	1 x 1
Future modification of concavity	3	2 x 3	3 x 3	2 x 3	1 x 3	0 x 3
Modification around shoulder	3	3 x 3	3 x 3	3 x 3	2 x 3	1 x 3
Thin profile	3	2 x 3	3 x 3	2 x 3	2 x 3	3 x 3
Strength	3	3 x 3	3 x 3	3 x 3	2 x 3	3 x 3
Transition	3	2 x 3	3 x 3	3 x 3	3 x 3	3 x 3
Totals		39	48	39	31	31

Fig 2

Holiday Crush: Holidaying with Wheelchairs

Jane Muir, Parent/carer and freelance writer

I used to be a ‘throw a few things in a bag and go’ sort of person – or at least that was the ideal I aspired to – I loved travel, and loved the idea of fitting everything I needed into a rucksack, and part of the thrill was in the spontaneity. Of course, having kids does change that for anyone – a family of four somehow takes up far more space than the sum of four rucksacks.

However, add a disabled child into the equation, and going away anywhere for any amount of time virtually requires a removal van. It is something that ‘Motability’, for one, have never understood: when I said I needed a bigger car to fit all the equipment we needed for going away in the summer, I was told, “We provide a vehicle based on day to day needs, not for holidays”. Nor do space and transport issues seem to occur to equipment manufacturers or, for that matter, accompanying friends…

Jane and her son on holiday

Long ago, I cut out one of those ‘missing consonant’ cartoons which struck me as particularly poignant in our situation. It shows a family entering the living room of a house, and the young boy is cradling a toilet in his arms. The caption says, “The Simpsons were taking a second loo around the property.” Armed with a power chair, a manual chair and a wheeled loo/shower seat, as well as all the other ‘stuff’ we need, I feel we might as well, indeed, be taking an extra loo, as well as the kitchen sink.

True we don’t always choose easy destinations. The croft in the Outer Hebrides is surrounded by long grass and rocky outcrops, but it is all on one level once you’re in and also, due to the kindness of friends, free. The power chair is needed inside the house, the manual is needed for the ferry and for walks, the rollover loo seat is not an option, and a bath support makes up for the lack of shower facilities. That is four major items already, and with struts, wheels and arms akimbo, they are not exactly the slot together, space saving, compact sort of items that you might wish for.

Taking essential equipment on holiday also, of course, entails taking tools to deal with the inevitable breakages. A wheelchair thrown onto a conveyor belt at the airport needs anything from a set of allen keys to a screwdriver or, that lifesaver on a roll, duct tape. Spare sets of nuts, bolts and screws can save a potentially ruined holiday, as we found when pushing our manual chair on the cobbles at the Edinburgh festival, and up and down the steps in Venice. These occasions had me regularly searching gutters after hearing the tell-tale tinkle of small metal parts doing their own independent run for freedom.

Remembering every little thing that might be needed is challenging to even one such as me who is addicted to list making. Getting all of it to co-inhabit limited car space, survive off-piste terrain, negotiate inaccessible buildings, stand up to devil-may-care airport workers and hold together when jammed into small spaces and awkward corners is what comes after list making. Forethought, imagination and unflappable organisational skills all swing into being days before, until by the start of the holiday one is already mentally exhausted. And then, on the day, you find there’s nowhere for the friend’s dog to sit.

Finally, having planned so carefully, packed up and ready to go, every space optimally used, feeling so proud because surely, now, nothing can possibly go wrong, the truth dawns: like every other carer, in thinking so hard about the needs of your child, you forget to think about yourself. You may have remembered the proverbial toothbrush, you can do without make-up for a week or so, and a hairbrush can be shared, but no, the shop on this small, out of the way island does not stock ladies’ knickers.

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No Wonder The Chairs Get Damaged

Natasha Kassir

Abstract: *This article describes the experiences, in her own words, of a young woman with mild cerebral palsy, reduced upper limb dexterity and spinal fusion, as she journeys to and from an assessment in Birmingham from her home in Mansfield, whilst travelling in her outdoor powered wheelchair, using a variety of modes of transport.*

This is my experience of using public transport to get to an assessment I had at the Conductive Education Centre, Selly Oak in Birmingham.

I have CP and a spinal fusion, which restricts my mobility. I drive a Pride Mobility Quantum Blast powered chair. This is too big for me to get into an ordinary taxi, so I have to use a minibus with a tail lift, or use other forms of public transport, when I want to go out in my powered chair.

One of the things I have found out is that power chairs are being made a lot bigger and bulkier now, which makes it awkward to access transport. The transport sector needs to look at their design of vehicles to accommodate the fact that wheelchairs are becoming bigger and more advanced in their design.

This was the first time I had decided to go on the train in my power chair and this was a big learning curve for me. It was not as easy as you might think. First I had to plan everything and organise everything. I found this hard so I asked friends to help me. I started to do a lot of research using many different sources, for instance phoning round the different places and using the Internet.

The planning side of it I found very hard: I used the net to find the maps, train times, and taxi firms which would be able take me. I have another difficulty which is I'm unable to duck my head and the height of my chair means I have to use mini buses with tail lifts to get from A to B.

Mini buses are very hard to find for wheelchair users; also it can become very costly. I found out too that you cannot do anything spontaneous like get on a train and just go – you have to book things months in advance and plan everything down to the last detail. When you have to do a journey like this one, it can become very frustrating and time-consuming as some of you know.

Natasha at home

Once I booked the British Rail assistance to get on and off the trains, ABC taxis in Mansfield and AFJ taxies in Birmingham, all the planning was out the way, and the rest would be straightforward, or so I thought.

On the morning the transport was late and I thought I might miss the train. I had to ring them up and check they were coming.

When the train came the guard was ready with the ramp but it was hard to get into the space required because there was no extra space to manoeuvre my chair myself. It was a good job I had my friend and carer to help with me because my wheelchair had to be manhandled round a corner – no wonder chairs get damaged.

There was someone to help when we got into Nottingham station, and when we boarded the train for Birmingham New Street Station.

The train for New Street had a lower entrance, bigger doors and plenty of room to manoeuvre around to park my chair, which I thought was great because I could do it myself. This train was bigger and a lot easier to get on/off. I think the design of newer trains is a lot better to access than the older ones.

There was also someone to help when we got into New Street station.

There was some confusion with transport outside the station when we rang the wrong taxi firm who knew nothing about a mini bus, although the vehicle we had booked did arrive at the time agreed, so panic over – our mistake. Oops! AFJ taxis were very helpful with securing me into the vehicle.

We arrived at the Conductive Education Centre and they assessed my ability to do certain tasks like transfers and exercises. After the assessment they gave us a cup of tea and a biscuit.

The transport arrived in good time to get back to New Street station, but when we got there, no one from the station came to help me get on the train. My friend had to run up to the office in the main concourse and remind them that we needed help. We only just made it onto the train in time before it left.

Again there was plenty of room on the train from Birmingham to Nottingham, but the train from Nottingham to Mansfield was very cramped, and there was more manhandling and pushing and shoving to get my chair into the train; we even had to take the footplates off so I could get round the corners in the train.

When we got to Mansfield the guard on the train helped us with the ramp to get off, but we knew there would be no one at the station to help in any way. We were told this when we made the bookings.

We walked back from Mansfield Station, as the mini bus was not available at that time in the evening. It took about an hour to get home – luckily the weather was OK.

Overall, the Disability Assistance team from British Rail were very helpful and nearly everything went smoothly. Trying to get into and out of the old Nottingham trains was the biggest problem. Hopefully these will be replaced with more accessible trains eventually.

I am glad I had my carer and my friend Geoff with me, because I wouldn't have been able to do the journey on my own. I would like to thank them both, for their help on the day.

RAatE, 1st December 2008

Kirsty-Ann Cutler, Clinical Lead, Birmingham Wheelchair Service
Unit 8, Selly Oak Industrial Estate, Elliott Road, Selly Oak, Birmingham B29 6LR

Abstract: *Feedback from RAatE 2008, held at the Design Hub, Coventry University. www.raate.org.uk.*

I report on the keynote speaker session and the parallel sessions I attended.

Keynote speaker: Martin Sabry

Martin is a product developer in inclusive design. He is a full-time wheelchair user, following a T6/7 spinal injury and head injury in a mountaineering accident. He completed his PhD in 1999 and, in 2005, set up an innovation and product development company with particular focus on inclusive design (www.@ideas.org).

Many think inclusive design takes additional time and money, but accessibility is not a separate issue from design. We must design for ability not disability. Many AT solutions can and often do improve mass market products and lead to improved product success and commercial value. Inclusive design makes good business and living sense.

Parallel session 1:
Equipment: development and design

Why are mobile hoists difficult to manoeuvre? Brian Abraham, OT and PhD student.

Brian discussed his research and how he developed and used a 'virtual' hoist to calculate the forces involved in mobile hoist manoeuvre and how some of these forces may be reduced. There are two basic problems with mobile hoists: moving sideways and initiation force (much like a shopping trolley). This research is not yet finished and experimental tests are in progress.

Design considerations in compliant seating for children with whole body spasms. Tim Adlam and Alison Wisbeach, BIME.

Tim presented a one-off product solution for a single client referral, a young boy with dystonic CP, epilepsy and severe extensor spasm. His rigid conventional seating was increasing his pain and spasms.

The solution was a postural support system comprised of a saddle seat incorporating a dynamic backrest using simple gas struts. The backrest and footrests were linked to move in conjunction when the child experienced severe spasm. This was interfaced into a static base initially. The outcome was improved head and arm function, widespread decrease in muscle tone and decreased pelvic obliquity. The seat has been further refined and has worked well for the child.

There is little or no research into measuring the force of spasm in those with neurological conditions. BIME are continuing their work with instrumentation in the seating to quantify their work.

An enabling cooker minder. Bruce Smith, BIME.
Cooking represents many different things for different people: values, independence, choice, function. For those with dementia there can be many safety issues with this activity. Currently available solutions detect the hazard, provide intervention and then restore the system automatically.

A new system is being developed to keep the control with the user, using no new cooking equipment or new learning and it needs to reassure the user.

It will have warnings for the user to remind them the cooker is on. It may also be able to send SMS messages to another person, a relative or carer.

Testing is currently underway with a new device.

Parallel session 2:
Education

Involving people with disabilities in education. Laraine Epstein, Coventry University.

This session discussed the use of inclusive teaching in the Health and Life Sciences modules at Coventry University, using webcasting with service users.

There are a variety of benefits:

- To encourage service user involvement in education and clinical practice. They feel they make a valuable contribution to the student and increase their own skills in communication and IT.
- Use of Coventry University learning technologist in the development and use of e-learning.

Robot Assisted Play
Two studies were presented in these parallel sessions.

- A long-term, qualitative study looking at assisting autistic children in play with interactive robots [Sony ‘Aibo’]. Play allows a child to develop learning and self expression. The study is looking at non-directive play based on Rogerian client centred therapy. The use of robots allows play to be facilitated and adapted to the specific needs and abilities of the child.
- Using Robots to Trigger Social Interaction. Josh Wainer, University of Hertfordshire. This is an exploratory study only looking at how children with autism communicate and collaborate in a ‘Robot class’ [Lego robots]. The thinking is that playing together with the robot as a social mediator increases the children’s ability to collaborate and communicate. Further research is planned with similar sessions to collect data.

Supporting personal narrative for children with communication difficulties. Rolf Black, University of Dundee.
Stories within communication form a major part of daily life. AAC systems are designed to support transitional communication, but not stories. This 12 month study is looking at the evaluation of an electronic prototype interface and a pilot study for the use of this prototype.

An electronic interface is required for communication devices to support the interaction required in storytelling. Radio frequency identification (RFID) tags were located in a variety of rooms and attached to children's wheelchairs in order to identify where the child went in the course of the day. This created the basis of a narrative which the child could then build interaction into and create a story via a number of switches.

The study is currently testing the interface with users and continuing to develop it.

Assisting whom. After lunch and networking Simon Stevens was the keynote speaker. www.simonstevens.com.
Simon is an independent disability consultant and trainer, and an experienced advocate. He has CP and first hand experience of the difficulties with inclusion. He gave a very enlightening and entertaining speech from the user perspective.

Regarding product design his opinion is that items: are overpriced, are too institutional, should use smart technology, are based on an incorrect perception of “lifestyle", and many other comments.

He strongly believes that for products to change and be inclusive, users must be involved at the design stage, which can be accomplished through disability consultants and user groups. Items need to be tested to destruction, and design should incorporate product ownership and pride.

Self management of health, wellbeing and independence, living in a community setting. Host Address: Simon Fielden, Coventry University, Health Design and Technology Institute (HDTi) www.coventry.ac.uk/hdti/
Simon described the drivers for this institute and its core activities. There is a new build in process for the department, ready in Spring 2009. Funding comes from a variety of sources. They help regionally based businesses and provide short term business services.

The products they have worked on are diverse and include a mobility trolley, toothbrush handle, adaptive clothing, and PC games controller.

Other HDTi activities described were AT workforce development and training, applied research, and innovation hubs which promote health service innovation and manage commercialisation of the ideas formulated.

See the website for more details of the many other functions of HDTi.

Parallel session 3: Service Delivery

Secret lives of people with dementia. Celia Price, 'Just Checking' www.justchecking.co.uk
'Just checking' is a system of using activity monitoring in the home to collect data regarding a person's movements. Simple passive infrared sensors (PIR) are installed in main rooms and contact switches on the doors. The information is stored on timelines and can be accessed remotely by relatives or carers. The system can be installed quickly and easily and is relatively inexpensive.

It can be used for a number of issues including helping to optimise the timing of carers, the planning of care packages, and reinstating routines following hospital stays. This system has allowed many people with mild confusion and dementia to stay in their own homes and for relatives and carers to be reassured about their wellbeing.

Measuring quality outcomes of community equipment services. Nick Smith, University of Kent.
This presentation described the information that is being collected about this issue via a service user questionnaire. There is a growing demand for such evidence.

Overall my opinion is that the RAatE conference gives a very good overview of the developments in the field of AT. This year the message of inclusive design was particularly strong and that it is essential to include users' views in product design and manufacture.

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ESS Study Day: Enabling Children with Complex Disabilities

Carolyn Nichols, Independent Physiotherapist

Abstract: *This interesting Study Day was organised by the European Seating Symposium, and was held at Chailey Heritage Clinical Services. The first European Seating Symposium, organised by the Central Remedial Clinic (Dublin), was held in Dublin in May 2007. Since then it has been decided to include the area of Assistive Technology, hence the title European Seating Symposium incorporating Assistive Technology (www.esats.ie). The next Symposium is to be held in Dublin in September 2009.*

Evidence base for postural management

This presentation by Dr. Terry Pountney, head of research at Chailey Heritage Clinical Services, started with a description of postural management including assessment and current recommendations for provision and surveillance. This was followed by a review of current, relevant evidence in the areas of orthopaedics, pain, function and outcomes.

There were interesting comments in the following areas:

- Posture management: There is now even further evidence showing the high rate of hip subluxation/dislocation at GMFCS levels IV & V, and long term outcomes of bony and soft tissue surgery suggest that windswept deformity persists despite hip surgery. Although there is some evidence that early and sustained posture management intervention has some effect on hip integrity, we still await long-term outcomes. These will be interesting to compare with long-term outcomes in Scandinavia where surgery is used earlier and more frequently than in the UK.
- Exercise on static bike or treadmill for children of low levels of ability (GMFCS IV & V): a pilot study at Chailey showed improvement in functional ability after 6 weeks of static bicycle and treadmill training. A larger study is now being undertaken.
- Botulinum toxin injections: A study by Fairhurst (2004), in children with complex disability and chronic, severe pain showed improvements in tolerating seating and standing supports, sleep, and toileting, and the effects lasted an average of 18 weeks. Other studies have shown reduction in pain and improvement in function, but no significant effect on the progression of hip dislocation.
- Bone mineral density: small studies show a small amount of change, but no conclusive evidence regarding best practice.

For a complete list of posture management references, contact Terry's PA: sam.weddell@southdowns.nhs.uk

Establishing the use of outcome measures in the Central Remedial Clinic (CRC) Assistive Technology and Specialised Seating Department

Mary McDonagh, physiotherapist at the CRC in Dublin, described a project carried out from August to October 2008 to trial the use of 5 selected outcome measures. The team spent 2 days in July, the 1st day gathering a list of validated outcome tools currently being used in different places, and the 2nd day choosing which tools they would trial. They initially chose WhOM (Wheelchair Outcome Measure), FEW (Functioning Everyday in a Wheelchair), QUEST (Quebec User Evaluation of Satisfaction with Assistive Technology), IMPT (Matching Person with Technology, modified to become the Irish MPT), and EATS (Efficiency of Assistive Technology and Services). The tools were trialled in 3 clinic locations, and 14 clinicians were involved in the trial. Each tool was used for 1 month, for 1 appointment each day. They recorded positive points, negative points, and comments, and the clinicians met for review and feedback in October. Since then, they have continued to trial WhOM including an adapted version for paediatrics and non-verbal clients, the WST (Wheelchair Skills Test, for active manual wheelchair users / powered mobility), the Goal Attainment Scale and COPM (Canadian Occupational Performance Measure).

Some of their learning points were:

- Some tools were not used properly – better familiarization / training needed.
- There is no validated tool for use with paediatric clients or complex clients, and there is difficulty catering for non-verbal / AAC users and clients with learning disabilities. Therefore, it may be necessary to adapt tools, but this may invalidate them.
- Staff felt they needed a good, activities-based questionnaire and/or examples of functional performance measures, as clients were not able to identify areas in which their performance was restricted because they were so accustomed to those restrictions.

Involving all the clinicians helps to create a sense of ownership in this project, and limiting the trial to one appointment per day ensures that the project is not too overwhelming.

The finding that there is no one measure appropriate for all clients re-emphasizes the need to define what the problem is, what the aim is, and what we want to measure in order to choose tool(s) appropriately.

Mary also briefly described a similar project carried out at Enable Ireland (Dublin) to trial tools to investigate the quality of life and participation of young people with CP in recreation and leisure activities.

Current Research Projects

Three therapists presented research being undertaken as part of a Professional Doctorate at the University of Brighton.

Power relationships in seating assessment

Sally Kyle is a physiotherapist who has worked in the Wheelchair Service, but is now working in private practice. Her study aims to explore the communication and "power" (who has the power in these situations; client-centred practice means handing over power to client/family) relationships during assessment for a wheelchair and seating system. She is looking at the dominant ways of communicating used by the children, their families and the professionals involved during assessment for a wheelchair and seating system, and whether these ways of communicating have an effect on the relationships between those involved. The study consists of analysing video and audio recordings of routine assessments carried out at two sites.

Use of actigraphy on sleep research and children with cerebral palsy

Jessica Underhill, another Prof Doc student, is using actigraphy (using an actiwatch, which looks and is worn like a wristwatch and collects movement-generated data over an extended period) as part of her research into the experience of sleep for children and young people with cerebral palsy and their families. Actigraphy is a fairly good way of defining when someone is asleep or awake, when used in conjunction with a sleep diary. It is used in a normal environment, unlike polysomnography (PSG), which is used only in a clinical setting. As well as actigraphy, she is using a sleep questionnaire, sleep diaries, and child self-directed photography about sleep / bedrooms. She also plans to investigate the effects of sleep systems on sleep quality and pain in children and young people with CP, using participants who already have a sleep system as their own controls (4 nights in their sleep systems, 4 nights out).

Experience of using a sleep system

Ginny Humphreys's research question is "What factors influence the experience of using a sleep system at night

for a child with cerebral palsy?" She also plans to explore the role therapists play in the child's and family's experience of using a sleep system, and whether sleeping in a sleep system affects the quality of sleep. In order to gather comments from non-verbal children, she is using a Talking Mat with appropriate vocabulary identified during pilot studies (see information about Talking Mat on the Leonard Cheshire website- www.lcdisability.org). Important points that she has identified include:

- A pathway is needed, with clear reason(s), for prescribing a sleep system and a process for educating families about postural management.
- There needs to be discussion about the "experience" of sleep, including communication with the child. She found that some children just don't like going to bed – it's boring and they are alone!

As a result of this research, Ginny plans to produce practice guidelines for prescribing night time postural management equipment including what factors need to be in place in order for it to be effective. She also hopes to highlight the need for sleep intervention services locally.

Enabling children using assistive technology

Donna Cowan, Head of Rehabilitation Engineering Services at Chailey, gave an overview about Assistive Technology, and described Chailey's Switch Communication and Mobility Potential Assessment (SCAMP) service. This is an integrated service to assess, trial, and prescribe for a person's potential or actual ability to use switch access for powered mobility, electronic assistive technology, and communication. She described some of the key factors in getting AT right:

- Multidisciplinary assessment needed.
- The positioning and support have to be right first.
- Don't use a "supermarket approach".
- Establish realistic expectations of the child's capabilities and match the needs to the equipment features.
- Trial equipment before purchase, and advise re: reliability of kit and after-sales service.
- Identify next steps, including support for and liaison with the local team.

Case study: how a teenage girl with complex physical disabilities communicates

Hilary Eggleston, speech and language therapist at Chailey, presented a case study describing the process of establishing a means of communication for a young woman with acquired brain injury (ABI). She described many difficulties associated with ABI which impact on communication – poor concentration, memory, and planning skills, fatigue, sensory difficulties, and behavioural factors including anger and disinhibition. As the client had demonstrated good verbal comprehension, good eye movements with clear yes/no response, and was able to spell, the Frenchay E-tran frame with the alphabet on it was used initially. She then moved on to the My Tobii eye gaze system (see www.cogain.org and also discussions on the SCOPE website). Hilary emphasised the importance of getting the postural support right, and of using low as well as high tech methods.

Powered mobility: how children learn – the evidence

Josephine Durkin, Head of Occupational Therapy at Chailey, presented her study into how children learn to use powered mobility. Her aims were to identify their learning stages and strategies and to develop a clinical tool for assessing children for powered mobility. Her methods included gathering observational data regarding children without a disability, focus groups with disabled children, focus groups with clinical peers, and observational data regarding disabled children.

She found that normal babies learning to move generally move from a position and then return back to where they started. Similarly, children in wheelchairs seem to like going in circles so that they are coming back to where they started. She developed a model describing the progression of stages of learning, briefly:

- First, learning the concept of movement from control of the body itself to making sense of using the machine for movement.
- Learning how to operate the machine – exploring it, moving and not moving, circling, crashing, bumping and stopping, developing directional control, moving forward, problem solving.
- Finally, learning how to use the powered wheelchair as part of everyday lifestyle skills – sticking to the plan e.g. of getting from A to B (child may well want to stop / wander), navigating around objects.

Interesting comments:

- Helping a child learn to drive a wheelchair must take into account the progression in levels of attention – from extreme distractibility, to channelled attention, to ability to shift attention; only a very proficient driver can drive a chair and have a conversation at the same time.
- We need to be aware that the mobility equipment may be used to express emotions, e.g. crashing into a

door to express anger – we shouldn't necessarily turn down the speed of the wheelchair but should understand what the child is trying to say.

- Research has shown that using computer programmes to learn wheelchair driving is not enough; the sensory input of actually moving is needed.
- "Safe routes" or use of Smart wheelchairs that avoid bumping into anything may inhibit learning. Technology needs to be applied at the correct learning level.
- A "responsive partner" to facilitate the client to progress is important.

Josephine is currently writing up her research and exploring joint working with Lisbeth Nilsson in Sweden, who is undertaking research in a similar area. She hopes to develop relevant resource material for children and parents.

This was an excellent, full day, and well worth attending.

If you are reading this, you could be eligible to win a prize! BES Rehab has kindly donated two of their best selling products to give away, so you could win one of the following items:

- Myself Pelvic Floor Muscle Trainer worth £85 ***OR***
- A Shear Comfort pure sheepskin Cushion-It worth £69

just by emailing pmgadmin@btinternet.com to say you have read this.

Alternatively, you can choose free membership of PMG for 2010. The first person to tell us they have read this notice will be awarded their chosen prize.

Closing date: 31st August 2009

Reference:

Fairhurst C, 2004, Analgesic Effect of Botulinum. Developmental Medicine and Child Neurology, Vol 46, suppl 98, pp 22

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Book Review: "Severe and Complex Neurological Disability – Management of the Physical Condition"

Author: Pauline M Pope, FCSP MSc BA SRP • Published: 2007 • Publisher: Elsevier Ltd.

Review by Julianna Arva

Target Audience: *Anybody working or looking to work with people with severe physical disabilities. Therapists, social workers, rehabilitation engineers, other allied health professionals, students, as well as caregivers.*

Recommended experience level of reader: *Intermediate*

Overview/Summary: *Pauline Pope's book thoroughly reviews a variety of aspects of the (primarily) physical management of people with severe disabilities. Its emphasis is not on treatment, in fact a key point carried throughout the book is the need to comprehensively manage these conditions. The book promotes a holistic approach in which caregivers and all related professionals work together to comprehensively assess and integrate the variety of management options. Topics include surgeries, pharmacological interventions, positioning methods, hippo- and hydrotherapies, as well as the physiological background requiring these interventions.*

Detailed topics: Various book chapters cover the following areas:

- Thorough overview of biomechanics and the variables contributing to the development of postural alignment, as well as secondary complications
- CNS impairment – description of symptoms, divided by location of lesion
- Assessment procedures, necessity to measure outcome
- Positioning guidance and challenges in sitting, lying and standing, review of some positioning devices, principles of creating a successful custom moulded seating system
- Discussion of complementary procedures, such as typical pharmacological interventions and surgeries. Description and benefits of horse riding and hydrotherapy, by invited authors
- General discussion regarding concepts of 24 hour care, caregiver psychology and the validity of evidence based health care.

Strengths and weaknesses: Pope's book is a collection of theories and practical approaches gathered through many years of experience. The theories presented are rather contemporary, the book is well organised and thoroughly referenced. The concepts of comprehensive management, analytical thinking and realistic expectations are highly welcome. You should not expect to learn everything you need in your daily practice here; on occassion, the book weighs heavily on areas of special interest to the author(s), while some other areas could gain proportionally more focus. Tools, materials, solutions and variables discussed are somewhat limited, primarily due to space constraints of a book covering such a large variety of topics. The book is recommended reading for anyone wishing to broaden their horizon regarding the comprehensive management and physical well being of people with severe physical disabilities.

What you can expect to learn: As the book does not in fact focus on one sub-specialty, allied health professionals can expect to broaden their horizon and learn more about other aspects of their clients' physical management routine. For example, as a seating professional, you may learn more about the pros and cons, as well as precautions for a variety of surgical interventions. If you are a treating therapist you may learn more about positioning methods. Everyone can use the book to review their own specialist field, and pick up on some solutions or theories related to their daily jobs. As the book is heavily referenced throughout, you may follow up with further recommended reading in any of these areas.

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Membership News and Information

MBE for Gordon McQuilton

Specialised Orthotic Services Ltd (SOS), Units 127/128 Fauld Industrial Park,
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Abstract: *In December 2008 long-time PMG member Gordon McQuilton was awarded the MBE for his 'Services in Special Seating for Disabled Children and Adults'. Here, in his own words, Gordon describes the day of his investiture.*

The investiture took place on December 18th 2008 and the MBE was awarded to me by Prince Charles. It was an amazing experience and the whole thing was just so well organised and like clockwork, but at the same time very relaxed.

Prince Charles asked about the work involved in the award and he was very interested to hear about SOS and everything that we have achieved over the years. He seemed genuinely interested and made the day very memorable.

We made a good day of it obviously and I had my wife Claire and all 4 children there with me to soak it all up. A day I will never forget.

Gordon McQuilton with his family at Buckingham Palace after receiving his MBE from Prince Charles

I was particularly pleased with the citation being specifically for services to Special Seating as I doubt if anybody has ever been given the MBE for that before and, as it's what I do, it was really great.

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Why do I never receive ebulletins?

We heard from a few delegates at NTE that they hadn't received reminders to renew their membership of PMG, even though a reminder ebulletin was sent out to 2007 & 2008 members last December and again in January.

This probably means that the email address in a membership account is incorrect or now out-of-date; or that it is a work email address and that the security settings are not allowing through ebulletin-style emails.

To ensure as much as possible that ebulletins are getting through to you, please:

- ✓ **Check that we have your correct email address**
- ✓ **Consider using your home email address instead of your work one**

Both of the above can be done by logging into your membership account via

www.pmguk.co.uk/members/login

The email address will be the one you used when you last renewed your PMG membership.

If you don't remember your password, please contact Olwen: pmgadmin@btinernet.com or request another by clicking on Forgotten Password?

Special Interest Groups

Clare Wright, Chair, PMG Special Interest Groups

Abstract: *Many of you will have had the opportunity to attend PMG's fabulous National Training Event at Warwick University in April. During the conference we held our first SIG general meeting attended by some 60 enthusiasts very early one morning. Although it is usual to provide a report for the autumn journal, there were a number of issues discussed about SIGs which are just too important to wait until then! So please take time to read this information – there are exciting developments affecting the way you can use SIGs and the forum which we think you will like.*

SIG registration and forum participation

You can now register for multiple SIGs, choosing all/any that you are interested in. *However, you need to update your choices yourself.* Follow the series of instructions below to help you through the process.

1 You can register or change your choices easily by logging on to the PMG website, and clicking on the purple SIGs "button" at the top of the PMG homepage.

Posture and Mobility Group (PMG) was created to advance and disseminate knowledge about the posture and mobility needs of people with disabilities.

PMG aims

- to provide an umbrella organisation for communication within the fields of posture and mobility
- to provide an interdisciplinary forum for continued education, research and debate
- to promote high standards of service delivery
- to encourage collaborative working between professionals in existing and evolving services

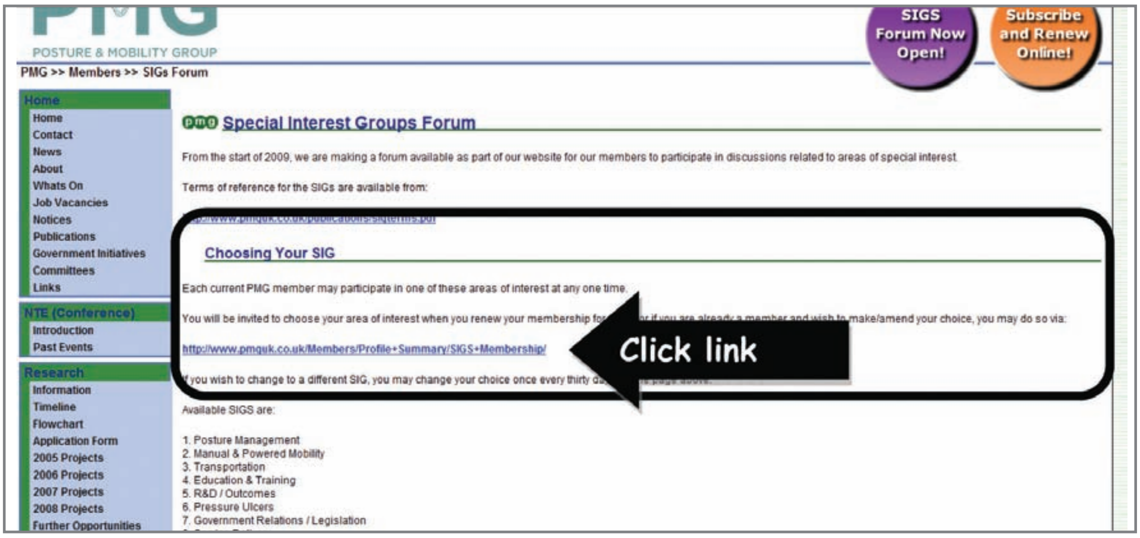
4th International Interdisciplinary Conference on Posture and Wheeled Mobility - "Best Practice: Hit or Myth?"

SECC, Glasgow, Scotland 7-9 June 2010

Call for Papers - www.mobility2010.org

News

2 Then click on the link in the "Choosing your SIG" section of the SIGs page. You will be prompted to choose, in order of preference, as many SIGs as you wish. It is important to note that you won't receive an email confirming your login details (your forum login uses the same email and password as your PMG login) or your SIG choices. However if you wish to confirm your choices, you can click on the link again and it will display the choices you have made.



Special Interest Groups Forum

From the start of 2009, we are making a forum available as part of our website for our members to participate in discussions related to areas of special interest.

Terms of reference for the SIGs are available from:

Choosing Your SIG

Each current PMG member may participate in one of these areas of interest at any one time.

You will be invited to choose your area of interest when you renew your membership fo make/amend your choice, you may do so via:

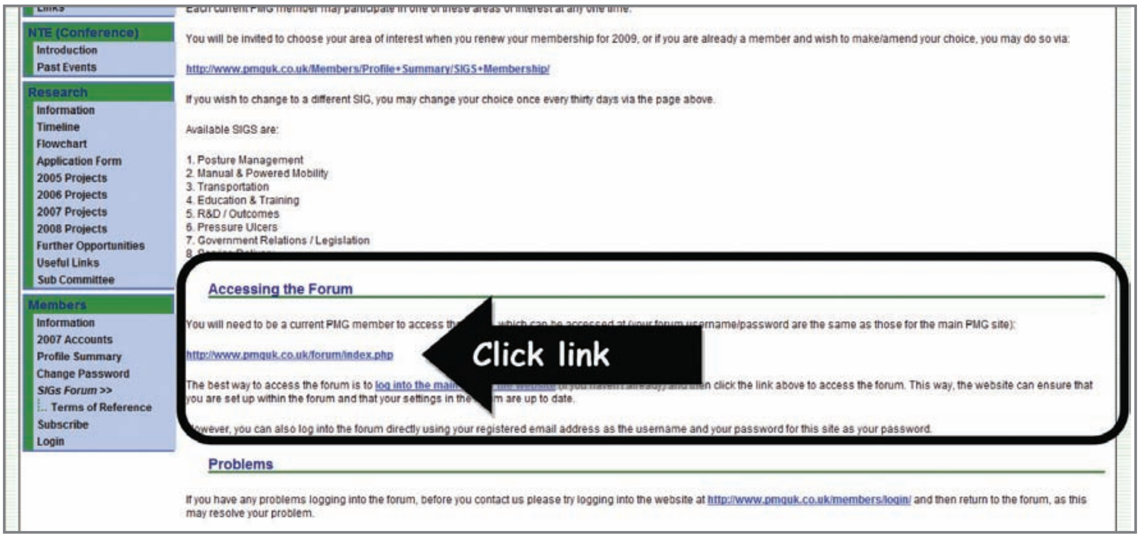
http://www.pmguk.co.uk/Members/Profile+Summary/SIGS+Membership/

you wish to change to a different SIG, you may change your choice once every thirty d

Available SIGS are:

1. Posture Management
2. Manual & Powered Mobility
3. Transportation
4. Education & Training
5. R&D / Outcomes
6. Pressure Ulcers
7. Government Relations / Legislation

3 To get to the forum you just scroll to the bottom of the SIGs page and click on the link in the "Accessing the forum" section.



You will be invited to choose your area of interest when you renew your membership for 2009, or if you are already a member and wish to make/amend your choice, you may do so via:

http://www.pmguk.co.uk/Members/Profile+Summary/SIGS+Membership/

If you wish to change to a different SIG, you may change your choice once every thirty days via the page above.

Available SIGS are:

1. Posture Management
2. Manual & Powered Mobility
3. Transportation
4. Education & Training
5. R&D / Outcomes
6. Pressure Ulcers
7. Government Relations / Legislation

Accessing the Forum

You will need to be a current PMG member to access th… which can be accessed at (your forum username/password are the same as those for the main PMG site):

http://www.pmguk.co.uk/forum/index.php

The best way to access the forum is to log into the mai… …n click the link above to access the forum. This way, the website can ensure that you are set up within the forum and that your settings in the …m are up to date.

…wever, you can also log into the forum directly using your registered email address as the username and your password for this site as your password.

Problems

If you have any problems logging into the forum, before you contact us please try logging into the website at http://www.pmguk.co.uk/members/login/ and then return to the forum, as this may resolve your problem.

4 This is what the forum homepage looks like. Another exciting change is that you are now able to view and respond to posts in any SIG on the forum *whether you are a member of that SIG or not*. So with multiple membership and unlimited access, it's much easier to get involved!

It is currently 07 May 2009 12:43
[Moderator Control Panel]

Last visit was: 01 Jan 1970 00:00

PUBLIC AREA	TOPICS	POSTS	LAST POST
General Discussion Description of your first forum.	1	1	by helen.rourke@tiscali.co.uk 22 Apr 2009 18:14

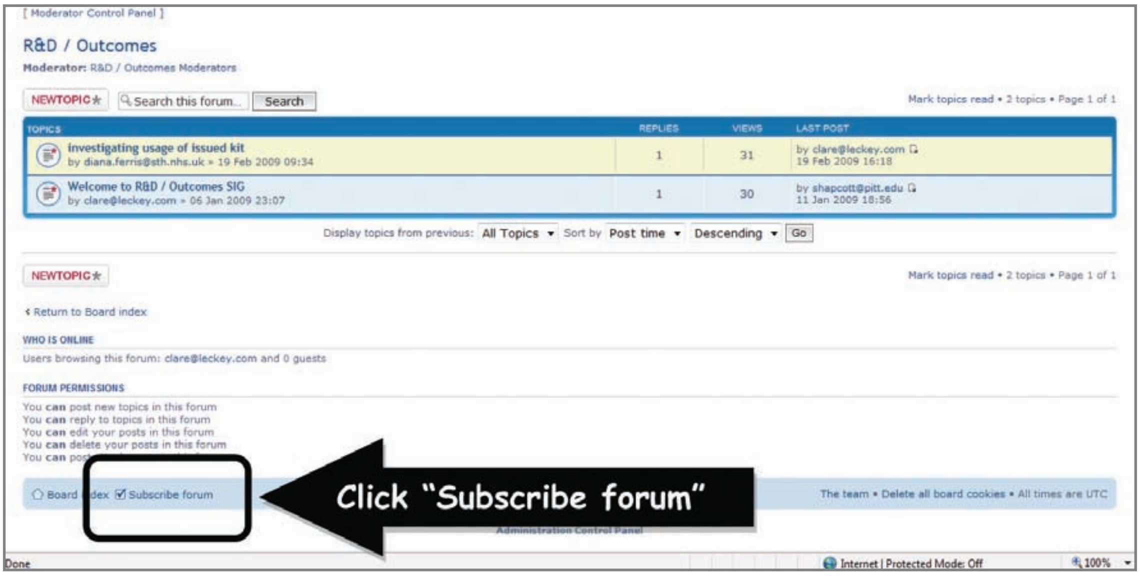
SIGS FORUM	TOPICS	POSTS	LAST POST
Posture Management **Moderator:** Posture Management Moderators	3	4	by dave.long@noc.nhs.uk 07 May 2009 11:42
Manual & Powered Mobility **Moderator:** Manual & Powered Mobility Moderators	2	6	by marianne.harvey@acute.sney.nhs.uk 02 May 2009 15:17
Transportation **Moderator:** Transportation Moderators	2	3	by alison.johnston@bromleypct.nhs.uk 09 Apr 2009 14:11
Education & Training **Moderator:** Education and Training Moderators	0	0	No posts
Pressure Ulcers **Moderator:** Pressure Ulcers Moderators	2	4	by kchaney@invacare.com 15 Jan 2009 09:54
R&D / Outcomes **Moderator:** R&D / Outcomes Moderators	2	4	by clare@leckey.com 19 Feb 2009 16:18
Government Relations / Legislation **Moderator:** Government Relations / Legislation Moderators	3	5	by helen.hislop@haringey.nhs.uk 06 May 2009 15:38
Service Delivery **Moderator:** Service Delivery Moderators	1	4	by Lisa.douglas@southdowns.nhs.uk 26 Feb 2009 12:50

Continues >>>

Automated emails

It was clear during our meeting that some people wanted to be prompted by automated emails when a new topic was posted to the SIG(s) of their choice. *In order to avoid unnecessary emails, you can enable this feature yourself if you wish to be notified of new topics.* Follow the instructions below:

1 First, enter a SIG by clicking on its blue title. The example below is from the R&D/Outcomes SIG to help you enable the notification feature. Simply click on "Subscribe forum" at the bottom of the screen to receive email alerts about new posts. The tick in the box will change to an "X" and the text to "Unsubscribe forum" when this is done.



[Moderator Control Panel]

R&D / Outcomes

Moderator: R&D / Outcomes Moderators

TOPICS	REPLIES	VIEWS	LAST POST
investigating usage of issued kit by diana.ferris@sth.nhs.uk » 19 Feb 2009 09:34	1	31	by clare@leckey.com 19 Feb 2009 16:18
Welcome to R&D / Outcomes SIG by clare@leckey.com » 06 Jan 2009 23:07	1	30	by shapcott@pitt.edu 11 Jan 2009 18:56

Display topics from previous: All Topics Sort by Post time Descending Go

WHO IS ONLINE

Users browsing this forum: clare@leckey.com and 0 guests

FORUM PERMISSIONS

You **can** post new topics in this forum
You **can** reply to topics in this forum
You **can** edit your posts in this forum
You **can** delete your posts in this forum
You **can** pos

Click "Subscribe forum"

2 Just click again to stop receiving emails.

FORUM PERMISSIONS

You **can** post new topics in this forum
You **can** reply to topics in this forum
You **can** edit your posts in this forum
You **can** delete your posts in this forum
You **can** post

Click "Unsubscribe forum"

You can also be notified of new replies to a topic in exactly the same way. Just enter a topic and click on "Subscribe topic" at the bottom of the page. Again, remove this feature by clicking "Unsubscribe topic".

The importance of valid email addresses

Of course, any alert service will only work if you have a valid email address. This should be the one you use to register your membership with PMG. Please remember to keep it up to date so that we can be sure you are receiving all relevant information.

Posture Management (PM) SIG

As posture is central to PMG there was discussion at our meeting about whether a Posture Management SIG (a) is needed and/or (b) overlaps with the Posture 24 forum. (www.posture24.com). Dave Long and Jo Jex (PM Chairs) have posted a topic about it on the forum and are looking for contributions to the debate. Your input would be greatly appreciated.

We hope that these changes will allow the PMG SIGs to continue to develop in a more practical and user-friendly way. It should be a real resource for us, but of course, as it's member-dependent, we need our members to use it!!

Contact details for Clare Wright: Email: clare@leckey.com

The NTE 2009 Webcast is here!

Paul Hewett

It became apparent early this year that the PMG webcasting project was floundering. In despair one day, and while discussing Active Design's stand booking for NTE with Paul Hewett, I found myself telling him all about the webcasting problems. Within days, he came back with an unbelievable offer of help and with a solution which has turned out to be a fantastic success. It has taken Paul hours and hours of dedication, determination and sheer effort to get to the end, so please take the time to look at the webcasts, if only out of respect for his enormous contribution.

You will also find it an enjoyable and rewarding experience.

Thank you Paul on behalf of everyone! Olwen

Finally, and after a lot of hard work by a number of members, the videos taken during the NTE this year are now available on the internet – the Webcast.

A webcast is simply a video or sound file that is distributed over the internet, either live or on demand. There are many hours of video, as well as copies of presentations and other files, now available for download. This will enable you to watch videos of papers you missed, or to go back over the ones you did attend.

We took a different strategy this year, primarily to reduce cost, but also to provide more flexibility in what would be displayed online, and how it would be displayed. This has saved PMG a significant amount of money, and has still ensured that the quality of the video and sound has been maximised. Videos that were recorded by an external company last year are also available on the website. So, most of this year's and last year's conference will be available online, including some of this year's pre-conference instructional courses. This amounts to more than 30 hours of video that is available to you – to view where, how and when you want!

To access this great resource, simply login to the members' area of the PMG website. Here you will find a link to the webcasting, and logon details for the service.

Over the coming months, the Website Development Sub-committee will be working hard to fully integrate this into the PMG website as part of the strategy to improve the design, ease-of-use and overall usefulness of the PMG web-based services. Combined with the SIG forum, these initiatives go a long way to encourage learning, and develop collaboration between members – important goals for the organisation. I do hope the organisation and its members will support James Hollington and his vision to significantly improve the service to the members. But do let us know your thoughts and ideas.

Of course the webcasting would not have been possible without the help of PMG members who volunteered, and the support from the venue staff, in particular the sound technicians. I would really like to thank all of those who volunteered or helped in some way, in particular Dave Gregory, Dean Williams, John Tiernan, Martin Seabrook, Fiona Walker, Sirobhin Sundar, Simon Hukku and Joe Searchfield. It would not have been possible to complete this project without their support.

Enjoy the conference – again – again – again – and again (and we filmed THE kiss)!

Contact details for Paul Hewett:
Email: paul@activedesign.co.uk