

POSTURE AND MOBILITY

Volume 30:1 Summer 2013

The Journal of the Posture and Mobility Group

Static Seating

Seating and Pressure Ulcer Prevention

Seating Provision for Nursing Home Residents

The Fife Staged Seating Programme

Trials of TravelChair

Trial of Forward Lean Seat with Young Adults



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POSTURE AND MOBILITY

The Journal of the Posture and Mobility Group

PMG

POSTURE & MOBILITY GROUP

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We welcome submissions from PMG members and
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The views expressed are those of individuals and
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Front Cover:

The 'bOne' chair is designed around the
concept of a human bone's microstructure,
the shell being similarly porous. Into the
pores go the "cells" – cylindrical
upholstered pieces whose placement in the
chair is entirely individual, thus creating the
best fit for the user.

Design: Björn Ischi / Julietta Di Filippo Roy

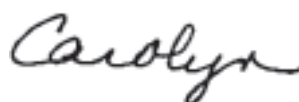
EDITORIAL

Once we had decided to focus on static seating for this issue, we had many discussions and queries asking, "What is static seating?"

For most of us, the term conjures up images of either riser recliner chairs, or static school seating, or big, "comfy", supportive seating. The fact that static seating is generally not funded by wheelchair services results in an artificial division between seating for mobility and static seating (as well as other postural management equipment). Rather than having separate services for provision of equipment for mobility, seating, posture management, and communication, doesn't it make sense for these closely related services to be considered as a whole?

With the changes to service provision being proposed, this must be an opportune time to

influence commissioners and service managers to remove this artificial division, and to encourage amalgamation of various relevant services into a posture management, mobility, and augmentative/alternative communication service, with areas of specific expertise related to clients' levels of ability and to their primary needs, such as comfort, pressure management, optimising activity (including communication), inhibiting/supporting postural deformity, and mobility.



Carolyn Nichols
Editor



NEWS

AGM ANNOUNCEMENT

The 2013 Annual General Meeting of the Posture & Mobility Group will be held from 12.15pm to 1pm on 12th July 2013 at the Exhibition and Conference Centre, University of the West of England, Frenchay Campus, Coldharbour Lane, Bristol BS34 8QZ. Only current PMG members are eligible to attend the AGM. Not sure if you have renewed your PMG membership for 2013? You can check via www.pmguk.co.uk/log-in.html

PASS IT ON

Please pass on the flyers included with this mailing, or post them on a prominent notice board. One flyer is for the NTE in July – still time for people to book; the other is for the Mary Massery mini-tour in

December (see back pages). Thank you!

CALL FOR VOLUNTEERS!

MUCHÍSIMAS GRACIAS to Paul Hewett (pictured) who has been managing the PMG conference webcasts since 2008. The PMG library of conference proceedings is an important resource, providing hours of CPD opportunities for all PMG members. Sadly for us, Paul is hanging up his camera after this year's NTE, and we are therefore seeking a volunteer (or volunteers) to take over from him. The role involves organising the video cameras at the event, editing the recorded content afterwards,



and uploading to the website. If you are interested in becoming PMG's new webcaster, please contact in the first instance olwen.ellis@pmguk.co.uk

FLAMMABILITY STANDARD UPDATED

ISO7176-16 (Wheelchairs – Part 16: Resistance to ignition of postural support devices. Requirements and test methods) has been revised and was published in late 2012. The major changes are that the old standard was based on furnishing standards, while the new one is redesigned around the needs of those in a wheelchair. The old standard was aimed at upholstered parts of a wheelchair, while the new one covers all secondary supports, including pads, belts, harnesses etc.

LETTER FROM THE CHAIR

Hello everyone and welcome to our first journal of 2013! Time certainly doesn't slow down and, as I write this, we are only eight weeks away from the slightly-later-than-usual NTE taking place in our new venue at the University of the West of England. The move to Bristol represents an expansion in our capacity to provide quality learning and networking opportunities for our delegates, presenters and exhibitors. Your support, as well as that of our speakers and business sponsorship partners has been overwhelming – and with an extended social programme this year, it is shaping up to be one to remember!

As always, this event doesn't just happen by itself, but is the product of some incredibly hard work by the NTE and PaM sub-committees, not to mention Olwen, and Ffion Lane who joins us this year for NTE event management.

The Executive Committee will be seeing some changes at the AGM in July. With limited space, I'd like to give a huge collective thank-you to all who are coming, going, staying or changing roles! PMG offers challenging, rewarding and fun opportunities. If you would like to get involved, don't hold back, we'd be delighted to give you a job.

Hope to see you at NTE!



Clare Wright
PMG Chair



FIONA MOVING ON...

When you receive an ebulletin from PMG, does it ever cross your mind how it comes into being? Well, for most of the past year, along with her website updating duties, the person responsible for mailing you the PMG ebulletins was Fiona Eldridge from the Publications & Marketing (PaM) sub-committee. Fiona (pictured) was looking for a



change of role this year, and has now joined the Research sub-committee. Fortunately for us all, she has promised to be on call if ever we need her help with website tasks. Thank you Fiona – PaM will miss you!

SEATING SYMPOSIA COMING UP

European Seating Symposium, Dublin, 5-8 November 2013.

www.seating.ie

30th International Seating Symposium, Vancouver, 4-7 March 2014. goo.gl/qL1CH

BPG ON SUPPORTED LYING

Unfortunately, due to unforeseen circumstances, the Best Practice Guide on Supported Lying, which was near completion, has had to be withdrawn. It is the intention to start this project again, with the initial step being a thorough literature review and grading project. If you have experience in supported lying and literature reviews, and are interested in taking part, please contact james.hollington@nhslothia.n.scot.nhs.uk

BARCODING IN THE NHS

The NHS is stepping up its requirements for using GS1 barcodes in many applications: regulations have been in place for over a year, for example in relation to patient identification. New requirements are coming in across the NHS, Europe, and worldwide that products be identified with bar codes which cover the minimum of a GTIN (a unique identifier); date of manufacture and/or *Use By* date; batch or serial number. This is to cover, for example, MHRA Track & Trace requirements and the revisions in the Medical Devices Directive. A guide for manufacturers has been produced by the BHTA. Further information can be obtained from barend@bescorporate.net

NEWS

SEATING AND PRESSURE ULCER PREVENTION IN AN ACUTE HOSPITAL SETTING — A COLLABORATIVE APPROACH IN ACTION

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BACKGROUND

In October 2011 the author, having been appointed as clinical lead OT at the Queen Elizabeth Hospital Birmingham, discussed the possibility of collaborative working with the lead nurse for quality and workforce and the lead tissue viability nurse around seating, positioning, and pressure ulcer prevention. At that time, in line with the NHS Midlands and East Ambition 1: *Elimination of avoidable Grade 2, 3 and 4 pressure ulcers by December 2012*, the hospital established a trust-wide pressure ulcer

action group. The group developed terms of reference in which the primary aim was to develop a call to action through shared values and commitment to a multidisciplinary and preventative approach to pressure ulcer prevention. Concerns had been raised around the issue of appropriate static seating for use on the wards, both by clinical staff and with the emerging of themes from the serious untoward incident reviews

across the hospital. The main seating options at that time were either wheelchair seating or very basic upright static seats, with little choice in between. Recliner style chairs were in limited supply but there was no standardised approach to equipment purchase or replacement for this

type of seating. The other concerns centred around ward staff knowledge of basic seating assessment principles and choice of products, including seating and the use of pressure relief cushions.

WORK IN ACTION

In conjunction with therapy staff, nursing, infection control, and procurement, criteria were drawn up for enhanced static seating which would then be used for potential suppliers to bid against. Criteria for the chairs included aspects such as aesthetic properties, tilt-in-space and recline functions, ability to adjust base, pressure relief, meeting infection control guidelines, and ease of transport. Following this, a variety of companies came forward and were invited to attend a showcase event where staff could see the potential products on offer, ask questions, and provide feedback in relation to the clinical areas for which the chairs would be required.

From this competitive tendering exercise, a product was chosen and initially five chairs were purchased for use on the Clinical Decision Unit. The purpose of the trial was to provide the opportunity for patients to trial the seating and for staff to collate feedback. The feedback from the trial phase was extremely positive and, as a result, the equipment standardisation group recommended this option of seating for use across the organisation. This agreement was cascaded through procurement and a standardised approach to equipment purchasing, which is part of the portfolio of the lead nurse for quality and workforce.

A further 29 chairs were funded for use across the hospital through a variety of funding sources, with the Queen Elizabeth Hospital Birmingham charity supporting the purchase of

ABSTRACT

The provision of appropriate seating for use by patients during their in-patient stay within acute hospitals remains a constant challenge. The situation has been compounded in recent years by the pressure to turn around patients more quickly to release bed capacity. The Queen Elizabeth Hospital Birmingham is a large acute hospital with several regional and national specialties attached, including major trauma. Consequently, the patients admitted to the wards are increasingly dependent, and often present with very complex needs. This article describes a multidisciplinary approach to the provision of more appropriate ward based seating, as part of a much larger pressure ulcer prevention campaign.

15 of the chairs.

Some of the positive outcomes of the enhanced seating options across wards have been that patients feel that they have a choice regarding what they sit in, and that staff feel there are seating options to better suit patient need. The chairs have been of particular benefit for use in post-operative recovery, for larger patients, and for a select few who refuse to go to bed.

The other aspects of the seating work streams focused around the need to improve staff awareness of the principles of effective seating, choice of products, and how these link to skin integrity and pressure ulcer prevention. Some of these messages were already being covered by the in-house tissue viability training packages and were included within the qualified nursing competency framework; however it was identified that this needed to be developed further in relation to increased multi-professional involvement. As a result the author designed a training package, initially for use within therapy services, to increase skill and awareness around posture management, seating, and pressure ulcer prevention. This training was rolled out over a two month period across therapy services, with places also offered to nursing and medical staff. Approximately 96 people attended the training sessions, predominantly occupational therapists and physiotherapists, but also a few registrars and a selection of nursing staff from the elderly medical wards.

Of the 96 who attended the training, 94% felt the course was relevant, 93% felt they would apply the messages and content to clinical practice, and 78% rated the training overall as 'excellent' to 'very good'. Other needs identified, by both nursing and therapy staff, were for additional training around seating and tissue viability risk, and more time spent on cushions. It was also identified that training may need to be offered at different levels, from basic to more complex. Overall, each professional group (including registrars) felt that the key messages around seating and risk should be built into multi-professional induction and training in the future.

SUMMARY

The reduction of the incidence and severity of pressure ulcers remains a key priority not only for the Department of Health and commissioners of services, but also for all involved in the care and rehabilitation of patients. However, consideration is not always given



Chair used for the project

to important aspects such as the length of time spent sitting, the type of seating used and related cushioning. It is hoped that future work will continue to focus on aspects such as multi-professional awareness, the development of a clinical seating guide for use on the wards, and further analysis regarding pressure cushion selection and use.

ACKNOWLEDGEMENTS

The author would like to thank Carolyn Pitt (Lead Nurse for Quality and Workforce) and Jo Swann (Lead Tissue Viability Nurse), Queen Elizabeth Hospital Birmingham, for their time and contribution. The author would also like to thank Kirton for supporting the project; the Kirton Encora was the chair chosen.

SEATING PROVISION FOR NURSING HOME RESIDENTS

Orlagh Daly

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Jackie Casey, Suzanne Martin and Martina Tierney

BACKGROUND

The outcomes of poor postural management are well documented and include: increased dependency (Turner 2001), tissue trauma, contractures and spasticity, poor systemic function (for example respiratory, cardiovascular, and digestive functions), immobility, increased pain and discomfort, and muscular fatigue (Engstrom 2002). As postural control is a prerequisite for most functional tasks, the inability to control posture has a significant impact on function (Hong 2002). A seating system that does not match the needs of the user is less likely to provide adequate postural support and may therefore limit function rather than promote it (Di Marco 2003).

Current expenditure by the NHS in the UK on pressure ulcers is estimated to be £2.1 billion annually (Bennett et al 2004), which equates to approximately £10,500 per sore. Anecdotal evidence suggests that correct seating provision is instrumental in reducing this cost by preventing ulcers through investment in chairs before ulcers develop (Bennett et al 2004).

RESEARCH PROJECT

We have recently completed a research project exploring the effectiveness of specialist seating with persons with physical disabilities in nursing homes. Aims were to identify the benefits of correct seating and positioning on the physical health and quality of life of this client group, and also the benefits for care home

staff. It is hoped that the results of this study will help to support the need for provision of appropriate seating equipment in nursing homes, and also show that carrying out a good seating assessment leads to a reduction in postural difficulties and incidence of pressure ulcers, therefore improving residents' overall quality of life.

We plan to publish the findings in a future edition of the PMG journal.

The Clinician's Seating Handbook by Martina Tierney OT is a reference guide for seating provision and is available free of charge to clinicians at www.seatingmatters.com

REFERENCES

- Bennett G, Dealey C, Posnett J. (2004) The cost of pressure ulcers in the UK. *Age and Ageing*. 33(3): 230-235.
- Di Marco A, Russell M, Masters M. (2003) Standards for wheelchair prescription. *Australian Occupational Therapy Journal*. 50:30–39.
- Engstrom B. (2002) *Ergonomic Seating – A True Challenge*. Posturalis Books, Stockholm, Sweden.
- Hong CS. (2002) Positioning for children with learning disabilities. *British Journal of Therapy & Rehabilitation*. 9:443–446.
- Turner C. (2001) Posture and seating for wheelchair users: an introduction. *British Journal of Therapy & Rehabilitation*. 8:24–28.

DEVELOPMENT OF THE FIFE STAGED SEATING PROGRAMME

Quintin Watt

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Joyce McDonald

Senior Practitioner Occupational Therapist

BACKGROUND

The Postural Management Service in Fife was established to work in partnership with mainstream services in order to provide a comprehensive and detailed assessment of postural management needs for service users with complex disabilities. It planned to do this by providing occupational therapists with ongoing training to deliver responsive and measurable services to support service users and their carers, as well as empower and enable the service users and their carers to self manage. Postural management, when used as a clinical tool to control or influence lying and sitting positions, is considered to be both therapeutic and rehabilitative and can include everything from specialist seating and supported lying equipment to moving and handling techniques. The service has continued to develop and evolve, with training for staff designed around an agreed postural management assessment process and pathway. Mainstream staff are fully involved in this pathway, supported by Joyce McDonald, Louise Howes (occupational therapy assistant), and the rest of the Postural Management Team.

The Fife Staged Seating approach evolved when the Fife Postural Management Team re-assessed its approach to supplying seating to people with varying levels of disability. The seating was developed by working closely with Joyce and Louise to meet their criteria, and to ensure the equipment was fit for purpose, meeting the individual needs of the service users.

FIFE STAGED SEATING

The three stages of seating are aimed at people with different levels of disabilities and complexities, and came about as a direct result of therapists tending to either overprescribe or inappropriately prescribe from the various

seating options available. This was due reportedly to limited understanding and training, and limitations in the seating options available to them; we therefore worked together to develop training and prescription forms for OTs and other healthcare staff in Fife, and to combat the issues.

Stage One seating (Figs. 1 & 2 overleaf) provides minimal intervention for people with lower level postural management needs. Stage Two seating (Figs. 3 & 4) includes a rise and tilt option with postural support for those able to weight-bear, and a manual tilt-in-space option with postural support for those who require hoisting. Stage Three seating (Fig. 5) is for those with more complex needs who require major intervention.

The **Stage One** chair comes in three seat widths with leg height adjusters and a choice of two and four-point pelvic harnesses to accommodate a wide range of users. Available with either a ramped foam cushion or a ramped gel cushion for added comfort, it also has lateral supports, hollow fibre neck and head support, a hygiene gap, and infilled arms.

The two options of **Stage Two** seating include the riser tilt chair "A" (ambulant) and a manual tilt "H" (hoisted). The riser is a single motor tilt-in-space chair, with multiple back options as well as adjustable seat height, width and depth. Individuals who are prescribed this will

ABSTRACT

A chance meeting between Quintin Watt of Kirton Healthcare and Joyce McDonald of the Fife Council turned into a programme to establish appropriate seating for people with varying degrees of disabilities. With the help of Kirton Healthcare, the Postural Management Team founded the Staged Seating Programme in order to provide its service users with seating in line with their individual requirements, with three stages available.



Fig 1. Stage 1 Chair with head and neck support



Fig 2. Stage 1 Chair with lateral supports and lap strap



Fig 3. Stage 2 Chair H for those requiring hoisting

potentially be able to weight bear for transfers or mobilise once standing, present with some changes in body shape, and will have some ability to move and alter their sitting position. Therefore, the postural support offered in this seating is primarily to promote a midline, upright, and neutral sitting posture. The Stage 2 H manual tilt seating, on the other hand, is geared towards those users who are non-ambulant, who again present with changes in body shape but have limited ability to change, alter, or maintain an upright, midline neutral sitting position and therefore require more robust postural support to influence their body shape and sitting posture. Along with the incorporation of a tilt-in-space pivoting system, other features include the ability to remove the arms of the chair in order to facilitate side transfers and seat width adjustment. Seat depth and seat height adjustment with a flip-up foot support are standard features on the chair, as are lateral support and pelvic harness options. It can also house different pressure relieving seat modules depending on users' pressure management requirements, and all of these seat modules can be offered with a ramped seat base. For added comfort, a multi-positional integral headrest has been incorporated into the chair, enabling more considerate head and shoulder positioning.

A chair which Joyce and a colleague had previously helped to design was introduced for **Stage Three** of the process. It has proven to be a positive development and seating intervention for service users, with an excellent success rate. Joyce explained: "The chair is extremely robust and can be easily set up, adjusted, and tailored according to the individual needs of the user, with the facility to be adjusted again to its original specification, and then tailored to the

needs of other users. That particular feature makes it ideal for service users with varying levels of complex disabilities needing varying degrees of postural support, and it avoids the need for customised, one-off seating which only meets the needs of one service user."

The Stage Three chair is designed to accommodate the changing needs of the individual, providing postural support and comfort for those who either find it very difficult, or are unable, to maintain an upright sitting posture and who require extra help and support from the seating equipment to achieve their optimum sitting position. It can incorporate a range of seating accessories to provide postural support for those presenting with major changes in body shape, and can be adjusted to provide correct seat height, depth, width, arm height, and back height as well as headrest angle adjustment, back angle recline, electrically powered tilt-in-space, leg rest elevation, and lateral support. It is available in three sizes to accommodate the changing needs of both adults and children.

Over the years, positive changes have been made to the Stage Three chair based on Joyce's and Louise's suggestions to improve its capabilities to meet the needs of service users with higher levels of postural difficulties. Quintin said: "We have been more and more involved with Joyce and the team at Fife since the launch of this chair and we now attend seating clinics where up to four service users come along at pre-booked times for assessment. A full seating assessment is carried out on each user to see if and how the chair will benefit them, so they can make an informed decision. In addition, we have loaned chairs to the team as trial chairs to enable them to carry out trial sessions of the seating with service users and



Fig 4. Stage 2 Chair tilted



Fig 5. Stage 3 Chair

their carers in the home environment, to ensure the seating prescription meets their needs.”

All cases that may require this type of seating are referred for assessment to the Fife Postural Management Team through the agreed postural management pathway. This joint assessment includes the Postural Management Team, mainstream staff where relevant, and equipment providers.

ACKNOWLEDGEMENTS AND COMMENTS

Joyce said: “The OT service plans ultimately to have a range of staged seating as core stock to provide staff with a comprehensive, easily accessible range of approved equipment as standard provision, reducing the need for one-off pieces and the administration associated with this, as well as reducing the risk of a build up of seating stock that may not necessarily be

appropriate and fit for purpose. Our work with Kirton has been with this outcome in mind. The Council has to engage in a tendering process that will ultimately determine what this stock will be; however, the opportunity to contribute to the design of the Kirton seating range of equipment has been welcomed and has allowed therapists, as the prescribers, and service users and carers who ultimately use the equipment, a voice in the manufacturing industry. Working with Kirton Healthcare on this worthwhile initiative has been extremely positive, rewarding, productive and educational for

everyone involved. Staff at all levels have been exceptionally responsive, receptive, motivated and have fully engaged in the programme; the outcome has been the development of a range of seating equipment which is flexible, and can evolve to meet the changing needs of service users with a range of seating needs.”

Quintin said: “Joyce, Louise and Nikki, and the rest of the Postural Management Team at Fife have been an absolute pleasure to work with. The team has been extremely receptive, and community OTs and other healthcare staff have engaged wholly with the training provided for all stages of seating; working together on this has given both sides a new and different outlook on equipment as a therapeutic tool in postural management. It has been a long but rewarding journey with lots of meetings, testing, and training, but we have started to see the benefits, which makes it all worthwhile.”



Edinburgh’s Bioengineering Centre is celebrating its 50th year anniversary. It opened in 1963 as the Powered Prosthetics Unit, later becoming the Orthopaedic Bio-Engineering Unit. In 2006 the service relocated to the purpose-built Southeast Mobility & Rehabilitation Technology (SMART) Centre. Services now include aids for daily living, electronic assistive technology, gait analysis, prosthetics and orthotics, wheelchair adaptations and seating.

TRIALS OF TRAVELCHAIR

Anna-Stina Ponsford
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INTRODUCTION

TravelChair (Fig. 1) is a chair for children with postural needs designed to be used in seats on aeroplanes. It was developed by MERU, a charity which makes bespoke equipment for children with complex needs. The approach in 2010 by several UK airlines to MERU resulted in MERU developing the design. The first period of the development phase included data collection about the characteristics of the user group in order to define a design specification. That study was published in a previous PMG Journal. At the end of that phase 12 prototype chairs were manufactured. One was given to the manufacturer and one to a subcontractor; two were tested for the integrity of the design for

CE marking and British Standards; five were used for the trials by families with disabled children to find out how well the chair met the children's postural support needs; and three were used for demonstration purposes.

This study focuses on the last stage of the design process, and documents experiences of the

usefulness of the chair by children with postural needs in real "flying" situations (Fig. 2).

10 families who have children with special needs flew from a wide range of UK airports to many international destinations inside and outside Europe, some as far away as Orlando, Tampa and Barbados. Children with the need for postural support helped MERU with the final stage of TravelChair's development process by trialling the chair on 20 flights.



Fig 1. TravelChair

AIM

The aim of this study was to find out how well the TravelChair functioned for children with complex needs when flying.

METHOD

The criteria for selection were that the sitting height of the children had to be under 52 cm and the weight less than 35 kg. Families were selected from a list of families who had participated in the first phase of the TravelChair project, The PACE Centre Aylesbury, Luton PIP (Parents in Partnership), ex clients, and by word of mouth.

To ascertain how well the TravelChair functioned, a questionnaire was designed. The questionnaire was filled in by parents who were planning to fly during the summer of 2012.

The design of the questionnaire used was based on lessons learnt from data in archived forms at Monarch Airways, of interviews about parental and staff experience. The list of questions used related to the nature of disability, special needs during the

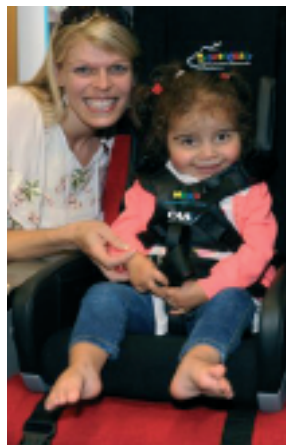


Fig 2. Happy and safe

ABSTRACT

TravelChair has been designed for children who need postural support when flying. The purpose of this study was to evaluate how TravelChair functions with special needs children and their families when used during real life flights. Each child had individual postural support needs. Parents were interviewed immediately after the flights. The results from the study indicated that the TravelChair did not give perfect support. However, 9 of 10 parents stated that they could not have flown without the chair.

flight, weight, height, behavioural problems, special needs, destination, number in party, and duration of flight. It was first come first served – no child was excluded from the trials as a result of their disability.

The airlines who participated in the pilot study were: EasyJet, Monarch, Sunwing, Thomas Cook, Thompson and Virgin.

SAMPLE GROUP

10 children with special needs, six girls and four boys, with an average age of 6.4 years took part. The average weight was 16.6 kg; average sitting height (data from eight children) was 37.5 cm. Seven children had cerebral palsy, one child had global developmental delay and severe sensory issues, and one child had Lowe syndrome with low muscle tone.

The 10 questionnaires were collected in a file, the borrowing of TravelChair was coordinated with flights, and a date for a post flight interview was arranged on return.

A semi-structured interview checklist was designed. 10 parents were interviewed by telephone and the answers were documented by hand on the interview check list. Four interviews were recorded by phone and transcribed.

QUESTIONS ASKED

16 questions were asked:

1. Did the “host belt”, the standard buckle belt provided in standard aircraft seats, provide adequate pelvic support?
2. Was the trunk support adequate?
3. Was the shoulder support adequate?
4. Was it possible for your child to sit with hips and knees at an appropriate angle?
5. Did the crutch strap provide adequate support?
6. Did the footplate provide adequate stability?
7. Did you find the ankle huggers useful?
8. Was the head support useful?
9. Was the size of chair appropriate?
10. How was the overall comfort?
11. When carrying, was the weight of the chair OK?
12. When carrying the chair, were the straps user friendly?
13. How easy or difficult was it to insert the seat in the host chair?
14. Were the clips user friendly?
15. What do you feel about the design and appearance of TravelChair?
16. How many travelled in your party?

13. How easy or difficult was it to insert the seat in the host chair?

14. Were the clips user friendly?

15. What do you feel about the design and appearance of TravelChair?

16. How many travelled in your party?

RESULTS OF THE INTERVIEWS

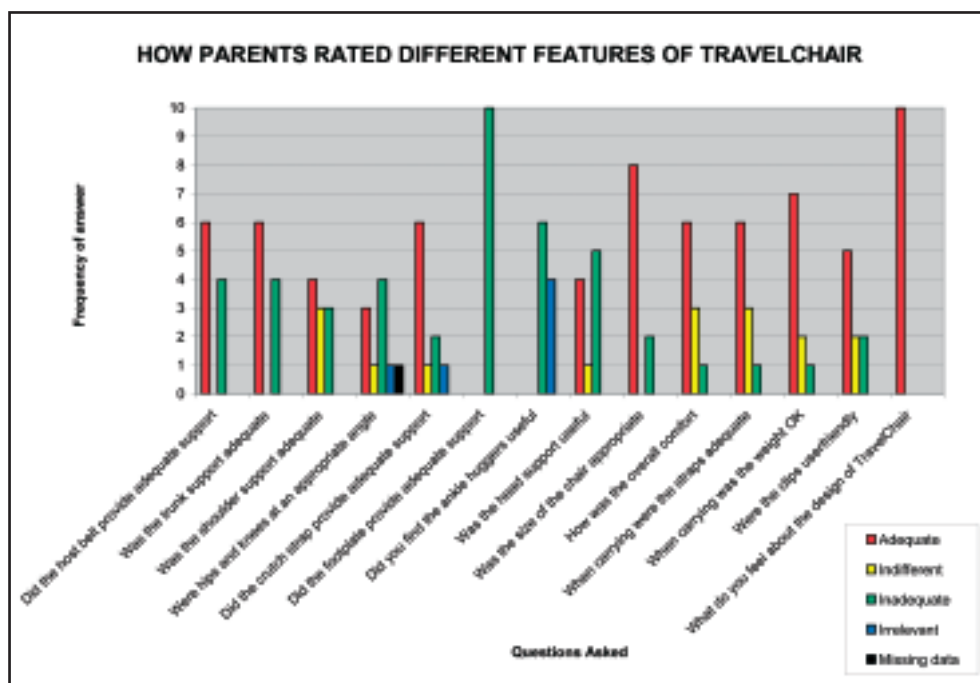
Ten families flew.

Question 13: Two of the families answered that it was easy to insert the chair. For the remaining 16 flights, cabin crew from airlines who piloted the flights helped to insert the chair. The interviewer had no access to names of the cabin crew, so it was not possible to get further information regarding this question.

Question 16: 1 in a party of 7; 3 in a party of 5; 4 in a party of 4; 2 in a party of 3.

The answers to the other questions were interpreted by the author and rated on a scale from 0-4 as follows:

4	Adequate
3	Indifferent
2	Inadequate
1	Not relevant (the child did not need support on this part of his body)
0	Missing data



One design specification was that the chair should fit into an overhead locker (Fig. 3).



Fig 3. Putting TravelChair in an overhead locker

QUOTES FROM PARENTS

Below are some selected quotes which highlight the impression parents had of the support features of the chair.

HOST BELT:

"The host belt was good enough; once it was in place he could relax."

"Not supported. He has very strong extensor spasm."

TRUNK SUPPORT:

"It was like the harness was too high on his chest, it wasn't actually properly on his chest, he was too small for it."

"Trunk, well I think it was ok. For him to sit positively he needs blocks. In his own chair he has blocks at the hips and at his chest. The harness helped. It was ok for a journey within Europe, I don't know about a long journey though. If we flew to America he would need more support on the sides."

"Not supported – Joshua kept leaning sideways. I had to hold him throughout the journey."

SHOULDER SUPPORT:

"The shoulders were not supported also because the waist belt had been pulled out."

"Shoulder support was good! The harness did that."

HIPS AND KNEES:

"Not a perfect angle."

"Her knees were kept straight."

"Hips were held in a good position."

CRUTCH STRAP:

"The crutch strap was good; good support there, we had the Velcro which we could adjust."

"I just wondered about the crutch strap – if he had

been awake and had one of his kicking sessions I wonder if he would have been able to wriggle himself loose."

"The crutch strap worked very well."

FOOTPLATE AND ANKLE HUGGERS:

"The footplate gave me some trouble."

"If it had not been dangling it would have been ok."

"Totally useless!"

"The ankle huggers were not appropriate as she moves all the time."

HEAD REST

"It would be better if the head rest had notches so it could be fixed (in position)."

"The head support was a problem because he has significant head lag; his head falls in different directions if it is not supported. If we had been able to use a neck collar and recline the chair he would have been ok. I had to hold his head most of the journey. A head band would have been perfect."

OVERALL COMFORT

"The chair was great – I don't know what I would have done without it."

"I think it was very good – compared to all the other possible solutions out there this is by far the best. It's been developed with my son in mind."

CARRYING STRAPS (Fig. 4)

"It was easy to carry; neat bag and handles."

"It was heavy to carry; it would be helpful to have wheels on the bottom of the chair."



Fig 4. Carrying TravelChair

DESIGN AND APPEARANCE

"Nice sleek, simple design."

"Perfect!"

"Yeah! It looked great."

DISCUSSION

To draw any definite conclusions regarding the suitability of the chair, this sample is too small. However some useful data was collected. All families liked the clean design of the chair. None of the children could use the footrests or ankle huggers. The chest support needs to be made more adjustable and the head rest was a real nuisance for one child. As MERU is used to tailor-making equipment for disabled children, they knew from the beginning that it was a tall order to satisfy all postural needs for children with a whole range and variety of impairments. The seat was for some children too deep so they had to sit with their legs straight out. Only four children found the shoulder support adequate. The safety belt that all air passengers have to use when flying was used to give pelvic support to the children. This proved surprisingly efficient and gave adequate support for the majority of children; however those children with CP and a strong pelvic thrust needed firmer support to be comfortable and safe.

The majority of parents said that without the chair they would not have been able to fly.

WHAT'S NEXT FOR TRAVELCHAIR?

Firstly, the TravelChair needs to be made available to those families that need it wherever they live. As air travel is intrinsically international, this presents logistical challenges. Beyond this, questions are already being asked about older children and adults, about how they are supported on aircraft, together with toileting needs and transfer options. The sky's the limit!

ACKNOWLEDGEMENTS

I want to thank all parents and the 10 young passengers who took part for so willingly sharing their experiences of flying using TravelChair. Thanks also to Dreams Come True Charity, The PACE Centre Charity, Devices for Dignity, Monarch Airlines, The UK CAA, The CAAi, EASA, Balfour, Virgin Atlantic, British Airways, The Oxted Group, Max Aviation Safety Group, and Graham Race, Tracy Doherty and Susannah Westby.

BACK BY POPULAR DEMAND!

Those of you who saw Mary Massery's presentations at the National Training Event in Warwick last year will be delighted to know that PMG has invited her back to the UK in December.

Read all about it on the back pages of this journal.

TRIAL OF A FORWARD LEAN STATIC SEAT WITH YOUNG ADULTS WITH COMPLEX DISABILITY

Carolyn Nichols

Physiotherapist (retired), Myriad Centre, Worcester

It's difficult to find a seat for adults with moderate to severe physical disability (equivalent to Gross Motor Function Classification System Level V) that supports them in the forward-lean ("prone") sitting position. Many of these adults have deformities – possibly not quite fixed, but "stiff" – which make it difficult to place and support them in positions that will optimise the use of their head, eyes, shoulders, arms, hands – for feeding, communication, joining in with activities. These deformities often include lack of adequate hip and knee flexion (i.e. unable to attain the near 90° angle necessary for traditional sitting positions), windswept hips with one or two subluxed/dislocated hips, scoliosis, hyperlordosis, and possibly kyphosis. Many have never really established their bottoms as a base of support, having spent years in a reclined/tilted position with their centre of gravity falling behind what should be their base of support. In order to optimise the use of their eyes, hands, etc. many of them need to somehow get their heads, upper trunks, and shoulders forward. This was fairly easy to do when they

were smaller and there were trained classroom staff to help them, but now that they are bigger and more difficult to handle, and no longer in school, it's a challenge.

At a day centre for young adults with complex disability

in Worcester, we have recently run an informal trial of a seat that supports the client in a forward lean position, with support at the front of the chest, from just below the axillae to (and including) the ASISs. Straps/buckles at the back of the pelvis and trunk prevent the client from falling/extending backwards out of this anterior support, with the crossover strap at the level of



Fig 1.

the posterior pelvis/PSISs being particularly important, as it holds the pelvis firmly in position and contributes to derotating a rotated pelvis and levelling an oblique pelvis (Fig. 1). The seat allows the hip and knee angle to be more open than 90°, and the feet can be either supported or not. Some windsweeping can be accommodated.

During the trial, the seat was used by two clients, both of whom are in their mid-20s and have cerebral palsy with ability level equivalent to Gross Motor Function Classification System Level V. One has limited speech and uses a communication system, the other has no speech and, although he has an unreliable yes/no response, he is very vocal and makes it clear if he is happy or unhappy. They both have limited hip and knee flexion, windswept hips, scoliosis with hyperlordosis. One uses a powered wheelchair with tilt-in-space, provided privately with seating provided by the wheelchair service. The other uses an attendant controlled manual

ABSTRACT

A "forward lean" seating system designed many years ago by Pauline Pope (Pope, 2007) and colleagues is still being used in some centres in the UK. This article describes a recent trial using the seat at a centre for young adults with physical disability in Worcester.

wheelchair with tilt-in-space and seating, all provided by the wheelchair service. They enjoy joining in with activities but they both have difficulty bringing their trunks, shoulders, arms, heads and hands forward in order to do so. The seat was trialled in order to ascertain:

- if their ability (heads / hands / eyes) improved when in this seat
- if their tone went down while in the seat

One used the seat seven times and the other four times (including the sessions when the seat was adjusted for each of them). The sessions lasted from 30 to 90 minutes.

Both clients showed noticeable improvement in the use of their hands and decreased tone when the seat was used, except for one session when one client appeared uncomfortable, and another session when the client had been standing in a standing frame just prior to using the seat and was therefore tired. The improvements in ability were demonstrated by: bringing arms forward with further and wider reach; improved grip (manipulation and strength); easier and more fluid movement when eating lunch and playing a game. The decreased tone was demonstrated by: legs relaxed so that it was easier to passively lift thighs and flex hips and knees; when in the seat initially, both clients needed their shoulders firmly held forward by a care worker (Fig. 2), and this became noticeably easier as time went on, with occasions when this support was no longer needed; care workers also noted that clients' arms felt "looser".

Each client indicated that they were comfortable when in the seat, except for the one session previously mentioned.

Staff (physiotherapist, physiotherapy assistant, as well as care staff) all felt that the clients benefitted from using the seat, but the big question is whether the benefit outweighs the time, effort, and manual handling required to get from one seat to another. Also, if a client generally uses powered mobility, being transferred to the static seat means that they lose that independent activity for that time. Currently, it is

difficult and time-consuming to adjust the seat between different clients.

We feel that the seat would be even more effective with this client group if:

- the client could be positioned with a greater forward lean of the trunk (the current seat does not allow the bottom/seat to go back far enough for this to be possible)
- there were supports to maintain the upper trunk/shoulders forward (although this may be less needed if there is an increased forward lean of the trunk).
- lateral support at upper trunk were to be provided for some clients

Additionally, we have larger clients who would benefit greatly from being in this forward lean position, but they would need a much larger seat.

We will be feeding back further specific comments to the suppliers of the seat, who are currently making plans for revising the seat's design. If the re-design means that the seat will better accommodate our adult clients, and is more easily adjusted each time it is used with a client and between clients, we may well be fundraising for one. It would mean that some of our clients would be more able to take part in various activities, and the sessions using the seat would provide some targeted, "hands-off" therapy.

For further information about using a forward-lean position, and about the development of this seat, refer to Pauline Pope's book (Pope, 2007).



Fig 2.

ACKNOWLEDGMENTS

With thanks to Smirthwaite who loaned us a SAM seat for this trial. Also thanks to the staff at the Myriad Centre, Worcester, particularly Sue Jennings (physiotherapist), Laural Kelly (physiotherapy assistant) and Nicky Doughty.

REFERENCE

Pope, P., 2007. *Severe and Complex Neurological Disability*. London: Butterworth-Heinemann Elsevier.

POSTURAL MANAGEMENT IN MS: RESULTS OF A SURVEY AND STAKEHOLDER EVENT

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BACKGROUND

Multiple sclerosis (MS) is a progressive, autoimmune disease triggered by environmental agents acting in genetically susceptible people. It is the most common disabling neurological condition to afflict young adults (Rejdak et al 2010).

The often devastating effects of MS can result in long-term disability and carry a high social

burden. However, when appropriate, intensive rehabilitation can reduce disability and physical impairment and improve emotional well-being and health-related quality of life (Rejdak et al 2010). It is widely accepted that the effective management of a chronic disease like MS requires a multidisciplinary and anticipatory approach and that there is a requirement for

timely, appropriate assistive technology and adaptations to support independence, help with care, maintain health, and improve quality of life (MS Society 2009; Scottish Government 2012).

People with MS can experience problems with their body posture. This can occur when sitting

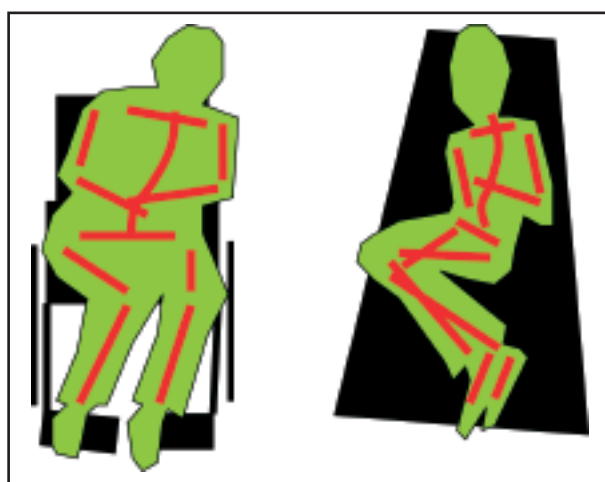


Fig 1. Poor uncontrolled (unsupported) posture sitting in a wheelchair and lying on a bed.

in a wheelchair or other type of chair, lying in bed, or other prolonged situations (Fig. 1).

Regular change in body position is essential for comfort and prevention of secondary complications (e.g. pressure ulcers) but is not always possible without assistance. Chronic poor posture and loss of mobility are strongly associated with problems such as:

- restricted breathing
- pressure ulcers
- hampered digestion
- body shape distortion
- restricted joint movement
- pain and/or discomfort
- difficulties with moving and handling (Clanet & Brassat 2000; MS Trust 2011)

In 2009 a group was set up by several professionals employed by NHS Lothian and the City of Edinburgh Council who were concerned that there was a need to improve access to advice and help for those with MS experiencing

ABSTRACT

Having assessed the level of local need for postural management (PM) provision, the Edinburgh Multiple Sclerosis Postural Management Working Group carried out a postal survey of NHS wheelchair users with MS in Lothian. This showed that, although the existing services providing PM advice and/or equipment appear to be good, accessing services is not always straightforward and there is a significant number of people with unmet needs. The survey results prompted the group to organise a multi-stakeholder event in which the foundations for a re-designed care pathway were discussed and possible actions to make this a reality identified.

problems with their posture. The Edinburgh MS Postural Management Working Group has grown and evolved and now has representation from service users, carers, health and social care professionals, academia, and the voluntary sector. This article describes the group's work, in particular its evidence-based and inclusive approach to assessing the level of local need for the provision of postural management. The group is raising awareness of postural management issues including the potential for service improvement, and re-designing the care pathway.

LOCAL POPULATION WITH MULTIPLE SCLEROSIS

The prevalence and incidence rates of MS are much higher (possibly double) in southeast Scotland than in the rest of the UK (Rejdak et al 2010; Rothwell & Charlton 1998). Based on 2011 population data (National Statistics 2012) and a prevalence rate of 203 per 100,000 (Rothwell & Charlton 1998), the number of people with MS in the area covered by NHS Lothian was estimated to be 1720. Of these, it was estimated that 615 (36%) were NHS wheelchair users. The total proportion of people with MS using wheelchairs was likely to be even higher as some would own privately funded wheelchairs. This is in line with the reported estimate that around 50% of people with MS will be wheelchair users 15 years after diagnosis (Souza et al 2010). It is assumed that the local MS population, although relatively high compared to other parts of the UK, is not otherwise atypical.

Although only 4.3% of all NHS wheelchair users in Lothian have MS, approximately 21% of people attending NHS Lothian's Wheelchair Seating Clinic have MS (Henderson & Dolan 2012). Henderson and Dolan (2012) also found that those requiring postural support in their wheelchair needed to be seen more frequently, and required more radical changes to their provision, compared to those with stable conditions such as cerebral palsy.

This analysis provided the group with evidence that there was a large population with MS in Lothian with a need for postural management services. The group decided to undertake a survey to gather further information.

SURVEY

The group undertook a survey of MS patients during 2011. The main aims were to determine:

- how common it is for people with MS to experience problems with body position and posture
- how many say they need help and advice
- the amount of contact people have with different services

METHODS

An anonymous questionnaire was designed and then piloted by a small group of people with MS who attended the Lanfine Unit at Liberton Hospital, Edinburgh, a short-stay inpatient rehabilitation service for people with neurological disorders who manifest moderate to severe disability. The questionnaire consisted of ten questions about the respondents' postural management needs, the equipment they used, and their experiences of services offering postural management advice and/or equipment. The questionnaire also requested demographic information. In February 2011, the questionnaire was posted to everyone with MS who had used the Wheelchair and Seating Service (WSS) at the Southeast Mobility and Rehabilitation Technology (SMART) Centre during the previous two years (Dolan, 2009). The survey was approved by NHS Lothian's Rehabilitation Quality Improvement Team and, since not defined as research per se, did not need NHS research ethical review.

RESULTS

Of the 391 questionnaires posted, 168 (43%) were completed and returned. 42% of returned questionnaires were completed by the person with MS only, the remainder jointly with a carer.

The demographic characteristics of the sample of people who completed the questionnaire were similar to those of the total population to whom it was sent (Table 1 overleaf). 65% of respondents were female. 81% were in the 40-69 years age range.

58% of respondents stated that they had required advice or equipment at some point to help manage their posture. 49% said they had an ongoing or current need for this type of help. Of these, 33% reported that they had not received such help. One carer stated that "...my wife has had postural problems for some time but we were unaware of any help." There were no differences in age, sex, or area of residence between those who said they required this type of help and those who did not.

80% of those who reported postural management needs experienced problems in more than one situation, e.g. wheelchairs, shower chairs, toilets, other types of chair, and lying in bed. The majority of those who reported the need for postural management help quoted several reasons for this, including: muscle spasms, aches and pains, skin care issues, and difficulties maintaining good posture. For example, one carer explained that her husband "...has no upper body balance. He often falls to the side in the wheelchair or when sitting in his chair."

		Sample Total N=168		Population Total N=391	
Sex	Female	109	64.9%	253	64.7%
Age	15-19	0	0%	0	0%
	20-29	2	1.2%	5	1.3%
	30-39	7	4.2%	16	4.1%
	40-49	38	22.9%	84	21.5%
	50-59	50	30.1%	127	32.5%
	60-69	47	28.3%	107	27.4%
	70-79	15	9.0%	40	10.2%
	80+	7	4.2%	12	3.1%
Area of residence	Edinburgh	76	46.6%	199	50.9%
	West Lothian	36	22.1%	79	20.2%
	Midlothian	27	16.6%	62	15.9%
	East Lothian	24	14.7%	51	13.0%

Table 1. Demographic characteristics of the survey sample compared to the population.

89% who said they had received advice or equipment for postural management said they had found it useful. One person noted that equipment was useful, but that more advice was required on its use. 21% said the help had not been at the right time to keep up with changes caused by their MS. One person explained that input "...needs to keep changing as the condition progresses." Another said that "MS changes are often rapid and it is difficult for services with the current resources to keep patients under regular review."

58% had been in contact with two or more specialist services in the previous year, excluding community nurses or GPs. 18% had not been in contact with any specialist services. One respondent provided a useful analysis: "Postural problems continue to worsen as MS progresses, and vary from day to day and at different times of the day. The wheelchair service has been helpful and has tried to find ways to help my posture, however there has been a lot of input from different people and maybe I could have been helped more quickly and efficiently if I was dealing with only one...."

SURVEY CONCLUSIONS

There are good reasons to believe that these survey results are a reasonably accurate reflection of the views of the wider population of people with MS in Lothian who use a wheelchair. However, due to the inclusion criteria, there may be a slightly greater likelihood that this group received advice, and therefore the survey results may underestimate the true level of need for postural management advice and equipment.

Simply stated, our survey indicates that for every 100 people in Lothian with MS who use a wheelchair, 49 have a current need for postural management advice or equipment, and 16 of these 49 have never received help of this type before (Fig. 2).

Most of those who have received postural management advice and related equipment have found it useful. People who receive help require follow-up to ensure the advice and equipment remain suited to their changing needs. People with MS have considerable contact with a range of services which provides ample opportunity for the provision of postural management.

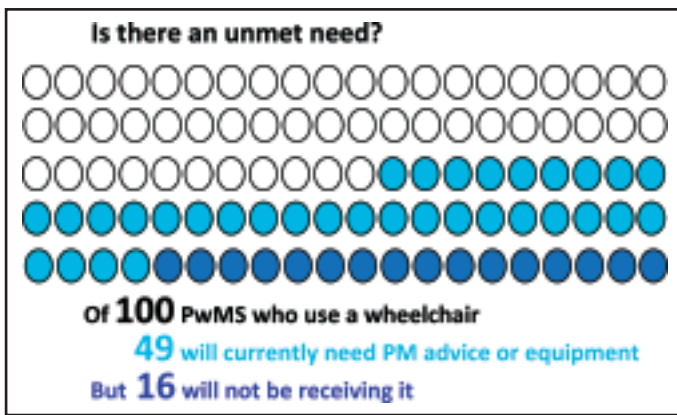


Fig 2. Illustration of estimated unmet need for postural management help.

As the results of the survey confirmed that the local provision of postural management could be improved, the group convened a multi-stakeholder event to start to address this issue.

STAKEHOLDER EVENT

A one day event for local stakeholders was held in August 2012. The aims were to:

- raise awareness of the importance of postural management
- engage decision makers and budget holders to buy into the concept of a postural management pathway
- develop a skeleton pathway for postural management in Lothian that can be taken forward towards implementation

The event was attended by 67 people including both NHS and local authority service managers, other interested professionals working in the area, people with MS, carers, and private sector equipment providers. The event began with short presentations covering the importance of postural management, case studies, and the findings of the survey. Jane Petty, MS Society National Programme Lead for Physiotherapy, shared her experiences of developing postural management pathways in the UK.

Most importantly, two small group discussion sessions were facilitated. During the first session, *Foundations for a Postural Management Pathway*, the groups were asked to reflect on the key issues in their experience and to identify areas for improvement in service provision such as what differences the groups would like to see in 3 years' time. In the second session, *Practicalities of a Postural Management Pathway*, the groups were asked to reflect on how the changes might be achieved in reality. Participants in the event were encouraged to sign up to one of three work stream groups that would continue to develop and implement actions identified in relation to each of the three aims of the day.

The group collated and analysed the themes and suggested actions raised during the event (Table 2) and produced a report in December 2012 that was circulated to all those who attended and to other stakeholders.

The three work stream groups are to meet in summer 2013 and will report back. In the meantime, work on some of the actions has been progressing in parallel with other related initiatives, such as the plans for the integration of adult health and social care in Scotland.

CONCLUSIONS

The group has estimated the potential population with MS in Lothian and established that, although the existing services providing postural management advice and/or equipment appear to be good, accessing services is not always straightforward and there are a significant number of people with unmet needs. The stakeholder event has raised awareness of the importance of postural management, identified a number of potential avenues for further work, and recruited people with an interest in helping to implement the actions identified. The Scottish Government's plans for the integration of adult health and social care and other related initiatives should ease the way for many of these actions.

ACKNOWLEDGEMENTS

The group would like to thank all those who responded to the survey or participated in the one-day event. The group would also like to thank the staff at the SMART Centre for validating the patient population details and sending out the questionnaires. The Scottish Postural Management Network generously provided funding to cover the survey costs. The group are also grateful to the MS Society who provided support and funding for the stakeholder event, and to Jane Petty for sharing her knowledge and experiences.

REFERENCES

- Clanet MG, Brassat D. 2000. *The management of MS patients. Current Opinion in Neurology*. Vol 13:3, 263-270.
- Dolan MJ. 2009. The redesign of the clinical delivery model of a regional seating service. *Posture and Mobility*. Vol 26:2, 15-18.
- Henderson G, Dolan MJ. 2012. A retrospective comparison of wheelchair seating provision for cerebral palsy and MS patients. *Proceedings of the 20th Postural and Mobility Conference*, Warwick, April 2012.
- MS Society. 2009. *Translating the NICE and NSF*

WORKSTREAM	THEME	ACTIONS (EXAMPLES)
Group 1 – Pathway development: Develop a skeleton pathway for postural management in Lothian	<ul style="list-style-type: none"> • Address all (progressive) neurological conditions • Pathway to be simple, streamlined, accessible, responsive, effective, with clarity of roles and avoidance of duplication • Aim for early identification and triage of need for postural management • Enable trials of equipment prior to purchase • Facilitate an anticipatory approach involving ongoing review or case management 	<ul style="list-style-type: none"> • Appraise different service designs • Produce a directory of services related to postural management to enable signposting • Develop a decision-making aid, e.g. a flow chart, to facilitate movement through the pathway • Explore potential for a ‘try and buy’ arrangement relating to equipment • Develop an early screening tool to identify postural management needs • Identify appropriate assessment tools and outcome measures for use within the pathway
Group 2 – Education and awareness raising: Raise awareness of the importance of postural management; provide education and training	<ul style="list-style-type: none"> • Raise awareness of the benefits of postural management and early identification and intervention with service users, carers, and staff • Raise awareness of services and equipment available • Ensure those using equipment provided are trained in its use 	<ul style="list-style-type: none"> • Set up a professional network • Seek assistance from voluntary sector organisations for awareness-raising activities • Engage people and organisations who are most likely to see postural management problems developing; encourage the incorporation of postural management strategies in their training
Group 2 – Engaging budget holders: Engage decision makers and budget holders and gain buy-in to the concept of a postural management pathway	<ul style="list-style-type: none"> • Relate the need for postural management to current agendas and targets • Seek to overcome barriers to pathway development involving budgets and service boundaries 	<ul style="list-style-type: none"> • Synthesise or develop evidence relating to postural management provision, e.g. economic analysis of a case study • Map current service provision and provide evidence of gaps • Identify points of contact • Seek sponsorship from decision makers and budget holders

Table 2. Summary of key themes and possible actions.

guidance into practice: a guide for occupational therapists. MS Society, London.

–MS Trust. 2011. *MS information for health and social care professionals*, 4th ed. MS Trust, Letchworth Garden City.

–National Statistics. 2012. *Mid-2011 population estimates Scotland: population estimates by sex, age and administrative area*. General Register Office for Scotland, Edinburgh.

–Rejdak K, Jackson S, Giovannoni G. 2010. MS: a practical overview for clinicians. *British Medical Bulletin*. Vol 95, 79–104.

–Rothwell PM, Charlton D. 1998. High incidence and prevalence of MS in south east Scotland: evidence of a genetic predisposition. *Journal of Neurology, Neurosurgery, and Psychiatry* Vol 64, 730-735.

–Scottish Government. 2012. *Clinical healthcare quality standards for wheelchair and seating services*. Scottish Government, Edinburgh.

–Souza A, Kelleher A, Cooper R, Cooper RA, Iezzoni LI, Collins DM. 2010. MS and mobility-related assistive technology: systematic review of literature. *Journal of Rehabilitation Research and Development*. Vol 47:3, 213–224.

THE DEVIL'S IN THE DETAIL FOR A SOUND BACK SUPPORT

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The back of a seating system is arguably the most important part of the seating system, but often receives the least attention. Maybe this is because for too long we have referred to it as a Back Rest! That's just been a cop out. In most cases it's a back *support*. Back supports need to accommodate a lot of individual variables. First, we *need* to understand what these variables are and what the needs are. Only then can we discuss how back supports can accommodate specific issues. This involves an assessment, and this is often not done.

With the back section of a seat we are looking, on the one hand, to provide *support* but, on the other, to allow *freedom for function and activity* of the user. We are trying to defy the distortional pulls of gravity while allowing freedom of movement. The 3-dimensional flexibility at each vertebra needs to be managed, while also using the back to help control the 3-dimensional flexibilities of the head, shoulder girdle, and pelvis. As we will see below, each of these aspects can present prescriptive conflicts and dilemmas. What is best for the end-user cannot always be achieved, and frequently there is a need to find a compromise. Before that point is reached, all the possibilities for producing the perfect solution should be explored, even though this may take some time. The principles outlined below are generally as equally valid for 'static' as for 'active' seating systems.

POSTERIOR SUPPORT

The back of the seat is a support surface, first and foremost. This support is there for safety, to stop us being pulled backwards by gravity, and to help us to relax the muscles we would otherwise need to keep the torso vertical and the head in the midline. An appropriately designed back support will assist in taking some of the body's weight, thereby helping to take some pressure off the ischial tuberosities and sacrum.

LATERAL SUPPORT

The torso is being pulled sideways by gravity as much as it is being pulled backwards or forwards. Lateral support built into the back system, or by secondary lateral supports, helps to provide lateral stability, but the design and placement of these devices is important to permit maximum freedom of movement. Adjustable laterals can initially help to stop scoliosis worsening, but ultimately can be used to help reduce the degree of 'flexible' scoliosis, by regular adjustments. Asymmetrical placement of lateral supports is often needed to achieve the best results.

DIRECTION OF SUPPORT

When considering where to place a support or 'block' in a seating system, angles are very important. Most seating systems encourage placement of these secondary supports in the vertical or horizontal plane. However, many of the movements or tendencies we are trying to control are at an angle, or are oblique (such as in pelvic obliquity or with scoliosis). This means that the forces can have a horizontal component or 'vector', as well as a vertical one (Fig. 1 overleaf). Thus, if we block just the horizontal component, this will redirect the horizontal component of the force into the vertical direction, making the obliquity worse (Fig. 2 overleaf)! The corollary of this is that placing any pads in the line of the force, or in a position to redirect forces into the required direction, is important. Please also remember that a redirected force vector will also have an

ABSTRACT

The back support of a chair has a complex role to carry out to position and support the most articulated part of the human anatomy. This article highlights the different components of the back that need to be addressed individually within a seating system's back support framework. While providing positioning and support, the back of the seat also needs to allow freedom of movement for the user to maximise his/her functional activities.



Fig 1.

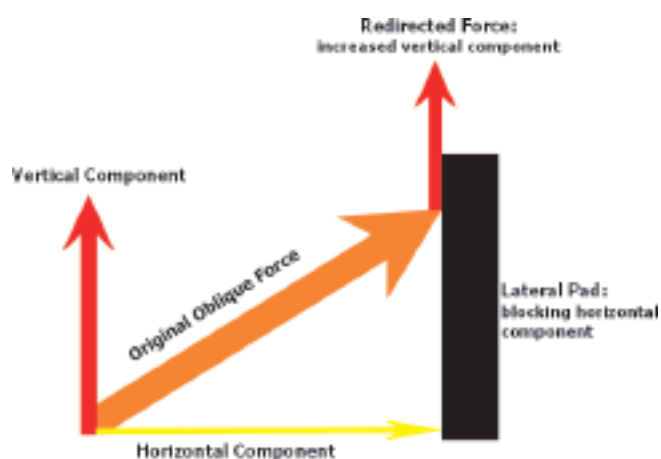


Fig 2.

impact on the integrity of the soft tissues of the skin, as any angular forces will be increasing the risk of shear damage to the cells and tissues of the skin.

BACK ZONES

Anatomically we have designated different zones to different sections of the spine, and we should consider the different attributes of these different zones as we work our way up (or down) the different zones of the back support. Just as the developmental process moves proximally to distally (from the trunk outward) so we need to follow that process as we work with the body. (Babies learn to roll – moving the trunk i.e. proximal control – before they learn how to use their hands purposefully, or before they learn how to walk.)

SUPPORT AND SPACE AT THE PELVIC LEVEL

Stability at the pelvis is important for control of both lower and upper parts of the body. To give optimal control of the pelvis in the posterior direction, it is important to provide firm support, or a 'block', at the level of the posterior superior iliac spines (PSISs). Provided that the seat cushion and postural support belts control the pelvis and prevent it from sliding forwards, the pelvis can be controlled to avoid 'posterior tilt', but still allow anterior rotation to permit functional forward reach.

Good lateral support at the level of the pelvis will reduce the risks of pelvic obliquity and rotation, and

subsequent development of unnecessary degrees of scoliosis.

The part of the back support level with the pelvis below the PSISs needs shaping to allow for the volume of the soft tissues of the buttocks, otherwise any pelvic block will not be able to operate.

THE LUMBAR SPACE

The lumbar region is the trunk of the vertebral tree. This is where the vertebrae are the chunkiest, and they are the least flexible as a result. Within the back support, it is possible to fill the gap created by whatever degree of lordosis exists, but do not confuse this space-filling with the role of a firm PSIS support. Putting a firm support in the lumbar area only tends to push the individual forward as they relax into the support, and this cancels out the benefits of the rest of the seating system, whereas a firm support at the PSISs helps to reduce the posterior rotation of the pelvis.

THORACIC CONTROL

The thorax is the area of the torso where most control can be exerted through the bones of the clavicles and rib cage, with least risk of damage to soft tissues. It is equally important that space is created for the scapulae, and for freedom of movement of the shoulder girdle.

Consideration needs to be given when applying laterals to the curvature of the rib cage, especially when the curvature has been accentuated as the result of scoliosis. Laterals where the support face pad can be adjusted in three dimensions will be more effective in offering postural support and minimising pressure problems at the pad-body interface (Fig. 3).

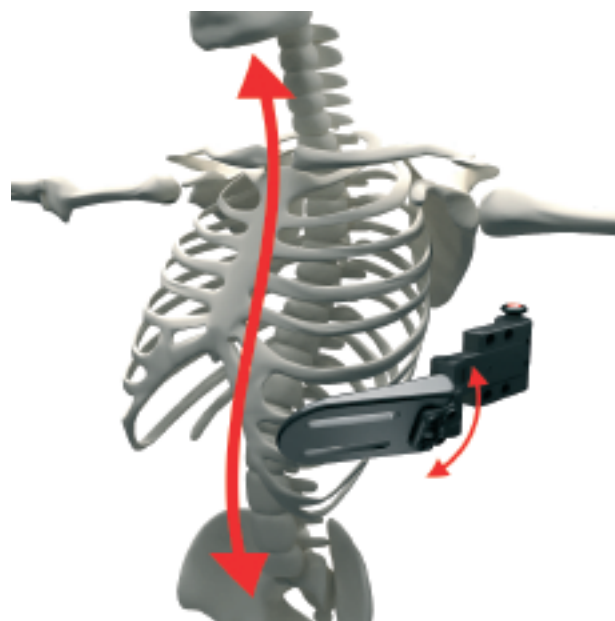


Fig 3.

Anterior thoracic supports (e.g. chest and shoulder harnesses, shoulder retractors, etc) can be supplied that are either fixed or dynamic. Either way, they should only be attached to a tall back where the top of the back is level with the top of the shoulders: if the top of the back support is too low, the shoulder supports will pull the trunk down.

It may be necessary to accommodate a thoracic kyphosis, if it is either fixed or is occurring naturally. If a kyphosis is not accommodated, it will be more difficult to provide adequate support in the lower zones and to achieve a good position of the neck and head.

HEAD CONTROL

Getting the head into the correct alignment is probably the most important function of a seating

system as this enables an individual to get on with the functional activities of life and to interact socially. The degree of intervention needed will depend on the state of different muscle groups from the abdomen upwards. Also, and of equal importance, is the rate of onset of fatigue experienced by the individual. Minimal support may be OK for 30 minutes, but over a longer period broader support may be needed. There are circumstances where a simple head *restraint* to prevent whiplash in a powered wheelchair, for example, is all that is needed, whereas a head rest may be needed to support the head in a tilt in space system, or a head *support* which also helps keep the head in a midline position. The latter is important where the individual's muscle strength is insufficient to fight the pull of gravity over an extended period.

LONG TERM CONDITIONS (LTC) CONFERENCE 2012

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PLENARY SESSIONS

After the Chair's opening remarks, the keynote address by Dame Sally Davies (Chief Medical Officer DH) advised on the need for putting self-help at the centre of LTC management. She reported that 70% of health spending is on LTC and 15 – 16 million people have at least one LTC. This number is increasing and people with LTCs are wanting to stay at home and manage their own condition wherever possible. These individuals may only see a health professional for six hours a year; the rest of the time they are on their own, so self care and management are important.

Communication → Engagement →
Empowerment → Choice, control
and supported self-care

People may need more support in the management of their conditions than health professionals are able to provide; tele-health is making this support much easier. Older people may need help to access tele-health, but an evaluation carried out through six universities is now proving that it is making a difference. The results obtained from 238 GP practices showed a 20% reduction in emergency admissions.

The Department of Health wants to improve the health of 3 million over the next five years in order to reduce dependency on over-stretched health professionals, and reduce hospital admissions, thus improving lives. Having tele-care embedded in everyday life is one of the government's targets.

The second session was led by GP Dr James Kingsland and focussed on Clinical Commissioning Groups (CCGs), which came into being at the beginning of April 2013. He viewed them as being the building blocks of care and efficiency, that they would see clinicians working across organisational boundaries, and there would no longer be primary, secondary, and tertiary care. If there is a session on CCGs at next year's conference it would be interesting to see how things have changed over the year.

Professor Andre Tylee (Professor of Primary

ABSTRACT

This year's Long Term Conditions (LTC) Conference was held in February 2013 in London, and is now becoming an annual event. This is a report of last year's programme, which was split into plenary and parallel sessions covering a wide range of topics.

Care Mental Health at Kings College London) introduced the four year plan for rolling out Improving Access to Psychological Therapies (IAPT). The starting point and assumptions for planning IAPT services is that there are six million people with psychological needs: of those it is estimated that 900,000 will present to the service; 300,000 will complete the treatment programme and recover; 25,000 could come off benefits and get back into work.

Roll out of IAPT over the four years from 2011– 2015 focuses on a complete service for adults, ensuring older people have access, and a stand-alone service for children. Plans also include development of models of care for people with long term medical conditions and severe mental health conditions.

Approximately 30% of the population have an LTC, and there are strong links between LTC and psychological stress; people with LTCs are up to four times more likely to have psychological problems. There is at present a high uptake of IAPT services by people with LTC if it is offered, but not everyone has access to the service.

Gilmour Frew, Director of NHS Improvement, described the key philosophy as “adding years to life and life to years.” People with LTC and carers were consulted and they identified four key areas that people with LTCs would like services to focus on:

- Stabilising the condition to get people back to living their lives
- Supporting people to live their lives through monitoring and review
- Timely intervention via the appropriate service when things go wrong
- Providing choice and support towards the end of life.

The impact of getting this right would require seven day working, giving more of a pathway approach focusing on individuals’ needs. However the benefits could be:

- Admission avoidance
- Early diagnosis and intervention
- Early supported discharge
- Confidence to manage their condition themselves.

PARALLEL SESSIONS

The rest of the day was split into parallel sessions of which it was possible to attend three out of the nine topics. These covered subjects such as diabetes, ventilated patients in the community, technology, commissioning, cancer care, and older people.

The first session I attended was *Managing Ventilated Patients in the Community*. It was a very informative

session led by Independent Community Care Management Ltd (ICCM). Their aim is to manage the safe discharge of individuals who are long term ventilated back into the community. Their assessment covers the individual’s needs from a multi-disciplinary team approach and the family dynamics and capabilities. The assessment of children is very similar, with some additions to help manage and allay family concerns and expectations.

There are barriers to safe discharge from hospital to community including:

- Bed blocking
 - Everything must be in place before a safe discharge can be effected
 - Hospitals are under pressure to discharge patients so as not to block beds
- Compliance
 - Integral care planning is necessary in conjunction with the patient, family, and carers.
- Equipment needs
 - Changes to any equipment
 - Wheelchairs and any other assistive technology requirements
 - Funding [equipment funding for wheelchairs and seating seemed to be left for the commissioners to sort out]
 - Provision and maintenance of suction machines, cough assist, ventilators, oxygen, etc.
- Clinical needs
 - Tracheostomy tubes – types, cleaning, changing tubes
 - Dressings and spare tubes
 - Emergency procedures
 - Where is the equipment coming from? Are deliveries organised?
 - Training of support workers
 - Emergency care pathway

Currently there are no NICE guidelines for ventilated individuals (only for Long Term Conditions 2007) and most research has been hospital not community based. ICCM have developed their own policies and procedures for best practice and competencies for the staff they train.

Plans are also in place to deal with power cuts. Ventilators are provided with a back-up battery that will last 12 hours and sometimes a generator. Patients will also be able to contact their local hospital if required.

A small number of clients may not be able to go home, for example those with a high spinal lesion who are prone to autonomic reflexia, or those for whom support mechanisms aren’t in place or the environment is unsuitable.

The second session I attended was led by the charity Sue Ryder, who run care homes and hospices for people with long term neurological conditions such as MS, Huntingdon's, and Acquired Brain Injury. They referred to the publication by Demos (Wood 2011) which outlines personalisation as applied to the individual not their budget, and gave a case history of a gentleman with Huntingdon's whose condition changed and the subsequent involvement of the patient and the family. The personalisation pathway may include end of life decision making which will also involve family members.

The final session was a whirlwind of information led by Professor David Oliver, DH National Clinical Director for older people, on innovations in therapies, techniques, and approaches to managing LTC.

When the NHS was launched in 1948, 48% of people died before they were 65 years old. Now 15% of the population is over 65, and the number of people who are over 80 has doubled. With increased life expectancy comes frailty and dementia and then, anything that would have been considered a minor ailment such as a urinary tract infection, becomes a much bigger deal.

Older people often have more than one LTC. 37% of the NHS primary care spend and 60% of adult social care spend is on the older population. Currently 1:4 beds in hospital are occupied by people with dementia, and those who have experienced falls have more bed days than someone with a stroke or myocardial infarction (MI). The LTC agenda is to reduce the number of hospital admissions by improving and extending community services.

The afternoon parallel session was rounded off by Jonathan Mason, National Clinical Director for Primary Care and Community Pharmacy DH, talking about the pharmacists' use of medicines in older people. There is a lot of over prescribing in the elderly, with the NHS spending £12 billion on drugs every year. 15 – 20% of hospital admissions are due to drugs and their side effects. For example, anti-psychotics used in dementia care cause 1600 strokes a year.

The elderly population with LTC are now major players in the health service; they are no longer the small minority. All health professionals need to be partners in their care.

REFERENCES

– Wood C. (2011) *Tailor Made*. Demos Publishing. London

FURTHER READING

- British Geriatric Society. (2011) *Quest for Quality*. BGS, London.
- Clark A et al. (2009) *Ageism and age discrimination in social care in the United Kingdom*. DH, London
- Ellis G et al. (2011) Comprehensive geriatric assessment for older adults admitted to hospital: meta-analysis of randomised controlled trials *BMJ*, 343:d6553.
- National Institute for Clinical Excellence. (2007) *National Service Framework – Long-term Conditions*.
- Tadd W et al. (2011) *Dignity in practice*. HMSO, London.
- www.improvement.nhs.uk
- www.rightcare.nhs.uk/index.php/atlas/atlas-of-variation-2011

CALL FOR PARTICIPATION

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USER INVOLVEMENT IN DECISION-MAKING AT A WHEELCHAIR SERVICE

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BACKGROUND

Patient involvement is not a new concept and has been a focus of UK health policy since 1997. It is defined as “ways in which patients can draw on their experiences and can apply priorities to the evaluation, development, organisation and delivery of health services” (Tritter 2009, p. 276). Involvement in individual treatment decision-making has been most widely researched and implemented (Tritter 2009). It is argued that enabling patients to be involved in treatment decisions alters the power and information balance from the historical paternalistic approach towards a more equal partnership between the patient and health professional and can lead to improved satisfaction with care, increased trust in professionals, and better treatment outcomes (Bastiaens et al 2007; Bradshaw 2008; Carlsen & Aakvik 2006; Charles et al 1997; Forbat et al 2009; Grosset & Grosset 2005; Klingenberg et al 2005; Loh et al 2007; Street et al 2006; UK Department of Health & Farrell 2004).

Despite this Government drive and research evidence, the concept remains unclear, making it difficult for health professionals to implement involvement and for patients to understand the concept and how it should apply to them (Entwistle et al 2008; Forbat et al 2009; Millard et al 2005). With growing numbers of people living with long-term conditions (UK Department of Health 2006) who require caregivers, an understanding of how involvement changes over time and of caregiver involvement preferences is relevant to optimising our practice. The wheelchair service provides an appropriate setting to explore involvement preferences throughout the patient journey, as the service users experience long-term conditions, may attend the service regularly over a long period of time, and often have a caregiver involved.

PURPOSE OF STUDY

The broad aim of the study was to explore how wheelchair users and their caregivers perceived involvement throughout their patient journey. This understanding could then assist in applying involvement appropriately in services for people with long-term conditions and their caregivers.

LITERATURE REVIEW

Whilst there are clear drivers and evidence of benefits to be gained from patient involvement, the literature also suggests that it is not as simple as involving all patients in every decision to the same extent. Aspects of health professional behaviour, characteristics of the individual, and the decision context have all been found to impact on involvement.

Research exploring the behaviours and attitudes of health professionals that facilitate or hinder how involved patients feel in decision-making has found that the following factors promote involvement for patients: being provided with adequate, clearly communicated information; having enough time to consider the information to be able to ask relevant questions; a supportive health professional; a health professional with a positive attitude towards sharing decision-

ABSTRACT

Patient involvement in healthcare decision-making has been a central part of UK government policy since 1997. This qualitative research project sought to explore what ‘patient involvement’ meant to wheelchair users and their caregivers in a wheelchair service context. Two broad themes emerged: developing expertise and involvement, and barriers to participation. The majority of participants preferred less involvement when deciding on their first wheelchair. As participants adapted to and gained expertise in their condition, they sought to become more involved in decision-making. Not all participants described the same journey, highlighting the complex interaction of factors.

making; and being listened to by the health professional (Carlsen & Aakvik 2006; Entwistle et al, 2008; Henman et al 2002; Skea et al 2004; Street et al 2006; Thompson 2007). Caregivers also noted that specific behaviours and attitudes of health professionals, such as being supportive and respectful, impacted on their ability to be involved (Goodwin & Happell 2007).

Personal characteristics of the patient, such as age, gender, and education level, have also been found to impact on involvement preferences. A narrative review by Say et al (2006) noted that younger, more highly educated females with less severe illnesses were most likely to want to be highly involved in decision-making. Older individuals with lower education levels who are making more serious decisions about their health are likely to prefer less involvement in decision-making (Beaver et al 1996; Chamot et al 2004; Hawley et al 2007; Sainio et al 2001).

Patients also tend to prefer less involvement when making a decision about a serious illness or a severe exacerbation of an existing illness (Carlsen & Aakvik 2006; Say et al 2006; Thompson 2007), suggesting that context also impacts on involvement preferences.

Literature reviewing changes in involvement throughout the patient journey has found some conflicting results, leading the authors to speculate that involvement preferences over time may depend more on how an individual adapts to being a patient, than on the illness itself or related experience of care (Say et al 2006; Thompson 2007). This indicates the complex interaction of factors that impact on involvement in decision-making (Fraenkel & McGraw 2007). The addition of a caregiver in decision-making can further increase the complexity as caregivers often have individual needs, such as the caregiver's health, capability, transport, and availability and these may impact on the equipment and treatment choices (Batavia et al 2001; Ham et al 1998; Reid et al 2002).

An understanding of why involvement preferences alter throughout the patient journey for people with long-term conditions and their caregivers is not clear from the literature, and it is relevant to explore this in the current political and social climate.

METHODS

A qualitative methodology was used for this study, as it has been found that this approach is appropriate when the experiences, interpretations, or perceptions of individuals are being explored (Avis 2005). Audio-recorded, semi-structured interviews were selected for

data collection. This choice was made after considering previous qualitative research into patient involvement which had utilised focus groups, interviews, and written questionnaires to collect data (Bastiaens et al 2007; Entwistle et al 2002; Katz et al 2005; Pellatt 2004; Thompson 2007). The individual nature of involvement and any concerns about communication were felt to be best managed in an interview.

Ethical as well as research and development approval for this project were gained prior to recruitment of participants.

Letters were sent to wheelchair users who had had more than one interaction with the service and had been seen at the service by a staff member other than the researcher in the last six months. The inclusion criteria were not otherwise restricted, as it was hoped this would allow a diversity of participants to be included, to reflect the diversity of the service. The selected wheelchair users could identify their caregivers for inclusion in the study. Potential participants were excluded if they were unable to give informed consent, unable to read or speak English adequately, or had been assessed as having an unsafe home environment for lone working.

Each interview began by asking the participant/s "Can you tell me about when you first got a wheelchair?" This led to narratives about the onset of impairment and the discussion was then guided by the researcher into the experience of decision-making.

RESULTS/FINDINGS

Six wheelchair users, all diagnosed with an acquired neurological condition, and four caregivers were interviewed in a total of seven interviews. All interviews lasted between 30 minutes and one hour and took place in the participant's own home or the home of the person they cared for. Data from all seven interviews was included in the analysis, which followed an inductive thematic analysis method. The wheelchair user participants had spent an average of 9 years using wheelchairs, ranging from 3 to 28 years.

Two broad themes emerged from the analysis: developing expertise and involvement, and barriers to participation.

DEVELOPING EXPERTISE AND INVOLVEMENT INITIAL RESPONSES TO IMPAIRMENT AND EQUIPMENT PROVISION

When first requiring a wheelchair, the majority of wheelchair users and caregivers expressed uncertainty about being involved in decision-making

and preferred to leave it to the health professional. They expressed that this was because they did not have adequate knowledge of equipment and that the equipment was often needed urgently, which limited the time available to obtain information and be fully involved in decision-making.

Wheelchair user: *If you're coming the first time you need a wheelchair then you've got to leave it to the... people who are the wheelchair service... you've got... no information to be involved... nor do you want to waste time trying to find this information, you just want your new wheelchair...*

Caregiver: *... you don't understand what they do.*

Additionally, the onset of impairment and loss of mobility are often associated with distress, loss, and disruption to sense of self and lifestyle for both the individual experiencing the impairment and those around them (Finlayson & van Denend 2003; Gallagher & Machlachlan 2001; Mayor 2006; Seamark et al 2004). Thus, it is possible that study participants were experiencing these feelings when they first came into contact with the wheelchair service.

Wheelchair user: *...my husband and friends went in it, but I didn't, for a long time. I wouldn't get into it, I mean. Because it was just such a...step...*

This emotional response and loss of identity combined with an unfamiliar impairment and situation, and a lack of knowledge about wheelchairs, may explain why participants felt less able to be involved in decision-making at this time.

One wheelchair user differed from all other participants and expressed that he was highly involved in decision-making about his first wheelchair and this was his preference at the time, demonstrating the individual nature of involvement as discussed in existing literature (Fraenkel & McGraw 2007; Pellatt 2004; Say et al 2006).

DEVELOPING EXPERTISE AND ONGOING IMPACT ON INVOLVEMENT

As participants gained experience with equipment, all felt more able to be involved in decision-making in partnership with health professionals.

Wheelchair user: *the wheelchair user...saying what they wanted but the wheelchair service with their knowledge and the two things have to come together and so a balanced decision is made together.*

Increasing involvement in discussions and decision-making with experience may occur as a result of the

adjustment process, and these adjustments may be life-long due to ongoing uncertainty about the long-term condition and the future (Galvin 2005; Mayor 2006). One method of overcoming this uncertainty is to develop expertise in living with the long-term condition (Mayor 2006). Wheelchair users and caregivers in this study supported this view by discussing the importance of developing expertise in their equipment management experientially.

Caregiver: *I kinda like know how to do it... you... learn from your mistakes.*

Wheelchair user: *...given information on the internet... in respite care especially I saw lots of people... with different types of wheelchairs.*

Developing expertise in these ways may have given these individuals and their caregivers a feeling of control over the equipment and their condition, and may have contributed to developing a stable sense of self and lifestyle (Mayor 2006). As a result, the individual may feel more able to be involved in decision-making. This is supported by other qualitative studies (Pellatt 2004; Say et al 2006).

THE CHOICE OF RETAINING FAMILIAR EQUIPMENT

It is likely that wanting to maintain control led several participants to express their preference to continue using equipment with which they were familiar when making decisions about equipment replacement.

Wheelchair user: *I'm very happy with this chair. I mean I'm used to it now.*

Caregiver: *I probably would say we'll have the same again, if they have.*

Being involved in decisions which result in ongoing use of familiar equipment is likely to enable some participants to feel in control of this aspect of their life. This familiarity is likely to inspire confidence that one aspect of their life will remain constant, when others such as their impairment could fluctuate (Mayor 2006). Taking control by being involved in decisions that enable stability in one aspect of life could contribute to developing a stable sense of self and to the ongoing adjustment to the long-term condition (Williams 2000).

However, several wheelchair users contrasted with these participants who wished to retain familiar equipment. For these wheelchair users, being involved in decision-making was about being provided with choices and being able to make the final decision on equipment.

Wheelchair user: *Very important ...let's say you go and buy a car... without allowing me to... choose the one I want ... I don't think it's right. So I want to be involved... make my choice what I want... even though I'm in a wheelchair... I can still...think and make my own decision.*

Wheelchair user: *For example, there was a range of colours available... I would certainly want to see them and chosen what... was suitable... A conservative colour but... something different.*

For these participants, their identity and the external image they presented were incorporated into their equipment. Having a choice of equipment was important to them as it allowed them to express their individuality and gave a sense of control over their identity. Recognising the participant's individuality in decision-making links in with the participant's on-going adjustment and development of sense of self, control over their lifestyle, and feeling of being a valid individual (Swain & French 2000).

DEVELOPMENT OF SENSE OF SELF

The concept of a developing sense of self has been discussed throughout this analysis. Evidence that this was occurring was noted, as most wheelchair users demonstrated a changed view of their impairment and wheelchair with experience. For most participants, the wheelchair became part of their self-image and lifestyle.

Wheelchair user: *... I could get out on my own... it was marvellous, marvellous to have the wheelchair... I felt a lot better, a lot happier... knowing that I wasn't stuck indoors all the time.*

The way wheelchair users now seemed to perceive their disability had moved on from their initial responses, where a sense of loss and 'giving up' were expressed, towards an affirmative model: where their impairment and wheelchair use were part of who they were as an individual (Swain & French 2000).

ALLOWING TIME FOR PROVIDING INFORMATION AND DECISION-MAKING

All participants felt their involvement in decision-making was enhanced by the health professional providing adequate information and spending enough time with them to understand their individual needs.

Wheelchair user: *... I felt that they had... chosen this one as really the exactly best one for me... they all made time, you know how busy you are... there they all were at the same time!*

This preference for adequate information and time spent by health professionals parallels previous research on involvement (Entwistle et al 2008; Henman et al 2002; Skea et al 2004). Participants noted that these health professional behaviours supported their feeling of being a valid individual, which links in with the developing sense of self and on-going adjustment to the long-term condition (Williams 2000; Swain & French 2000).

CAREGIVER PERSPECTIVES

Caregivers viewed the decision-making process as one in which the wheelchair user's views, preferences and individuality should be considered uppermost. All caregivers felt that any experience and input they contributed to decision-making was secondary to that of the wheelchair user. This supports the findings of Morris & Thomas (2001). Caregivers were very supportive of the identity of the wheelchair users they cared for and reported advocating for the inclusion of the wheelchair users in decision-making as a way to support the wheelchair user's individuality and confidence.

Caregiver: *... if you don't involve the person it's like... there's no respect... because it is him, he is sitting on the chair, and he knows how he's feeling, we don't know how he's feeling...*

Caregivers also noted that they had their own individual needs that were affected by equipment.

Caregiver: *Because when he gets a problem with the wheelchair, I have to go with him... I need the wheelchair to get easy and he go out himself and I stay at home...*

This suggests that caregivers' involvement in decision-making is important as caregivers can assist wheelchair users to maximise their involvement by advocating for them (Morris & Thomas 2001). Additionally, caregivers have needs that should also be addressed in decision-making (Batavia et al 2001; Goodwin & Happel, 2007; Morris & Thomas 2001).

BARRIERS TO PARTICIPATION

Although these will not be discussed here, the analysis of the interviews highlighted the following barriers to participation in decision-making:

- Environmental
- Attitudinal
- Equipment
- Health related
- Health service limitations

DISCUSSION AND CONCLUSIONS

The initial distress at the onset of impairment or loss of mobility (Finlayson & van Denend 2003; Williams 2000) was reflected in a preference for less involvement when first in contact with the service. As participants gained expertise in their condition and the equipment, they felt able to be more involved in decision-making. This study supported previous research that noted involvement is individual and affected by the interaction of several factors (Fraenkal & McGraw 2007; Say et al 2006; Thompson 2007).

This study notes that caregivers have individual needs and that these needs are felt by the caregivers to be secondary to the patients' needs and preferences. These findings have been noted in previous work (Goodwin & Happell 2007; Morris & Thomas 2001), but this study contributes to current knowledge by recognising that the journey that caregivers go through is similar to the journey of people with long-term conditions in terms of gaining expertise and preferring more involvement in decision-making as the journey progresses.

These findings have value for all health professionals working with individuals with long-term conditions and their caregivers. Recognising that adjustment to long-term conditions may impact on preferences for involvement is useful for health care professionals to consider when approaching decision-making with their patients and caregivers. Understanding the importance of providing adequate time and information to enhance involvement and decision-making is also important.

Future work in this area could look at decision-making in other long-term conditions and across services or multi-disciplinary teams.

CONFLICTING INTERESTS

As the research was carried out in the service where the author worked, there is a risk that participants modified what they said in the interviews in view of the fact that some had contact with me in the past and all would possibly have contact with me in the future. Also, participants may have felt more able to share their experiences with me, as they may have felt I understood this area and their experiences. Conversely, participants may have felt pressured to give the 'right' answers, to preserve a relationship with me, and to ensure their participation did not affect future equipment provision. The recruitment method aimed to minimise concerns service users may have had about participating, by being non-coercive.

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REFERENCES:

- Avis M. (2005). Is there an epistemology for qualitative research? In Holloway I (Ed), *Qualitative research in health care*. (pp. 3-16). Maidenhead: Open University Press.
- Bastiaens H, Van Royen P, Pavlic DR, Raposo V, & Baker R. (2007). Older people's preferences for involvement in their own care: A qualitative study in primary health care in 11 European countries. *Patient Education and Counselling*, 68, 33-42.
- Batavia M, Batavia AI, & Friedman R. (2001). Changing chairs: anticipating problems in prescribing wheelchairs. *Disability and Rehabilitation*, 23(12), 539-548.
- Beaver K, Luker KA, Owens RG, Leinster SJ, Degner LF, & Sloan J. (1996). Treatment decision making in women newly diagnosed with breast cancer. *Cancer Nursing*, 19(1), 8-19.
- Bradshaw PL (2008). Service user involvement in the NHS in England: genuine user participation or dogma-driven folly? *Journal of Nursing Management*, 16, 673-681.
- Carlsen B & Aakvik A. (2006). Patient involvement in clinical decision making: the effect of GP attitude on patient satisfaction. *Health Expectations*, 9, 148-157.
- Chamot E, Charvet A, & Perneger TV. (2004). Women's preferences for doctor's involvement in decisions about mammography screening. *Medical Decision Making*, 24, 379-385.
- Charles C, Gafni A, & Whelan T. (1997). Shared decision-making in the medical encounter: what does it mean? (Or it takes at least two to tango). *Social Science & Medicine*, 44(5), 681-692.
- Charles C, Gafni A, & Whelan T. (1999). Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Social Science & Medicine*, 49, 651-661.
- Entwistle V, Tritter JQ, & Calnan M. (2002). Researching experiences of cancer: the importance of methodology. *European Journal of Cancer Care*, 11, 232-237.
- Entwistle V, Prior M, Skea ZC, & Francis JJ. (2008). Involvement in treatment decision-making: its meaning to people with diabetes and implications for conceptualisation. *Social Science and Medicine*, 66, 362-375.
- Finlayson M & van Denend T. (2003). Experiencing the loss of mobility: perspectives of older adults with MS. *Disability and Rehabilitation*, 25(20), 1168-1180.
- Forbat L, Hubbard G, & Kearney N. (2009). Patient and public involvement: models and muddles. *Journal of Clinical Nursing*, 18, 2547-2554.

- Fraenkel L & McGraw S. (2007). Participation in medical decision making: the patients' perspective. *Medical Decision Making*, 27, 533-538.
- Gallagher P & MacLachlan M. (2001). Adjustment to an artificial limb: a qualitative perspective. *Journal of Health Psychology*, 6(1), 85-100.
- Galvin RD. (2005). Researching the disabled identity: contextualising the identity transformations which accompany the onset of impairment. *Sociology of Health & Illness*, 27(3), 393-413.
- Goodwin V & Happell B. (2007). Consumer and carer participation in mental health care: the carer's perspective: part 1 – the importance of respect and collaboration. *Issues in Mental Health Nursing*, 28, 607-623.
- Grosset KA & Grosset DG (2005). Patient-perceived involvement and satisfaction in Parkinson's disease: effect on therapy decisions and quality of life. *Movement Disorders*, 20(5), 616-619.
- Ham R, Aldersea P, & Porter D. (1998). *Wheelchair users and postural seating. A clinical approach*. Edinburgh: Churchill Livingstone.
- Hawley ST, Lantz PM, Janz NK, Salem B, Morrow M, Schwartz K, et al. (2007). Factors associated with patient involvement in surgical treatment decision making for breast cancer. *Patient Education and Counselling*, 65, 387-395.
- Henman MJ, Butow PN, Brown RF, Boyle F, & Tattersall MHN. (2002). Lay constructions of decision-making in cancer. *Psycho-Oncology*, 11, 295-306.
- Katz SJ, Lantz PM, Janz NK, Fagerlin A, Schwartz K, Liu L, et al. (2005). Patient involvement in surgery treatment decisions for breast cancer. *Journal of Clinical Oncology*, 23(24), 5526-5533.
- Klingenberg A, Hearnshaw H, Wensing M, Ferreira PL, Raposo V, & Szecsenyi J. (2005). Older patients' involvement in their health care: can paper based tools help? A feasibility study in 11 European countries. *Quality in Primary Care*, 13, 233-240.
- Loh A, Simon D, Wills CE, Kriston L, Niebling W, & Harter M. (2007). The effects of shared decision-making intervention in primary care of depression: a cluster-randomized controlled trial. *Patient Education and Counselling*, 67, 324-332.
- Mayor, V. (2006). Long-term conditions. 3: becoming an expert patient. *British Journal of Community Nursing*, 11(2), 59-63.
- Millard L, Hallett C, & Luker K. (2005). Nurse-patient interaction and decision-making in care: patient involvement in community nursing. *Journal of Advanced Nursing*, 55(2), 142-150.
- Morris SM & Thomas C. (2001). The carer's place in the cancer situation: where does the carer stand in the medical setting? *European Journal of Cancer Care*, 10, 87-95.
- Pellatt GC. (2004). Patient-professional partnership in spinal cord injury rehabilitation. *British Journal of Nursing*, 13(16), 948-953.
- Reid D, Laliberte-Rudman D, & Hebert D. (2002). Impact of wheeled seated mobility devices on adult users and their caregivers' occupational performance: a critical literature review. *Canadian Journal of Occupational Therapy*, 69(5), 261-280.
- Sainio C, Lauri S, & Eriksson E. (2001). Cancer patients' views and experiences of participation in care and decision making. *Nursing Ethics*, 8(2), 97-113.
- Say R, Murtagh M, & Thomson R. (2006). Patients' preference for involvement in medical decision making: a narrative review. *Patient Education and Counselling*, 60, 102-114.
- Seamark DA, Blake SD, Seamark CJ, & Halpin DMG (2004). Living with severe chronic obstructive pulmonary disease (COPD): perceptions of patients and their carers: an interpretative phenomenological analysis. *Palliative Medicine*, 18, 619-625.
- Skea Z, Harry V, Bhattacharya S, Entwistle V, Williams B, MacLennan G, et al. (2004). Women's perceptions of decision-making about hysterectomy. *BJOG: An International Journal of Obstetrics and Gynaecology*, 111, 133-142.
- Street RL, Gordon HS, Ward MM, Krupat E, & Kravitz RL. (2006). Patient participation in medical consultations. Why some patients are more involved than others. *Medical Care*, 43(10), 960-969.
- Swain J & French S. (2000). Towards an affirmation model of disability. *Disability & Society*, 15(4), 569-582.
- Thompson AGH. (2007). The meaning of patient involvement and participation in health care consultations: taxonomy. *Social Science & Medicine*, 64, 1297-1310.
- Tritter JQ. (2009). Revolution of evolution: the challenges of conceptualizing patient and public involvement in a consumerist world. *Health Expectations*, 12, 275-287.
- United Kingdom Department of Health & Farrell C. (2004). *Patient and public involvement in health: the evidence for policy implementation. A summary of the results of the health in partnership research programme*. London: Department of Health.
- United Kingdom Department of Health. (2006). *Our health, our care, our say: a new direction for community services*. Norwich: HMSO.
- Williams SJ. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness*, 22(1), 40-67.

LINKED: BREATHING AND POSTURAL CONTROL

3 one-day workshops by Dr Mary Massery in December 2013

December 2nd – London; December 4th – Scotland; December 6th – North of England

Venues and times tbc

ATTENDANCE FEES

PMG members: £100 + VAT

Non- members: £135 + VAT

INTRODUCTION BY DAVID LONG

"I was fortunate to be able to go to the Vancouver International Seating Symposium in 2010, following acceptance of an abstract I had submitted for a parallel conference session. I attended many very interesting lectures, but it was Dr Massery's session that really gripped my attention. Here was I, a reasonably experienced clinician in posture management and a chartered engineer, who had never really paid much attention to what is a fundamental aspect of postural management and that could be described in simple engineering terms. If you've ever even glanced at a chest strap, let alone fitted one to a wheelchair or classroom chair, this is for you. If you've set up any form of seating system, even once, this is for you. If you're involved in the provision or fitting of spinal jackets or corsets, this is for you. In summary, I would wholeheartedly recommend these workshops to any practitioner in the field of posture and mobility, be you engineer, nurse, orthotist or therapist."

Dave Long, April 2013

LINKED: BREATHING AND POSTURAL CONTROL

These workshops will challenge the practitioner to make a paradigm shift - to acknowledge the importance of the cardiopulmonary system as an integral component of postural control.

Dr Massery will present a model of postural control ("Soda Pop Can Model") that demonstrates how breathing mechanics are linked to motor and physiologic behaviours. This is the cornerstone for her multi-system clinical approach to the evaluation and treatment of trunk and/or respiratory impairments.

Dr Massery will describe how to use this information clinically to develop positioning and ventilatory strategies that establish the pulmonary system as an asset, rather than a liability, for patients. Her presentation will focus on the patient who has multiple physical and physiologic complications including chronic lung disease, cerebral palsy, developmental delay, congenital anomalies, GI dysfunction, and congenital heart defect.

Bookings will open in late summer 2013 and there will be regular updates via the PMG website and ebulletins as arrangements are finalised.

Email pmgadmin@btinternet.com to register your interest in attending.

Dr Massery received her BS in Physical Therapy from Northwestern University in 1977, her DPT from the University of the Pacific in 2004, and her DSc from Rocky Mountain University in 2011. Her publications and interests focus on linking motor behaviours to breathing and/or postural mechanics in both paediatric and adult patient populations. Dr Massery has been invited to give over 700 professional presentations in 48 US states, 9 Canadian provinces, and 11 countries worldwide. She has received national awards from the American Physical Therapy Association, including its highest clinical award, ***The Florence Kendall Practice Award***, and the honorary ***Linda Crane Memorial Lecture***. She continues to maintain a private practice in Chicago, specialising in ventilation and postural dysfunction.

PMG presents Dr Mary Massery Tour

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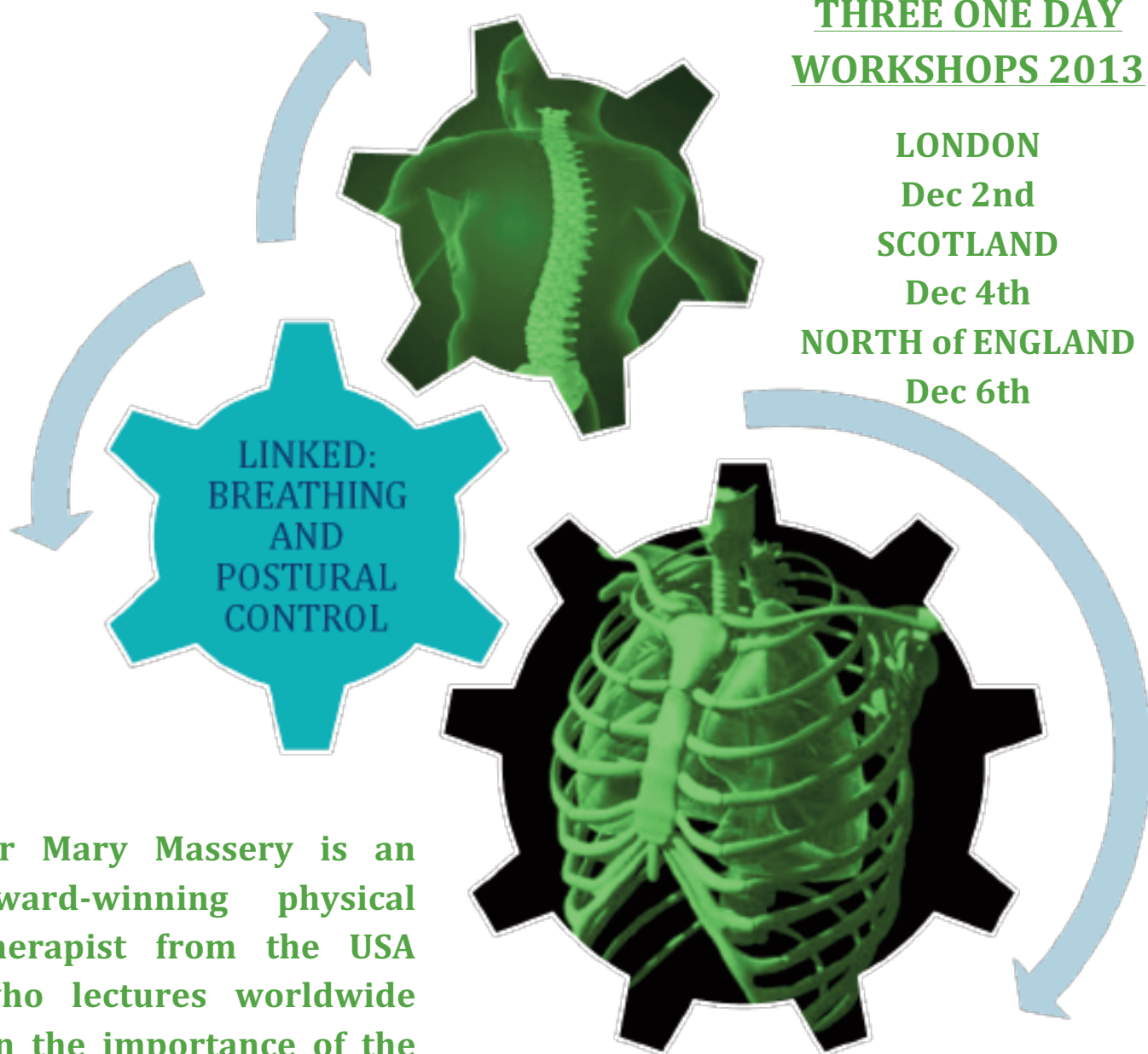
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Dr Mary Massery is an award-winning physical therapist from the USA who lectures worldwide on the importance of the cardiopulmonary system as an integral component of postural control. See inside cover for further information.

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For booking details visit www.pmguk.co.uk from August 2013