POSTURE & MOBILITY GROUP

NEWSLETTER

Volume 8

Summer 1998

Cover Page: Somewhere in Uganda, any guesses as to where?
Photo courtesy of the Editor

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Editorial

Hi from the Editorial team and welcome to Volume 8, which is full of feedback from various meetings and events. Thanks to all those who have contributed.

I'd like to use this space to raise the issue of discrimination. Are disabled people being discriminated against within the health service? With more clients being re-located in the community, being kept alive by gastrostomy, and generally living longer, where's the extra therapy, engineering, medical, administrative and equipment resources required to maintain an appropriate level of care. If the health service is here to support disabled people and provide for medical and equipment needs, it should do so in an appropriate time scale with regular review to ensure that the provision still meets the need. I'd be interested to see the real breakdown of expenditure for the various services the NHS provides. If this indicates financial discrimination, should the PMG be more political in raising the profile of the services it represents? In this way real change could be a reality, not a wish.

Phil Swann
Editor

Telephone call to the Rehabilitation Engineering Unit, Chailey Heritage:

"Can you supply a toilet seat liner for my father because he has become so emancipated he is falling through the hole!!!"

Letter from the Chairman

And so our 1998 Conference passes into history, the dust raised - in this case due in no small part to the barn dance - gradually settling. I look back on the event as another successful undertaking by the Group and it is, of course, the whole hearted involvement of the membership that makes our annual meeting so worthwhile. Our impact depends on both the individual involvement and the numbers involved. The nature of the majority of our membership is that professionals join and leave the field at frequent (irregularly regular ?) intervals and there is thus a continual need to recruit the new entrants and those more experienced staff who have yet to become members. Three hundred members has a comfortable feel.....

The Annual General Meeting was conducted to enable the business of the Group for the forthcoming year. For the first time in its history, the Group came to a postal ballot of the members to elect members of the PMG Committee for 1998. The details of the ballot are published elsewhere in the Newsletter but this does give me the opportunity to thank on your behalf all those retiring members who have laboured within the Committee to such great effect. Equally, I welcome the new blood to the Committee and I look forward to their contributions to the workings of the Group. Barend ter Haar is our new Treasurer - a willing volunteer - and Julia Cunningham our new Honorary Secretary.

Your Committee has been much troubled in the past by the problems of collecting membership fees and felt that the membership should be given the chance to consider abandoning a separate membership fee. This proposition was overwhelmingly defeated by the membership to the apparent joy of some. I am pleased to tell you that your new Committee feel that a more simplified means of maintaining membership via e fee can be arranged. Details of this will be published in a forthcoming Newsletter.

The Cambridge Medical Book stand proved a popular attraction, allowing the Group to further fulfil its educational role. The supply of books was not the quickest but I understood that most members now have their physical reward for Conference attendance. I believe that the Group should continue this element of the Conference although we may consider another “provider”. Any views from the membership about other forms of educational incentive will be welcomed by the Committee.

The Group once again offered prizes to the most worthy free papers presented at the Conference. As usual, all free papers were marked by a panel of judges using a uniform assessment scheme. The winners were: Dr Linda Marks and Phil Swann. The fact that one of the winners is a member of the Committee should encourage the rest of the membership to stand for election! Many of the papers were of high standard and it is a pity that at present the Group does not have its own medium for formal publication. I shall return to this in due course.

The 1999 Conference is beginning to take shape, topic selection leading to some heated debate within the Committee. The venue is to be a new one for us - we have noted your views about the 1998 venue - and will therefore require careful vetting. The typical attendance at a Group conference is too big for most hotels and too small for most conference centres. When the additional constraints of timing and location are considered, choices are sometimes difficult. For 1999, the University of Glamorgan appears promising and is due a site assessment. More information in due course.

The Committee exists to execute the business of the Group but you, the membership, are the Group. The Committee therefore asks you, through the Chairman’s letter, to consider what the role of the Group should be and to express your views for general discussion. Please examine the Constitution of the Group (published elsewhere in the Newsletter) and consider the future activities of the Group in the light of its aims and objectives. Should we have a formal role in specialist training? Should we become the accrediting body for professionals in our sphere of work? Should we promulgate research and development initiatives? Should we convert the Newsletter into a journal? Would we have volunteers for any or all of these activities? A significant part of the next Committee meeting will be devoted to these concepts but we must reflect the views of the membership, so - over to you.

Your Chairman is now off to assess the impact on posture of a generous application of retsina to the cerebrum. Meanwhile, consider if you will that a seat belt is safety but a pelvic strap is restraint.....

Robin Luff FRCS FRCP
Chairman, PMG

Transportation For Wheelchair Users

Study Day Held On 25th March 1998 At Newham Community Health Services NHS Trust.

Introduction
Transport has become a high profile topic for wheelchair providers and users. At Dundee'97 a paper presented by Ros Ham, Superintendent Physiotherapist and Wheelchair Service Manager from Newham, attracted a good deal of interest resulting in a study day at Newham Wheelchair service.

Edward Stait, Mobility Unit, Department of Environment, Transport and the Regions, spoke about **Guidance From The Department Of Transport.** He explained that guidance for transportation of wheelchairs is a complex topic and can only be of a general nature. There has been an increase in research, including crash simulation and the potential effect on wheelchair and occupant during the 80's.

A video of a simulated crash at 30 mph showed that supporting surfaces and restraints can fail catastrophically if the design is inadequate. Clamping the wheelchair in a sideways position makes it less stable and the effectiveness of the chair and body restraints are severely diminished.

Mr Stait explained that a European Directive has led to ten years of negotiations concerned with access to buses. ISO 7193, Maximum Overall Dimensions, defines a 'standard' wheelchair. When ascertaining the area required to transport a wheelchair in a vehicle, size alone is not of value as space for manoeuvrability, type of wheelbase and drive, design of chair and dexterity of the user are all relevant. The Disability Discrimination Act (1995) refers to right of access for disabled people. As a result, the Department of Transport, through a wheelchair working group, propose to produce guidelines which will help manufacturers and service providers to understand the range of needs of disabled people.

Mr Stait concluded by highlighting some of the improvements either in place or being addressed at present in relation to making public transport more accessible for disabled passengers. The Medical Devices Directive (MDD) will place an increased amount of responsibility for safety on the manufacturer/supplier and so influence future developments.

Dave Batty, R&D Department, Remploy, looked at **Implications For The Manufacturer, Including The Relevance Of BSI/ISO For Us All.** He displayed a list of ISO Standards published, or in progress, which relate to wheelchairs.

Using a modular electric chair, he illustrated the virtual impossibility of meeting all ISO standards. To assess stability in every possible combination would require many thousands of tests, making the costs prohibitive. Mr Batty advocated risk assessment, rather than compliance with every aspect of the standards.

Mr Batty illustrated the shortcomings of one standard in particular, that for stability. The test conditions are very controlled and relate to a specific situation in that they are carried out with a chair and 100kg occupant on a 10° incline and a surface akin to emery paper. As previously mentioned, however, it is impossible to test for every eventuality and not every chair will be crash tested. To comply with many of the standards, and strengthen the chair in critical areas would most likely negate any of the intended benefits in providing lightweight or compact chairs. With powered wheelchairs the position of the battery can significantly affect safety in the event of a crash.

Useful advice was provided on preventative maintenance of chairs. It is very expensive to carry out preventative maintenance on every chair. A scoring system was outlined, with points given for heavy/active users, the environment of use and the vulnerability of the user if a failure occurs. A user who is vulnerable should a failure occur is very much a high priority for preventative maintenance under the system presented.

A talk on **Fixing Methods** was given by **Campbell McKee, Managing Director of Unwins Safety Systems.** There are, he said, many thousands of permutations with regard to transport methods, models of chair and of course users.

As a result of work being carried out in relation to the Disability Discrimination Act (1995) and a European Directive, it is intended that in due course there should be wheelchair access to some 100,00 public transport vehicles.

Wheelchair Tie down and Occupant Restraint Systems (WTORS) are used to provide safety for wheelchair

users and fellow passengers. The weak link in a restraint system may be misuse of the clamping or restraint system. Mr McKee spoke in terms of relative safety, not absolute.

Floor space is lost if adhering to the three point restraint system, as it makes it very difficult to position chairs centrally in the floor space. This has cost implications for those providing transport. Placing chairs centrally is also precluded as access to emergency exits are hindered.

The impossibility of crash testing for every possible combination and situation was also emphasised. It was stated that if all standards were adhered to there would be hardly any chairs in transport.

Mr McKee foresees developments, such as individual docking bays for chairs, that will no longer require staff to get on their hands and knees. Care should be taken not to over tighten clamps as this could distort the frame. Also, Quicklock clamps should not be used for electric chairs. Passengers should never be transported whilst sitting on a scooter. Neither head rests nor postural supports are restraints and are therefore not included in current standards.

Anna-Stina Ponsford, Mobility Advisor from Banstead Mobility Centre, addressed **Wider Transport Issues**. She outlined the services and assistance provided in several aspects of wider mobility by Banstead Mobility Centre. Therapists carry out comprehensive two hour wheelchair assessments with a written report. A variety of chairs can be compared. during the assessment.

Assessment, advice and information is also available for car adaptations, vehicle conversion, hoists, transferring and lifting systems for a disabled person or their equipment and a range of other products related to wider mobility.

The mobility centre has a driving school offering residential accommodation if required, and tuition with an instructor in an appropriately modified car. Banstead is one of many mobility centres around the country though the services offered vary from centre to centre. A full list of centres can be found in the Wheelchair Training Resource Pack (1996) or is available from: Banstead Mobility Centre Tel: 0181 770 1151.

The final presentation explained **How The London Borough Of Newham Has Tackled The Problems**. Details were given of a combined project undertaken in Newham by the Wheelchair Service, the Education Service and the Environmental services. The aims of the project were to:

- ⇨ implement good practice
- ⇨ promote safer transportation of wheelchair users
- ⇨ liase with other services (education)
- ⇨ give confidence to parents of wheelchair users.

The opening speaker, **Ros Ham, Newham Wheelchair Service Manager**, spoke on **Implications For The Wheelchair Service**. Many problems existed in the borough in terms of safe transport. The process of improving the situation began by identifying those problems:

- ⇨ Transporting chairs sideways.
- ⇨ Lack of clamping and restraining equipment.
- ⇨ Insufficient training for transport staff.
- ⇨ Provision of non-clampable mobility equipment.
- ⇨ Safety of wheelchair accessories when in transport.
- ⇨ Transport of EPIOC's
- ⇨ Lack of training of education support staff.
- ⇨ Lack of information for parents.

Problems facing the wheelchair service included:

- ⇨ Few crash tested models on the market.
- ⇨ Buggies and some wheelchairs not clampable.
- ⇨ Securing accessories.
- ⇨ Lack of head restraint and suitable harnesses.

After consultation between the relevant parties, actions carried out by the wheelchair service were:

- ⇨ Public relation exercise with all concerned.
- ⇨ Explanation to staff and children, particularly some children who preferred sideways sitting as it made communication more convenient.
- ⇨ Compilation of list of models suitable for transport.
- ⇨ Re-assessment and withdrawal/re-issue.
- ⇨ Budget management.
- ⇨ Risk assessment with trust insurance department.
- ⇨ Future purchase of crash tested items when possible.
- ⇨ Routine assessment questions.

Peter Richardson from **Newham Education Department** provided his view on the **Implications For The Education Department.** The presentation illustrated some of the LEA's legal responsibilities. The wheelchair service initially identified all wheelchair users and their model of chair. Changes then had to be

made to comply with the strategy in Newham for inclusive education and meet the stated educational needs.

Implications for the education department included:
- ⇨ Short term - The immediate problem of changing chairs from side to forward facing.
- ⇨ Long term - To comply with the legislation.

Achievements from the project have included:
- ⇨ Co-operation between those concerned.
- ⇨ Meeting the legislation.
- ⇨ Meeting user needs and requirements.
- ⇨ Information exchange with parents and users as well as other service providers.

Future considerations include:
- ⇨ Shorter routes.
- ⇨ Review methods of transport.
- ⇨ Economic use of vehicles.

Finally, **Alan Wilson, Environmental Services Manager** spoke of the **Implications For the Environment Services**. The department manages in excess of three hundred vehicles on a day to day basis. Fifty of those vehicles are for wheelchair transport, fifteen have tailgates.

Changing to forward facing proved to be very expensive. It required the purchase of an additional three vehicles with tail lifts and recruitment of drivers. Initially there were problems with some drivers who were uncertain about transporting children facing sideways (being against the recommendations). They were reassured that the department were working towards meeting standards and legislation.

Summary

Whilst there have been significant costs involved for all three departments both in staff time, equipment and vehicle changes, the benefits have been significant for users and providers, not least in the improved communication and collaboration between all concerned.

Mr Stait commended both Newham and Cheshire* authorities and services for tackling the problem.

Marcus Friday
Bioengineer, Newham Wheelchair Service

References For Transport And Safety:

*Advise Services Manager, Community Transport Association, Highbank, Halton Street, Hyde, Cheshire, SK14 2NY

Disability Discrimination Act - Information Pack which includes a leaflet on Public Transport Vehicles (DL110) can be obtained by calling 0345 622 633.

DETR Mobility Unit Information bulletins reporting on the implementation of the transport provisions of the DDA.

Department of Transport 1994. 'It's not my problem'. The transportation of children with special needs. Department of Transport. 'Door to Door' 5th Edition. 1996 HMSO London.

Department of Transport 1987 Code of Practice: The safety of passengers in wheelchairs on buses. VSE87/1 from: DETR, Mobility Unit, Zone1/11 Great Minster House, 76 Marsham Street, London SW1P 4DR

ISO/BSI standards: ISO 7193 *Maximum overall dimensions - wheelchairs.*

The following standards are underway but not yet available from the British Standards Institute, 389 Chiswick High Road, London W4 4AL

ISO 10542-1 1997 Wheelchairs- Tie down and occupant restraint systems for motor vehicles - Pt1:General requirements.

ISO 10542-2 1997 Wheelchairs - Tie down and occupant restraint systems for motor vehicles- Pt2: Particular requirements for belt systems

Joint Committee on Mobility for Disabled People. Information sheet 1-97: Travelling in vehicles while in a wheelchair. Information Sheet. 2-97 The Limitations of Public Transport. Available from RADAR, 12 City Forum, 250 City Rd. London EC1V 8AF

Medical Devices Agency Competent Authority (UK)Directive Bulletins MDA London

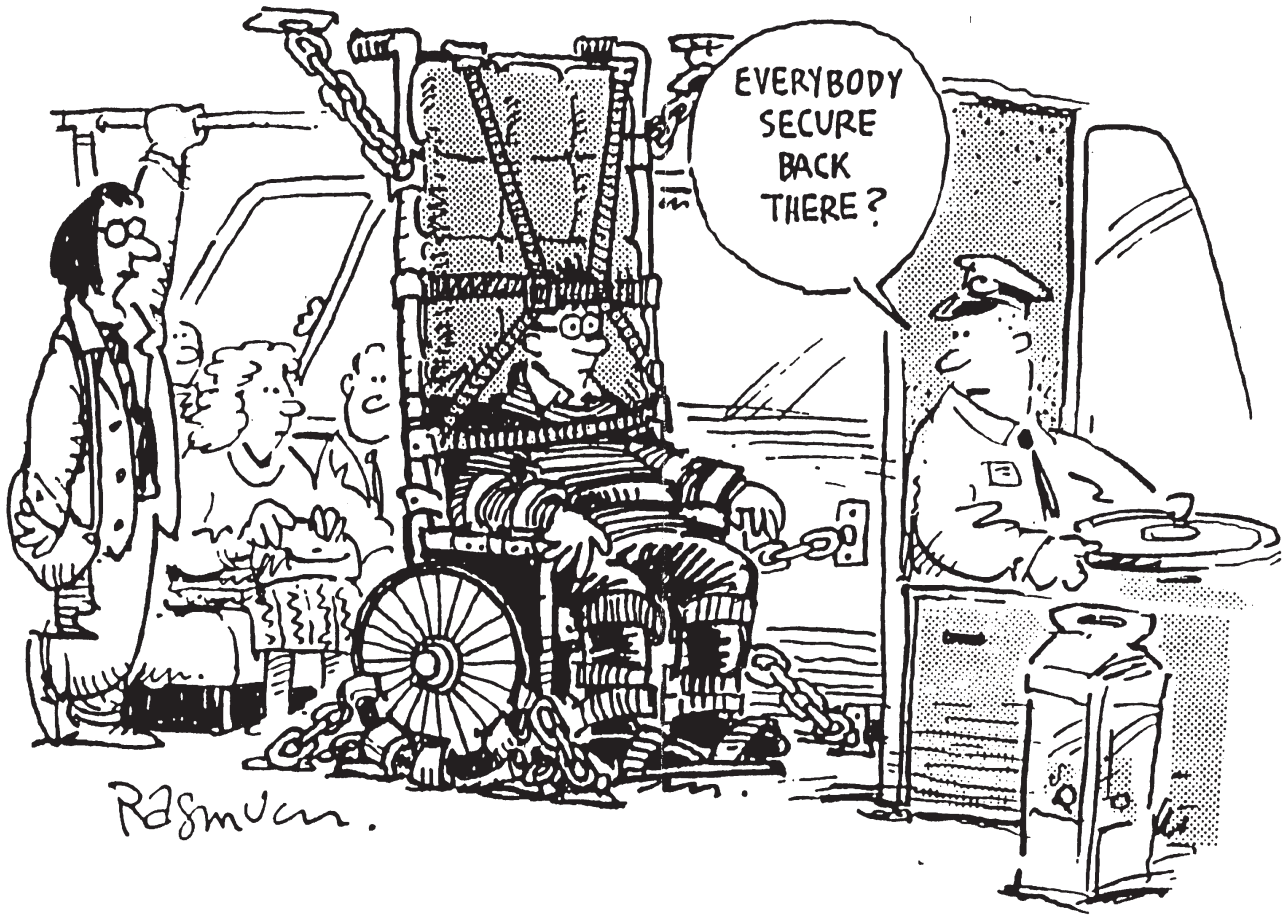
MDD Report: Safety Guidelines for Transporting Children in Special Seats. 1992 Ref: MDD/ 92/07.DoH Publications, PO Box 410, Wetherby Leeds LS23 7LN

Safe Journey Home to School. Transport for Children

in Wheelchairs. A guide by the Association of Transport Co-ordinating Officers.1996 Trevor Dobson, Transport Co-ordination Service, Cheshire Community Council, Riveacre Business Centre Mill Lane, Ellesmere Port, Cheshire L66 3TL

Information from manufacturers:
Unwin Safety Systems, Willow House, Artillery Road, Lufton Trading Estate, Yeovil, Somerset, England. BA22 8RP. Information on using Unwins equipment is available from:Peter Knight5 410 920.

'Q'straint, UK Ltd. 10 Wilson House, John Wilson Business Park,Thanet Way, Whitstable, Kent CT5 3QU



Visual Standards for Wheelchair User. EPIOCS

Most Wheelchair services have some reference to visual acuity as part of their criteria for being eligible for an indoor/outdoor powered wheelchair. There has been criticism from many users and indeed national voluntary groups regarding the severity of these standards. As a result of the many enquiries received by Banstead Mobility Centre regarding eye tests that should be applied when assessing individuals for an EPIOC, Morigue Cornwell, Director of Banstead Mobility Centre, contacted Dr. Rowse, Senior Medical Adviser to the DVLA for advice. Following this, Dr. Rowse sought an opinion from the Visual Standards Sub-Committee of the Royal College of Ophthalmologists who have stated:

'It was the unanimous opinion of the Committee that it was unnecessary to set a minimal visual acuity for such a vehicle (EPIOC/pavement vehicle) which has a maximum speed of only four miles an hour, which is of course a brisk walking pace. We do however suggest that each patient should be assessed individually and that a full field of vision may be more important than good central visual acuity'.

The Chairman of the Visual Standards Sub- Committee ends his letter by adding:' I hope this helps and will not limit the use of such wheelchairs to those people who might otherwise be better served by them because of their other disabilities.'

Whether or not someone has a full field of vision, I am sure that anyone assessing an individual for an EPIOC will also be sure to look at this in relation to other factors. Some of those for whom provision of an indoor/outdoor powered wheelchair will provide increased independence do indeed have limited vision, but are fully aware of this and are able to compensate by head movement or taking extra care. Assessment with a practical test in a realistic situation often provides the most accurate results.

Extract from a letter to **Morigue Cornwell,**
Director of Banstead Mobility Centre

User Orientated Opinion

I feel especially privileged to be invited to write an "opinion" for your excellent Newsletter. It is evident from some of the headings in your Annual Report -e.g. EPIOC PROVISION, VOUCHER SCHEME, PROVIDING AND COMMISSIONING - that you are User-Orientated.

We Users need all the friends we can get - as do the professional staff who keep us mobile and to whom we are eternally grateful.

Your Group has a vital role in enabling the NHS "system" (or lack of it) to cross organisational boundaries. The User benefits from having all the skills needed for rehabilitation gathered together. The whole then becomes greater than the sum of the parts, and effectiveness (not efficiency which is seen up in Leeds as a 3% cut per annum) becomes the key word.

Alignment is an interesting specific topic. After a hip replacement many years after my amputations, I experienced immobilising pain in the groin. At times I could not lift the artificial foot on the replacement side off the ground. I was convinced that the operation had failed me. After three years of frustration, it was discovered that I was leaning forward. As soon as I was correctly aligned the pain disappeared. Yet I am told that most aligning in practice is by "eye-balling". How do you (the reader) align someone in a wheelchair, or wearing a prosthesis or orthosis?

Finally please support us in our endeavours to have cuts in budgets restored, and more funds found for R & D.

Sam Gallop OBE
Chair of the Limbless Association and of emPower

FEEDBACK FORUM

Hull 98 ~ a delegate's view

The stunning success of the Dundee conference seemed only a few short months ago, and Hull '98 had a lot to live up to. However a different venue and a different focus created a conference that was successful in its own right. Benefits were evident from being able to attend a higher percentage of workshops, greater audience participation in discussion, more effective networking and shorter queues for coffee. All were enhanced by choosing a venue where (almost) everything was under one roof.

The session on the management of spinal deformity presented benefits and limitations of surgical, orthotic and postural management interventions, and the relationship between these approaches. This session further highlighted the need for access to multi-disciplinary input in the management of complex spinal deformity while alternative approaches to spinal challenges were proposed on day two. A timely reminder of the need for comfort in seating was thoughtfully provided in the form of the conference room chairs - though demonstration of the principles of pressure management were observed amongst those who seated themselves across two chairs...

Other topical issues which featured during the conference were implementation of the wheelchair voucher scheme, transportation issues, and common clinical challenges which confront all professionals in the field. What was evident from the presentations was the commitment of professionals and the innovative approaches which are pushing forward the frontiers of knowledge in the field of wheeled mobility and postural management.

It was good to have a debate, once again, included in the programme. The proposal that posture and mobility needs are best met by charities was passionately posed and opposed by the presenters, stimulating lively discussion from the audience which indicated a belief in providing excellence in service provision whatever one's background.

Two short days sufficed to pack in a wealth of information, the opportunity to update on equipment, network with old friends and new, and enjoy the lively social event which has become a familiar feature of PMG conferences. On reflection, the conference presenters illustrated the breadth of challenges experienced in the management of complex disability. While confirming that no single approach can supply all the answers, year on year the body of knowledge is increasing and this can only be to the benefit of our service users. Roll on PMG conference 1999!

PS Overheard amongst delegates - observations that, however early your place was booked, those with names at the end of the alphabet were accommodated in the 'Comfort Friendly' (sic) Hotel. Conference organisers, please note for next time!

Liz White
Wheelchair Therapist, Kent and Canterbury

Hull 98 ~ another delegate's view

Welcome to Hull!

Fish Trailers

It must be said we were honoured to be the host town for this year's conference. We managed to switch on the sunshine for most of the time, shame about the evening downpours though.

The conference focus on the management of spinal deformity was interesting, useful and gave us plenty of thoughts and plans for future action. Not least when our local surgeon, Mr Amir Mohsen, commented that he was not aware of our group, until being asked to speak to us, or the work the professionals are doing in the field of special seating. This must call for some urgent communication with that department. I feel a letter coming on! Chris Drake's question " who's responsibility is posture management?" is so relevant in light of this.

The workshops on vouchers and transport I found particularly interesting and a useful addition to the general theme of the conference.

The presentations of all the free papers were excellent, it really is good to be able to hear how colleagues are addressing various problems out there. I'm sure the committee have a difficult job deciding on the prize winners.

Apart from the formal lectures and workshops the whole conference gave the opportunity to; discuss and share problems with colleagues at a national level, to pick up new ideas from the exhibition, to learn more to be able to improve our clinical practice, to confirm that everyone working in wheelchairs and special seating, wherever they work, have similar problems, anxieties and stresses and that we are all working to a common goal - to provide the best seating and mobility solution for our patients/clients.

On the social side of the event I have just a few words for those hardy souls that did walk half the "fish trail" in record time - well done! Another well done to those who are now very proficient in the Doe-see-Doe. The barn dance certainly did get plenty of people on their feet. Thanks to Steve and Pandemonium for keeping us on line!

Kathleen Moore
Wheelchair Therapist, Hull

The Implications for Special Seating: Surgery

Mr Amir Mohsen
Consultant Orthopaedic Surgeon, Hull

Mr Mohsen gave a relatively light-hearted overview of surgical options and procedures starting with the rather worrying statement that, like all spinal surgery where nothing ever goes right, his first slide had disappeared!

The only options for spinal surgery were:

- ⇨ to decompress the spine were:
- ⇨ to fuse the spine were:
- ⇨ to correct deformity

and it was a very clever surgeon who managed to fulfil more than one of these at any one time. The spinal cord cannot be touched because damage will almost certainly result. Patients don't like this, but solicitors do! The key is to rotate the bone whilst leaving the cord alone.

Success is very subjective, and Mr Mohsen emphasised the need to clarify and confirm the patient's expectations and requirements. Surgery is like gardening - select soil and seeds carefully or you get weeds and not flowers. So patients need to be selected carefully, since their needs and requirements are not always declared at the outset. He gave an example of surgery on a young girl where excellent correction had been achieved and the surgeon had assumed 100% success. The young girl, however, had been left with a long scar which she felt prevented her from wearing a bikini, one of her undeclared aspirations, which left her considering the surgery a failure.

The biomechanics of spinal surgery were highlighted where the required forces to correct the spine determined the nature of the surgical instrumentation used. Since damage to muscle tissue repairs and the muscle forces are then re-established, the spine has to be fused to overcome this. The easiest thing a surgeon can do is to make the patient worse - the best is to assume he can only make some difference. Slides showed the progressive wiring up of the spine to the rods showing the need for caution against overtightening as this can cause failure.

New techniques involve keyhole surgery via four holes in the chest for the use of scopes and instruments. There are very high risks of pinching large vessels but techniques are improving and the risks reducing. The normal surgery time of 14 to 15 hours is reduced to 3 or 4 hours using this technique, which in itself reduces some risks. Some deformity is inoperable or carries high risk of paralysis. Mr Mohsen gave an example of a child with that degree of deformity. An added risk was that both parents were solicitors! He operated and the child, though straighter, was unfortunately paralysed.

There is an increasing range of tools being made available to surgeons. The 2-D images of x-rays are to be replaced with 3-D images from C T Scans. Work in the USA is set to create computerised models of the human body, with muscles and ligaments, so the outcome of surgery can be predicted or demonstrated. In Hull vertebrae are being modelled from C T Scans

from which rapid prototyping is being used to create mirror images of deformity for corrective shapes to be made, i.e: overcorrecting potential deformity before it occurs and before supportive devices would normally be considered.

Discussion

What is the potential for the use of shape memory alloys to correct the spine?

The long term reaction of the body to these is as yet unknown, work continues but biocompatibility has not been achieved. At present the alloys require at least 40∞C to return to shape and this in itself is not biocompatible.

Is it possible to predict deformity to carry out surgery early and if so how?

This is difficult and relates to lung function and rate of change of shape. Surgery is best done with good lung function but this brings a risk of carrying out surgery too early and sometimes unnecessarily. Current numbers are too small to give reliable predictive data.

Do you advocate physiotherapy before surgery?

All my patients have physiotherapy prior to surgery, the surgeon just whizzes in and out. The therapist knows the patient better, and that relationship allows the patient to get more information about the surgery, as well as the therapy, before thus improving the success rate.

Fixing the spine relative to the pelvis often disrupts the pelvis position for seating i.e. creates a posterior tilt. What do you do about this?

You can't predict what happens to the pelvis - we "close up and get out", cut corners and accept the limitations of the operation, especially the effects on seating. 3-D modelling may help with the predictions in the future. There is awareness of the problem but no solution.

If the person is a "sitting person" do you get advice before surgery?

No, we didn't know the services existed and don't know about posture work. There is a lack of training for surgeons in this area and a need for publications in surgery journals.

Do you carry out surgery for correction or to enable improved postural support?

This is a good point and is debatable. The spinal forces are too are high for seating to correct and need 24 hour orthotic control until growth has ceased. Seating is for support only with limited correction.

The Implications for Special Seating: Orthotics

Chris Drake
Principal Consultant Orthotist, Queen Mary's Hospital, Roehampton, London, SW15 5PN.

Chris opened by saying that generally he was called in when cases got bad. Clients were usually referred with a combination of problems which might include; windsweeping, pelvic obliquity, pelvic tilts, internal and external rotations, increased tone, and possibly hip subluxation or dislocation. Attempts to correct subluxation had often led to other problems; in particular the legs had gone awry and needed correction.

Chris Drake outlined the process of assessment and the criteria for providing an orthosis. Clinic assessment proceeds through several distinct stages:

- ⇨ Recognise and define the problem and what is potentially achievable from this starting point.

Remembering to bear in mind what the patient wants, which may not be what is ultimately achievable. They may not actually want, for instance, the brace which the professionals see as the answer to the particular challenge.

- ⇨ Agree the aims of the consultation within the constraints of the patient's choice.
- ⇨ Define the technical solution to achieve these aims.
- ⇨ List the actions to be taken (and by whom) both to produce the physical solution and to make it work with and for the individual patient.
- ⇨ Follow up (did it work; is it still working).

Chris' special expertise is in spinal bracing techniques and his solutions generally include spinal bracing, combined hip and spinal bracing, or hip bracing alone. In providing any of these it is vital to remember that

bracing needs to come both above and below the joint to be corrected. Otherwise there is simply no bracing. Thus abduction splints alone are no good for stabilising the pelvis as the patient is wobbly above the pelvis. A spinal brace must come below the waist and lock on the iliac crests.

Chris reminded us that the function of an orthosis is to:

- ⇨ protect a body segment or joint
- ⇨ prevent deformity
- ⇨ provide stability
- ⇨ encourage function

Generally one or two of these are attainable and Chris did say that most prescriptions are for postural control.

The initial indications for prescription of a hip-spinal orthosis are therefore:

- ⇨ to prevent hip/spinal deformity
- ⇨ as an alternative to special seating and lying boards
- ⇨ for post-operative management
- ⇨ to improve functional independence

One cannot achieve post-operative spinal fusion management in a seating system. Functional independence is generally improved as braces are worn usually for 24 hours, whereas seating systems are used for, at best, the waking hours.

The essential features of Chris' braces are that they provide total contact, afford hip abduction in flexion and extension, and the aim is for symmetrical pelvic/spinal control. The need for seating systems disappears if there is only spinal deformity which can be controlled by a spinal brace. Clearly in these cases the orthosis is a complete alternative to seating. If the problem is compounded by a pelvic obliquity or rotation then it becomes incorrectable but manageable to a state which allows a seating solution. Thus, in these cases, the orthosis is an adjunct to specialised seating.

We come back, however, to the fact that the patient cannot always be in the seating system, and indeed may choose not to be at times. At least the brace will give a measure of control when the wearer exercises his or her choice for independent sitting.

The advantages and success of providing an orthosis were illustrated by a young girl who demonstrated a common deformity of hip obliquity associated with a 'c' curve of the spine and a kyphosis. This could be disguised but not controlled by a seating system. X-raying a client in their jacket or in the seating system, it was possible to assess the degree of control. In some cases there would be a need for both an orthosis and seating system, though use of the brace would generally reduce the complexity, size and weight of the seat. In general, braces were more acceptable for their appearance as well as their adaptability. Use of an orthosis would improve stability; organise posture, provide a feeling of security and be acceptable as it can be covered by clothing.

In the subsequent discussion, Lone Rose (Stoke Mandeville) said that they also used braces a lot and wondered whether Chris found that there was an age limit to acceptance.

Chris replied that if the compliance level is high, which means that the results are good, then there is very little rejection. There is, however, a practical limit of, say, 14 to 16 years of age when it becomes difficult to do anything on a strong and developed body.

Robin Luff (Kings Healthcare) commented that the problem is where to go. Chris agreed. Given that he had earlier condemned most braces in the UK as, shall we say, ineffective, there was an unspoken answer to Robin's question.

Clinical Challenges

Led by: Dr. Linda Marks
Consultant in Rehabilitation, Stanmore DSC

This was easily the best attended workshop of the series and due to the interest shown by all participants at the conference, the findings of the workshop were presented by Dr. Marks on the second and final day of the meeting.

Dr. Marks had prepared six questions for those taking part. These covered key areas of concern or difficulty experienced by all working in the field of posture and mobility.

How do we ensure that children and adults with learning difficulties or behavioural problems are 'safe' in their systems without being restrained?
The group considered methods of restraint and the fact that restraining a person could be a positive action for posture or safety or alternatively, could be requested for other reasons, such as easing the life of a carer. There was unanimous agreement that straps or restraints of any kind should not be provided for this latter reason, particularly when it was against the wishes of the individual. There was discussion around why we should restrain, when we should do it and what constituted restraint. Restraints for safety were acceptable, particularly when an individual could cause damage or injury to themselves or others. The methods used depended considerably on the function and environment. What might be considered safe and acceptable in one situation might not be so in another. Dr. Marks quoted a situation where carers requested that a client was restrained in a particular position for travelling in order to prevent them from curling into a ball when on the move. As the person concerned was not in anger from harming themselves or others and seemed perfectly happy in a curled position for the travel period, there was, she said, no grounds for restraint in this case. The conclusion was that each request should be considered independently and aims and risks involved assessed before applying restraints. Education of users of equipment is equally important so it is used appropriately and built into the overall care plan.

How do you seat someone who is floppy?
Another difficult scenario for most practitioners. Establishing the medical reason for the hypotonia and whether it is changeable or treatable was the agreed starting point. The importance of environmental stimulation was discussed and facilitating improvement of muscle tone by various strategies, e.g. standing, work and rest positions. Participants agreed that one could make use of gravity, with tilt in space systems offering whole body assistance the answer in some cases. Other suggestions included using orthoses, anterior supports in the form of a harness with or without a tray to prop on. There was some discussion regarding shoulder restraints, though it would appear that these are not in common use it was advised that if used, they should be assisted by gravity - in other words, the individual should not be in an upright position. Safely and comfortably securing the head was considered important though there were differing views on how to achieve this and the best systems for success. Some of the hardware options being neck collars, travel pillows, Lecky headsupport, neck rolls and others.

What can you do to control axial rotation in a seat?
This was acknowledged difficult, if not impossible (in some situations) in terms of seating but which needs a holistic approach with a planned postural management programme. The use of orthotics, changes in position, correct lying, night time positioning all featuring in the program of control. One member had achieved a degree of success by using a matrix system which restricted forward movement of one shoulder. This could create difficulties with placing a person into a system, though this would depend upon the method used. Whether or not the pelvis should be allowed to rotate was another difficult issue, this again depends on a number of factors including function, eye contact, feeding and general care requirements. Other solutions included a combination of an orthosis with custom made seating, restriction in the lower limbs by the use of Putney knee pads, ASIS bar to keep the pelvis back and a lycra body garment secured to the system on one side. A difficult issue with no easy answer it seems.

What do you do with someone whose knee flexion is greater than 90°?
The underlying problem needs to be addressed first, is it a spasm/contracture or both. Will medical intervention with surgery or drugs help? Postural management programs were felt to be the most

common approach rather than looking for solutions in hardware. The importance of stretching out joints was emphasised with night time stretching to increase the range of movement or delay further deterioration being a practical and beneficial approach. Addressing the underlying high tone purely by means of surgery has been tried, though there is a high risk that the deformity will return in quite a short space of time. Some of the hardware options included; the carcasson foot sling to provide support for the feet under the seat, a saddle seating system and various modifications to wheelchairs to accommodate leg position without interfering with castors. Calf straps were not recommended since the user can pull on them increasing rather than reducing the problem. Certainly whatever equipment was seen to be best the need to combine this with other postural management and therapy input was seen to be central to any success, however small.

What to do about clients or parents who refuse to accept your professional advice?

DOCUMENT EVERYTHING was the conclusion of this problem that brought increased interest from all taking part. Responses included:

- ⇨ There is no point in issuing equipment that is not going to be used.
- ⇨ It is the assessors/professionals' responsibility to point out the pros and cons to the client and their family or carer.
- ⇨ Find out what they expect and will accept and work round this in order to avoid outright refusal.
- ⇨ Introduce them to user groups and other clients.
- ⇨ Ensure they understand exactly what they are going to be given. Seeing and handling equipment whenever possible prior to provision will reduce rejection.
- ⇨ Allow time.
- ⇨ Referral for a second opinion.
- ⇨ The consequence of non provision.
- ⇨ When does refusal become abuse?
- ⇨ If a compromise cannot be reached, make sure that you record all the relevant details and the action agreed.

How do you handle severe fixed windsweeping?

Working with the user the key question was as to whether you have eyes front or feet front or a compromise. With pelvis correctly positioned and eyes front, the legs are allowed to sweep to the side. This may mean a wide system with potential problems getting through doorways, the solution therefore is often a compromise attempting to prevent the posture from getting worse. The question was raised as to whether the wheelchair service should take responsibility for solving what is sometimes an insurmountable problem which lead on to when others should be involved? The dilemma of major surgery was discussed along with the problems encountered getting surgeons to respond when you present them with this problem? On the whole it appeared that those present did not have easy access to the surgeons, or indeed a positive response when they do approach them with a problem to be shared. There are however always exceptions and a few had a positive working relationship with other disciplines including the surgeon. The risks of surgery may prevent intervention and if surgery is agreed, it is essential that this is supported by appropriate rehabilitation if it is to be successful.

Whilst many problems are insurmountable, this session provided the opportunity for the airing and sharing of ideas. At the end of the day, comprehensive assessment, multidisciplinary working; good communication with and between professional and client and clear aims and decision making are key to success. The increasing range of equipment available is helpful, but, it would seem that there will always remain areas where no action may be the final decision taken. A properly planned programme of postural management from an early stage and at all times is a basic and essential ingredient if deformity is to be reduced or delayed.

Collaborative Funding

Led By: Janet Ledward
Locality Purchasing Manager

Janet Ledward was formerly employed by the NHS Supplies, but is now the Locality Purchasing Manager for Pendle in East Lancashire. She has a £60 million budget and is responsible for the development of Primary Care Groups within Pendle District. Amongst her other duties, she is responsible for the provision of Wheelchair Services, the implementation of Calman's recommendations on Cancer Services and the development of Paediatric Intensive Care.

She introduced her workshop by considering Collaborative Commissioning; what it is and what are the benefits. The essence of Collaborative Commissioning is working with other agencies to common goals, with the objective of maximising resources. She gave the example of the Pendle Partnership between Public and Private Sectors in the development of Drug Rehabilitation Services. The process initially involved an assessment of needs, followed by an application of a bid for regeneration monies from the Government. The Drug Rehabilitation Service has been commissioned with a £2.6 million grant from the Central Government, together with a sum considerable greater than this pledged by local private source. Janet reminded us of the statutory obligations of the NHS, and of some of the other factors limiting NHS activities:

- ⇨ National Health resources can only be spent on Health Care.
- ⇨ Items purchased by the National Health Service remain the property of the NHS, with the exception of wheelchairs purchased under the new Voucher Scheme legislation.
- ⇨ Resources are limited.
- ⇨ Resources do not match demand.
- ⇨ Public expectations are high.
- ⇨ Other agencies are also under financial pressures.
- ⇨ There is never enough time.
- ⇨ The service is always changing.

Janet then summarised some of the advantages of collaboration:

- ⇨ Common aims.
- ⇨ Provision of a seamless service.
- ⇨ Shared ownership and responsibilities.
- ⇨ Maximum use of resources.
- ⇨ A more powerful voice (to justify e.g. additional resources).
- ⇨ Facilitation of change.

Some areas where collaborative action may be inappropriate:

- ⇨ Where one of the parties stands to make commercial gain.
- ⇨ Where there is not consent of patients or carers.
- ⇨ Where there are severe time constraints.
- ⇨ Where there may be issues of confidentiality.

The Workshop then split up into smaller groups, to consider aspects of Collaborative Funding in greater detail. One group considered which agencies, organisations and individuals it may be appropriate to commission collaboratively, and a large list was produced!

- ⇨ Health Authorities.
- ⇨ The new GP Commissioners.
- ⇨ Social Services.
- ⇨ Educational Authorities (both local and county).
- ⇨ Housing.
- ⇨ NHS Trust's.
- ⇨ Commercial Firms.
- ⇨ Individual (Benefactors).
- ⇨ Industry.
- ⇨ Remap.
- ⇨ PACT.
- ⇨ Housing Associations.
- ⇨ Professional Bodies.
- ⇨ User Groups.
- ⇨ The Lottery.
- ⇨ Access Groups.

Another group discussion potential barriers to collaborative funding, when a number of issues were raised:

- ⇨ Time constraints.
- ⇨ Large numbers of people involved.
- ⇨ Organisations and individuals with vested interests.

- ⇨ Inadequate clarity of process.
- ⇨ Inconsistencies in documentation.
- ⇨ Fear of the unknown.
- ⇨ Boundaries (professional and/or geographic).

A third group met to consider what advice to offer to other organisations about developing Collaborative Funding when providing services. A number of important recommendations resulted:

- ⇨ Working Parties being set up early to consider common issues and potential areas for collaboration.
- ⇨ It will be advisable to start with some of the smaller problems, in order to define the process.
- ⇨ That a clearly defined process be established early on.
- ⇨ That personnel involved in Working Parties should be of a sufficient seniority to get things done.
- ⇨ That representative User Groups feed into the Working Parties.
- ⇨ That the whole process be supported by accurate gathering and recording of data.
- ⇨ That the whole process be subject to standard procedures of audit.

The consensus at the end of the Workshop was that there were very significant advantages in collaborative ventures and a pooling of resources which could benefit a large number of the agencies described.

Transport and Safety

Led by: JACKIE MACKAY

There were 55 people attending the morning workshop on this topic which has been, and will be with us for ever, but which seems to be the hot topic of the moment.

Jackie introduced three particular areas of concern for people travelling as passengers in wheelchairs: Safety, influenced directly by the equipment in use and the standards which define both how equipment is tested and used.

The word 'standards' is loosely used to cover various types of document of varying legal enforceability or recognition. These include;

- ⇨ Legislation
- ⇨ Standards (national or international)
- ⇨ Codes of practice
- ⇨ Recommendations and guidelines

Only actual legislation (Statutory Instruments) has the full force of law. However, failure to comply or follow standards or codes of practice may count against a defendant in court (as with the Highway Code).

In this area of transport safety we have the Department of Transport document VSE 87/1 which is still current and the Medical Devices Agency report MDD/92/07. Neither is legally enforceable but ignore them at your peril. There is also ISO 10542 Parts 1 and 2 in draft (Restraint systems - wheelchair tiedown and occupant restraint systems for motor vehicles).

Who are the PMG members on the committee considering these and other standards?

Remember that none of these laws, standards, etc are intended to prevent wheelchair users travelling. They are designed to make travelling safer for the user (and, indeed, for other non-wheelchair passengers).

Jackie then played two videos, the first from the Transport and Road Research Laboratory in Crowthorne (TRRL). This was about seven minutes long and illustrated TRRL report 1087. Part 1 dealt with access and handling and part 2 with safety, showing film of sled tests using an anthropomorphic dummy.

At a 6g deceleration from 20 miles per hour a dummy with lap strap only folded at the waist. The head of a vehicle passenger would have smashed into the seat in front. At 25g the wooden floor splintered under the front castors of the wheelchair. Some of the film was fairly alarming and it was perhaps the first time some of the audience had seen it. However, the findings of the report were, I hope, well known to all:

- ⇨ Secure the wheelchair to the vehicle
- ⇨ Secure the passenger to the vehicle

- ⇨ Remove pommels, trays, knee blocks
- ⇨ NO sideways travel
- ⇨ Transport is ultimately the responsibility of the transporter and appropriate training is therefore required to ensure;
  - which securing system for which wheelchair
  - which wheelchairs are suitable for occupation during transportation

The second video was from Unwins and in five minutes illustrated the use of some of that company's safety systems. It covered the floor rail system and a variety of restraint systems that fitted into it. The Quiklok clamps (to side rails of chair), the webbing restraints (four straps to front and rear vertical frame tubes), and the Rearlok and Easilok systems in which the wheelchair is secured against a backstop arrangement by webbing straps.

Various harnesses for securing the chair occupant were shown (but note that the four point static harness has now been replaced by a two point floor rail anchorage system). There are double inertia reel systems which are either two point floor rail anchored or three point (floor and wall anchors). These can offer lap/diagonal restraints or full shoulder/waist harnesses and there are arrangements to secure both the wheelchair and the passenger (as recommended in the MDA report).

Difficulties arise with special seating, which can present a transporter with a large variety of geometries to be secured, with buggies, very heavy electric's or when there is simply nowhere to clamp (e.g., on scooters where there is generally no frame visible). The answer is to talk to the chair manufacturer.

The discussion brought up several points. The prescribers of wheelchairs and seating should take some responsibility for considering transport needs and inform the users. The problem is that although the wheelchair may have been successfully crash tested, if it has been modified the impact performance may have been affected, and the liability issues certainly have.

Training in risk assessments should be given to all involved in the provision process.

Incorrect tyre inflation, so often seen on wheelchairs, can allow tyres to come off rims on impact so that clamps become ineffective. An ignorance of what is available is apparent on both sides (wheelchair manufacturers and restraint manufacturers). Given the rapidly expanding number of wheelchairs, especially import, this is perhaps not surprising.

The suggested removal of passengers from special seats for transportation brings conflict with the manual handling regulations (unless the vehicle also has a positionable hoist). There was much discussion about the securing of seating systems to their wheelchair bases.

Alan Lynch, MDA, says that some 60 wheelchairs have now successfully passed crash testing and several failed. The MDA will be issuing a new document later in the year but it will probably more likely highlight the questions than give all the answers.

There was a small display of Unwin equipment in the meeting room whilst outside the hotel were a Ford Galaxy and Peugeot Chairman. The latter would take two wheelchairs with clamps in the rail system or one with the four point webbing restraint. Lap/diagonal harnesses fit in all the possible positions. The Galaxy could take only one wheelchair with a four point webbing system and lap/diagonal harness.

Value of EN46000 & ISO 9000

Led by: Dave Calder
Service Development Manager, King Healthcare

Dave presented a review of the requirements of various parts of the standards and gave some guidance on their potential application.

ISO 9000 defines the principal concepts of the 9000 series of standards. ISO 9001 covers design and development, production, installation and servicing of equipment. Rehabilitation engineering establishments making original equipment should work to this standard. ISO 9002 covers production, installation and servicing and ISO 9003 relates to final inspection and test of equipment. It applies to companies which purchase equipment from elsewhere and inspect and test before selling on. ISO 9004 contains guidance to the operation of the 9000 system.

The EN 46000 system enhances the 9000 series standards and starts with some definitions:

- ⇨ A product is the result of an activity or process
- ⇨ A supplier is the organisation that supplies the product to the customer
- ⇨ Refurbishing means the processing or reprocessing to specified requirements of a medical device that has previously been in use

The enhancements in the parts of 46000 are as follows.

46001. **Design Input** to identify safety requirements for the equipment being considered. (This is not done in 9001.)

Design Verification includes details of tests and trials performed with the equipment.

Documentation which must be maintained for the life of the equipment and provide traceability throughout this life. It should include service records.

Retention of purchasing documents, including drawings, to aid identification of the source in the future should the need arise.

46002. **Identification** of each product received for refurbishment to provide traceability of service history.

Non-conforming product concessions may be allowed if regulatory requirements have been met. Facilities should be available for quarantine and testing of faulty products.

Corrective action will include the publication of advisory or recall notices. There is also a requirement for a *named* responsible person.

The benefits of these quality management systems are that they do actually help in the management of processes and can *reduce* the paper work, as some of what is currently recorded may not actually be necessary. They also enable a manufacturer/repairer to:

- ⇨ Control material
  - purchasing documents, traceability
- ⇨ Control spares (new and used)
  - purchasing documents with batch and serial numbers
  - identification of wheelchairs to which parts have been fitted
- ⇨ Identification of correct spares
  - to ensure different manufacturers' parts are not mixed
- ⇨ Record spares used for repairs
- ⇨ Record spares used for refurbishment

In the provision of solutions they guide the design process:

- ⇨ Calculations
  - not always needed depending on complexity and function of the part.
- ⇨ Design review
  - fully documented.
- ⇨ Documentation
  - risk assessments, drawings, discussions with professional colleagues and any other interested parties.
- ⇨ Drawings
  - to BS 308.
- ⇨ Testing
  - records.

and the actual supply of the solution and beyond:

- ⇨ Fitting
- ⇨ Testing
- ⇨ Training
- ⇨ Maintaining
- ⇨ Review

and the recording/reporting of the provision process:

- ⇨ Who was seen
- ⇨ Where
- ⇨ Details of assessment
- ⇨ Equipment tried and results
- ⇨ Risk assessment
- ⇨ Prescription
- ⇨ Actions

Actually the ISO 9000 series does not have such a list; it simply requires that you record your actions. The above is a typical list for a wheelchair service.

Some say that quality management systems get in the way. Dave said that they do; but in a way that requires you to think about what you do and how you record it. The systems are only as good as their users, and if not used correctly the systems are of little value. Regular audit, which is in any case needed to maintain registration, will show up deviations from procedures, but also in-built procedural errors needing correction. Thus quality moves forward and this is what the standards are about.

There was little discussion. One questioner asked about any relationship between evidence based medicine and

outcome measures and the ISO 9000 standards. The standards ask for review, including statistical methods if appropriate, so that one can say that consideration of the evidence refines the procedures.

Going through the accreditation process sets your house in order. Any well run business will generally be doing most or all of the required things, but the procedures will be formalised and some of the headings will probably be changed to align with the standard.

In the context of this meeting, it is a real problem for wheelchair services with limited resources, both financial and staff, to implement and *maintain* a system. One solution might be to use the RE services to help.

Voucher Scheme

Led by: Sheelagh Richards

Sheelagh started by summarising key developments in the evolution of the voucher scheme:

- ⇨ Guidance issued in December 1996.
- ⇨ VAT question was resolved.
- ⇨ At the 3rd quarter return in 1997, 20 authorities had issued vouchers but actual numbers of vouchers issued were difficult to determine as some authorities used actual figures and some estimated the figures.
- ⇨ In the early part of 1998, HSC 1998/004 was released which allowed any underspent money from the voucher scheme to be used for the EPIOC and ordinary wheelchair service budget.
- ⇨ Monitoring and Evaluation. A small group conveyed by Sheelagh Richards is to start meeting shortly.

The workshop was then opened to comments, questions and general discussion.The points bulleted below outline the key points and views raised:

- ⇨ Partnership option clarification was sought. It was suggested that these chairs are bought in-house using NHS contracts. Calculation of a voucher for the partnership option is as follows:

  8L plus VAT = Voucher

  Cost of partnership chair is chair plus VAT. The balance paid by the client is the difference between the two calculations minus the VAT on the purchased chair less the voucher value.

- ⇨ The returns to the regional health authorities for EPIOC purchases asks for money spent and includes committed moneys. The voucher scheme returns ask for actual spend. No money can be counted until it is actually spent.

- ⇨ If a chair needs modifying the specification needs to say this. Modification costs on a voucher chair can be higher. We can say no if the modification cost is very large.

- ⇨ Cushions are not included on the voucher scheme, they should be provided by the wheelchair centre.

- ⇨ To work out the amount given for repair the likely maintenance on a standard chair should be calculated.

- ⇨ There is a lot of pressure on services to provide the voucher scheme - are people assessing downwards? This is not what the scheme is all about.

- ⇨ When the voucher scheme is assessed and evaluated nationally more than just the spend will be taken into account. There will also be a service profile including; geographical area, level of disability and environment. It is possible that different areas will be looked on in terms of conurbation's, rural areas verses urban areas etc.

- ⇨ When partnership chairs are returned to the centre they should be put back into centre stock and used as normal chairs.

- ⇨ Vouchers are at present only for use with manual chairs - no change to this until at least 2000.

Any request by health authorities to use the vouchers for EPIOCS should be resisted.

- ⇨ Clients requesting to purchase a second-hand chair on the independent option. There is no official guidance on this but it was not felt to be a good idea.
- ⇨ The amount of money spent on vouchers in l999/2000 in each wheelchair centre will determine the amount received each year after that.

DEBATE: POSTURE AND MOBILITY NEEDS ARE BEST MET BY CHARITIES

Proposer: Kate Organ, Whizz Kidz
Seconder: Kieron Slocombe, Wheelchair Technology

Opposer: Henry Lumley Manager, Bristol DSC
Seconder: Roy Nelham Director, Chailey Heritage.

The debate brought the two day meeting at Hull to a close and was attended by a large number of the delegates. The proposal was presented by Kate Organ, Director of Children's Services for the well known charity, Whizz Kidz.

Kate opened by saying she felt like the annual sacrificial lamb. In the event this proved close to the truth, primarily due to the number of NHS employees present compared that of charity employees and supporters in the audience.

Kate stated that she was putting forward this proposal from the view point of recognised, national, well organised charities. She indicated that smaller local charities were not included. This was due to the fact that local charities rarely had the ability or knowledge to either appropriately advise or provide back up for donated equipment. Kate urged the audience to concentrate on the word 'best'. Charities she argued are able to offer; money, time, and specialisation. For example, Whizz Kidz and similar organisations (e.g.Muscular Dystrophy Group, Scope and ASBAH) have knowledge and experience in a specialist field. They employ their own therapists and fund raisers and thus the combined knowledge of their many members.

Introduction of the voucher scheme had not opened the door wide enough for people to obtain the equipment they required. There was particular concern about children in the younger age groups.

The charities should not be opposed to statutory provision, but should work alongside and support it. They can be invited into clinics as part of the team, whilst finding the financial means to fund appropriate equipment. The fact that equipment provided by the NHS in one area is not necessarily available in another creates problems for users and their families. They are unable to understand why obtaining appropriate equipment depends not so much on clinical need but address. Charities have no such divisions and can provide at any price from any range. In addition to this, Whizz Kidz, and other charities can provide training for therapists. They work to high standards, are aware of regional variation and will never interfere or take over unless requested.

Some assessments can take several hours or be extended over a long period of time. Charities are more flexible and able to cope with this compared to statutory bodies. In addition they have the support of a team of fund raisers and trustees to ensure appropriate use of money. Their members, through user groups, are a valuable source of information regarding the value and suitability of equipment.

Charities do not retain ownership of equipment which places greater onus on individuals to use and care for the equipment provided, although help can be obtained in the case of hardship. Charities are not restricted by red tape and unrealistic budget levels.

Opposing the motion Henry Lumley admitted that this was the first time he had spoken up on behalf of the NHS. Best is all very well he stated, but the NHS can provide:

- ⇨ A seamless service for all age groups
- ⇨ A total package of care
- ⇨ Multi professional input

They have:

- ⇨ a requirement to meet clinical need
- ⇨ a minimum obligation to each person
- ⇨ an obligation to serve users of all abilities that could not be matched by charity provision
- ⇨ a national perspective.

Expanding on the seamless service, Henry stated that this covers referral, professional assessment, either in a clinic or in the home, issue of equipment, a responsibility to maintain all equipment and provide review as and when required. In addition to the range of professionals available in the assessment team, there is easy access to specialist and other units. The NHS provide an overall package of care with options to change an inappropriate prescription.

With regard to funding issues, he stated that block contracts reduce costs with overspend being carried by the Trust. The service is supported by the wider Department of Health and, despite trust status, there continues to be a wide sharing of knowledge, such as the meeting of PMG. The NHS provide a service by right and not by charitable status. It is not a selective service.

Keiron Slocombe, speaking from the suppliers point of view, supported the motion presented by Kate. A high proportion of business for the suppliers comes from the charities who have an increasing number of professional advisers and, due to their business like approach, take advantage of discounts by meeting payments quickly. Where, asked Kieron, do users go when the system cannot or does not support them? To the charities. This gives them freedom without any of the NHS bureaucracy. Assessment to delivery time is far quicker. Response to problems is prompt due to instant payment and less paper work.

Charities support development of new ideas, prototypes and pilot projects. They frequently support the suppliers in other ways, such as combined training schemes. They bring together all the best for each individual without any of the negative issues which are found in the statutory bodies.

Roy Nelham, supporting Henry Lumley in opposing the motion, said that he felt passionately about this debate and that posture and mobility needs were definitely not best met by charities. The charities are a one off snapshot service whereas the NHS are there before, during and after provision. It is also rare to find a truly multidisciplinary team in any charity. Children need a rapid response which charities can't provide because of long delays in provision whilst money is raised. Roy supported Henry's views that the NHS have a clinical responsibility, are there for all and all are treated alike.

Charities often adopt an attitude which emphasises disadvantage, e.g. the 'what a shame' approach

provoking sympathy to raise money. They are in danger of disempowering people whereas the NHS encourages independence. If an individual demonstrates challenging behaviour the charity are likely to leave them and move on to the next request, whereas the NHS see it through. Charities do have a role to provide assistance in posture and mobility working in partnership, but they cannot meet needs best on their own. They can never replace the NHS where there is equal access, equal status and no disempowering of individuals. Charities dip in and out of people lives whereas the NHS cares about people and their lives - long term. NHS rules. It does it better and is good for users. Following a brief summing up from both sides, the debate was opened for discussion. The two opening speakers, both from the field of paediatrics, indicated support for using charities. The NHS was frequently slow and could not always provide the prescribed modifications or accessories. Both speakers used charities in order to get the best for their clients. On the other hand, more than one speaker felt that charities supported children to a certain age and then abandoned them. Kate agreed that this could be so as charities were set up to deal with specific age groups or disabilities.

Alan Turner Smith pointed out that Universities are classified as charities and they frequently picked up some of the more tricky problems where the NHS had failed. Whilst another speaker questioned whether charities might, in some cases, be used as a 'let out' for the NHS.

Dr. Elizabeth White, from Canterbury, pointed out that both of the speakers who opposed the motion came from specialist units. Smaller units may have greater need of charity support. More than one speaker accused charities of using any support for local publicity and others said that raising money for equipment was often of similar duration in equipment provision to the NHS. There were also accusations from both sides of the debate that incorrect prescriptions by one had to be corrected by the other. The charities were accused of

picking up on NHS mistakes in order to get publicity.

Dr. Linda Marks pointed out that the NHS was an enormous organisation and supplied to thousands of people, whereas charities picked up on a very few. She would challenge whether charities could cope with the same numbers.

It was pointed out that one of the most recent successes in the NHS was the provision of EPIOCs. The introduction of this scheme had been due to the hard work and pressure placed on the government by the charities led by the MDG. Whilst acknowledging this was so, it was questioned as to why the charities had insisted that the scheme should then be run by the NHS. Was this because the charities were not well enough organised to run the scheme as efficiently as the NHS?

Charities and the NHS both do different things and both do them well, stated one participant, whilst Pru Cartwright, Manager of the National Wheelchair Mangers forum, felt we should be looking at collaboration and not competition.

Following a brief summing up the vote was taken resulting in a defeat for the motion. Whilst not agreeing that provision by charities is best, it was clearly felt that charities had an important role to play in supporting NHS provision.

Warming up.....

...and enjoying, Pandemonium!

ResMag Update

NEW! IMPROVED!

The Rehabilitation Engineering Services Managers Group has changed its structure, but before I describe this and how it will work, it may be useful to relate something of the history of this now well-established and hardworking group.

In 1990(?) Dr Peter Woodford, the then Chief Scientific Officer to the Department of Health, called together 10 good men and true as follows:

Louis Blache
Alan Calverd
Peter Herbert
Denis Hill
George Hindhaugh
Philip Lowe
Alan Lynch
Warren Macdonald
Roy Nelham
David Rowley

This group was called TIRE (Training in Rehabilitation Engineering) but actually was quite tireless in working to produce a training manual entitled First Stage Technician in Rehab Engineering. This was published in December 1991.

During that year Alan Lynch formed a small group called TTGM (Technical Training Group in Mobility), to feed comment to TIRE during the latter stages of development of what became called the basic training manual. This group comprised several of the engineering services managers based at DSCs around the country.

The manual was officially launched in March 1992 at Hannibal House at a meeting addressed by Lord Holderness with presentations by most of the TIRE group members.

Dr Alan Calverd of the Department of Health introduced plans for an advanced in-service training manual and the TTGM had significant input to that document. This was published in November 1992 and officially launched in March 1993 at Skipton House.

By now TTGM had been renamed RESMaG and regularly had representatives from 12 of the 16 English regions at our meetings. In May 1994 we started on two major projects. First was the development of standards of practice for REs and this was initiated by an approach from some wheelchair service managers in North Thames (East). The second was the writing of a constitution.

The first was a mammoth task which seemed to go on for ever, through umpteen drafts, but looking now at the publication date of May 1996. I think the boys and gels, for we had much help from our therapist colleagues dun good. The committees of the BES and IPSM, joined later as the IPEMB (now IPEM), providing useful comment to refine the document to a publishable and workable standard.

The constitution appeared at about the same time.

In the meantime the first of our sub-groups had been launched. The RESMaG Limb Group, now called POIG (Prosthetics and Orthotics Interest Group) had its inaugural meeting in November 1995 at Birmingham.

The Electronic Assistive Technology Group got off to an excellent start in March 1997 at Hull and a review of its meetings to date, by Donna Cowan of CORE, appeared in the Spring 1998 issue of REview.

July 1997 saw the publication of the second standards booklet, covering services for wheelchairs and special seating and as I write POIG has its standards at an advanced stage of draft.

Also during 1997 approaches were made by and to Wales, Scotland and Northern Ireland about representation.

Now, the changes. RESMaG started very much as a wheelchair topic group because in truth that is the business area in which most rehab engineers and technicians work. With the success of the POIG and EAT sub-groups it seemed to us about time to take the wheelchair and seating business out into a similar group and have an umbrella board or council meeting less frequently.

The changes have been agreed and RESMaG will now have a council comprising of a chair and secretary for each of the topic groups, two members from each of the eight English regions, two members each from Scotland and Wales and one from Northern Ireland. As before there will be a representative from CORE and from MDA.

The topic groups will have 51% of the voting power on the council and a new constitution is being drawn up.

We envisage that the council will deal with the more global issues such as education and training, contract matters, publications, and liaison with other national groups.

The inaugural meeting of the Wheelchair and Seating Interest Group will take place in Birmingham on 9 July and the main council first meets on 22 September. I am sure this refocussing will lead to further and greater developments and improvements for all those working in the field of rehabilitation engineering in its fullest sense.

René Parison
Rehabilitation Engineering Manager, Harold Wood

INDEPENDENCE FOR LIFE THROUGH MEDICAL CENTRE OF EXCELLENCE emPower 27th May 98

This well attended conference focused primarily on the work of the DSCs and in particular on the recent changes that have taken place in the provision of environmental controls and communication aids.

The morning session was introduced and chaired by **Lord McColl**, who suggested that in spite of constant changes we should not become like the army platoon who, finding themselves lost in the desert were visited by a senior officer. 'Do you know who I am?' he asked on arrival. 'Blimey' said one of the troops 'This is a fine state of affairs, we don't know where we are and he doesn't know who he is!'

Using illustrations from his work as a surgeon at Guys, Lord McColl indicated that we should concentrate on the needs of our clients and not be diverted by red tape and unnecessary dogma.

Severely enabled - achieving independence through Electronic Assistive Technology (EAT) was the title for the morning session. **Roger Potter**, a Consultant Medical Physicist from Lincoln, looked at recent progress in the field of environmental controls, whilst **Dr Clive Thursfield**, Clinical Manager of the Regional Centre at Birmingham, provided some interesting statistics. He stated that only 25% of environmental controls issued in the past were in fact being used. Today the average cost of an environmental control system is £2,000. These could benefit some 8,000 people. He explained the work of the ACT centre at Birmingham and the value of communication aids. Dr. **Emlyn Williams**, Consultant at Aintree Centre for Assistive Technologies has responsibility for provision of environmental controls in the North West Region. He said that on average there are 100 systems per million population, though there are noticeable variations around the country. Suitable systems can be made available off the shelf for many. His team provide:

- comprehensive assessment by medical and professional personnel for potential users
- quick provision, good maintenance and reliability for eligible individuals

His figures showed that the majority of users have neurological conditions with MS being the largest group.

Dr. Williams was critical of the funding split between different agencies and in particular the fact that children supplied with communication aids by the education department were often prevented from taking them home. He ended by stating that integration between services is essential if people are to truly benefit from EAT and feared that primary care groups purchasing their own services could create a danger for specialist services such as Environmental Controls. Devolving these small and specialised services simply would not work.

The final speaker of the morning, **Dr. Rajiv Hanspaal**, explained how the EC service ran in North Thames. Based at Hillingdon, the service has 441 users; 5 co-ordinators (therapists); 11 assessors (doctors) and undertakes 90 to 100 installations a year. A survey undertaken to assess the use of existing installations

had found that many systems were not being used due to inappropriate placing of equipment, poor maintenance or the user simply not wanting a system. Whilst providing people with greater independence, environmental controls could not replace a carer, though they could improve the quality of life for carer as well as user. North Thames now had funding to run a one year pilot project to identify how many people require environmental controls plus communication aids.

During the lunch break delegates were able to look at the exhibition of a variety of environmental control systems and communication aids. The afternoon session was chaired by **Dr. Dougal Morrison** from Oxford who spoke about the BSRM publications on setting standards. Four short presentations followed providing an overview of wheelchair provision and the current situation in DSCs in general. Whilst **Joe Hennessy** from the Muscular Dystrophy Group criticised the variation in standards of provision countrywide and proposed there should be a national focus and agreement on service standards. **Stephen Bradshaw** from the Spinal Injuries Association related two cases where need had not been met, clearly illustrating some short comings in the service where policies prevented addressing individual and special needs. **Sam Gallop** from the Limbless Association and chairman of emPOWER spoke briefly on the achievements of the specialist centres and their need to build upon existing success, and **Patsy Aldersea**, a wheelchair service manager reported on a basic research questionnaire sent to wheelchair services in England prior to the conference. Before the meeting was opened up for questions and discussion, **Ian Nixon**, Planning Manager for Kingston and Richmond Health Authority provided delegates with information and views on the White Paper; Green Paper and the present document on specialist services which is now out to consultation.

During discussion time it became clear that many of those present felt that there was a need for a central body and voice to represent the specialist services. It was suggested that emPOWER might take on this task. **David Condie**, from Scotland, expressed disappointment that the BSRM documents on standards had been produced exclusively by a medical group without input from other disciplines or interested parties. **Dr. Morrison** stated that this was an important and relevant point. The drafts had been circulated widely for comment prior to publication but he recognised the need for wider communication and co-operation.

A member of the audience, using his communication aid, criticised doctors and nurses who in their ignorance regarded his communication aid as a game and would address his carer rather than speak to him directly. The audience acknowledged that this was an area neglected in medical training.

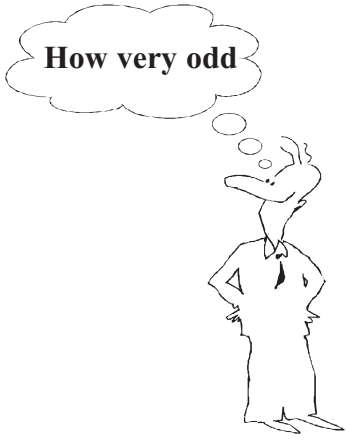
The day provided delegates with a range of information and opportunity to air some of their problems. It is hoped that having set up such a well attended consensus conference, emPOWER will find a way of carrying the views of the delegates on to the decision makers.

Patsy Aldersea
Wheelchair Services Manager, Merton and Sutton

"Is this what the funding crisis in the NHS has brought us to?"

We requisitioned for "Snow tyres" for fitting to Apollo wheelchairs. The requisition eventually came back from finance who felt that we were wasting valuable resources by purchasing snow tyres in April.

A patient with a non-united fracture of the tibia said that the doctor had told her she could wear the special boot and splint for life or that she might be able to have a "BONE GRANT".



PMG News

Results of the elections for the four vacancies on the PMG Committee, 1998.

At the 1998 Annual General Meeting at Hull, six nominations were received for candidates wishing to be elected to the Committee of the Posture and Mobility Group. All nominations were in order and in accordance with the Constitution of the Group a postal ballot of the full membership was held. Dr. Alan Turner-Smith, retiring Meetings Secretary, was the Returning Officer.

The closing date for receipt of voting slips was the 29th May 1998 and the voting was as follows:

The following are duly elected to the Committee of the Group:

Roy Nelham
Philip Swann
Barend ter Haar
Christine Turner

I wish to express my thanks to all the candidates, especially Dave Calder who is stepping down after three years of work on the committee. Thanks also to the Returning Officer and to all those who expressed their voting intentions. I have already welcomed the new members to the Committee.

Robin Luff FRCS FRCP
Chairman, PMG

Exploration of a Millenium Scientific

Discussions are currently under way with a view to exploring the possibility of a joint meeting with ISPO in the year 2000. The area of common interest between ISPO and PMG is likely to be orthotics and the meeting is likely to be in the autumn of the year 2000. There is much work to be done exploring the financial implications, exhibition organisation and, last but not least, the venue. Roy Nelham has been nominated to represent the PMG and he is working with David Simpson, Chairman of the Scientific Meeting Sub Committee of ISPO to draft a formula which will be submitted to both organisations for approval. The next meeting between Roy and David is due to take place during the summer.

Eur Ing R L Nelham, B.Eng, C.Eng, MIMechE, FIPEM, FISPO,
Director, Rehabilitation Engineering Unit,

Congratulations to Dr Marks and Phil Swann for winning the two best free papers at Hull 98.

Dr Marks' excellent paper entitled 'experience with phenol blockage in 'unseatable' clients' presented respective data on the outcome of phenol Blockade in 8 patients, who because of spasticity, painful spasms and/or lower limb contractures were having difficulty or were unable to sit. Indications for Phenol blockage and practical details of the technique were described. The results showed gratifying functional gains and improvement in quality of life.

Phil Swann presented an honest paper entitled 'in search of high speed seating, the on site solution' in which he described a process of analysis which highlighted the critical delay in the provision of seating, to be within the NHS. He went on to show how this could be improved with service providers and manufacturers working closer together.

The PMG would like to extend a **BIG THANKYOU** to all the exhibitors listed below for their support in making the annual conference at Hull such a success.

Manufacturer	Address	Telephone No.
Active Design Ltd	Unit 68K, Wyrley Road, Witton, Birmingham, B6 7BN	0121 3267 506
BES Rehab	9 Cow Lane, Fulbourn, Cambridge, CBl SHB	0122 388 2105
Cambridge Medical Books	PO Box 16598, London, SW6 3ZZ	0171 736 2067
Delichon Ltd.	King's Yard, Martin, Fordingbridge, Hampshire, SP 3LB	0171 5519406
Disability Information Trust	Mary Marlborough Lodge, Nuffield Orthopaedic Centre, Headington, Oxford OX3 7LD	0186 522 7592
Hampshire Medical Developments Ltd.	Apollo House, The Quadrangle, Abbey Park Romsey Hampshire, S051 9AQ	0179 451 1555
Kendall - Camp Orthopaedic	30-32 Sovereign Road, Birmingham B30 3HN	0121 433 4411
Nursing Care Products Ltd.	Pegusus House, Waterberry Drive, Waterlooville, Hants P07 7XX	0170 578 4280
Otto Bock Orthopaedic (UK) Ltd.	32 Parsonage Road, Englefield Green, Egham, Surrey, TW2O OJW	0178 443 8841
Qbitus Products	Unit 12 Lightowler Road, Halifax, HX1 SND	0142 2381188
Radcliffe Rehabilitation Services	5 The Sidings, Top Station Road, Brackley, Northants, NN 13 7UG	0128 070 0256
RBF Healthcare Ltd.	55 Comet Way, Southend on Sea, Essex SS2 6UW	0170 252 7401
Rehabilitation Manufacturing Services Ltd.	Medway House, 277 Gillingham Road, Gillingham Kent, ME7 4QX	0163 457 8881
Sumed International (UK) Ltd.	Unit 1 Wildermere Road Ind Est., Banbury Oxfordshire, OX 16 7TL	0129 527 0499
Vine Seating & Support Ltd.	PO Box 193 Ampthill, Beds, MK4S 2HG	0152 584 1348

Minutes of the Hull 98 Annual General Meeting will appear in the winter 98/99 Newsletter.

POSTURE AND MOBILITY GROUP FOR ENGLAND AND WALES CHAIRMAN'S REPORT TO THE ANNUAL GENERAL MEETING April 28 1998 THE QUALITY ROYAL HOTEL, HULL

INTRODUCTION

It is an honour and a pleasure to report to the 1998 Annual General Meeting on the activities of your professional association, the Posture and Mobility Group of England and Wales - and indeed several other countries. This has been an active year for the Group culminating in playing a major role in Dundee '97 which was perhaps the most significant academic meeting in our field of work for some years.

THE COMMITTEE

Since the international meeting in September took the place of our normal Spring annual conference, and since the membership of the Committee did not require alteration, your Committee was elected enbloc for a further year. I pass on to the members of the Committee my very real thanks for their assistance in promoting the activities of the Group. With many regrets I inform the membership of the resignation of Tony Harman who fulfilled the roles of Treasurer and Membership Secretary from the very earliest days of the Group's existence. He has left the UK to live and work permanently in Australia and I am sure you will all wish him and his family every success. He says he would be pleased to welcome visitors...

With equal regret I inform you of the resignation of our Meetings Secretary, Alan Turner-Smith. Alan has been an invaluable asset to the Committee but following his promotion to Reader in the King's College School of medicine and Dentistry his work load has increased to the extent that he is unable to continue his Committee role. Fortunately, he will continue to bid for the role of our Conference organiser since he retains his role in the Centre for Rehabilitation Engineering. As a result of other members of the Committee completing their periods of tenure, there are a total of four vacancies to be filled at this Meeting. A postal ballot of the membership is necessary only if the number of nominations exceeds the number of vacancies. I apologise on behalf of the Committee for the problems with getting information about the nomination process to you all, this arose from problems with publishing the last Newsletter which were entirely outside our control.

RECRUITMENT

This has been a good year for the Group assisted greatly by its high profile at Dundee '97. A number of new members joined, encouraged by the Guidelines document and by the book subsidy, Since we now have members from a number of other countries, perhaps we should consider amending the name of the Group.

THE CONSTITUTION

We shall be debating and voting on substantial changes to the Constitution at this meeting. These are necessary to remove some irregularities still present despite several previous series of amendments. I am grateful to Roy Nelham for his painstaking revision of the Constitution which he will present to this Meeting. There is a Motion from the Committee relating to membership fees, which we will debate.

EDUCATIONAL ACTIVITIES

The Committee is conscious of the importance of the educational role of the Group and has sought ways of fulfilling this role to the best benefit of the membership. The Group is reasonably secure financially, needing to keep sufficient reserves to fund the next Conference and to maintain the Newsletter. We were able to provide Bursaries for Dundee '97 and to provide members attending the Conference with a substantial discount against books purchased at the Conference. With the co-operation of Cambridge Medical Books we have been able to repeat this incentive to members attending this Conference. Subject to our financial position we shall continue this activity for future Conferences.

PUBLICATIONS

After considerable efforts on the part of a sub-group of the Committee, the Group has published an updated and revised set of Guidelines for Wheelchair Services. I recognise here the work of David Calder who was instrumental in pulling together a number of disparate sections into a cohesive whole. This substantial loose leaf - which may therefore be updated - volume was launched at Dundee '97. This has been widely circulated but there are copies in reserve if any member wishes for a particular individual or service to be provided with a copy. The Committee will review this

document but welcomes any contributions from the membership.

Part of the Group's role at the Dundee Meeting was to record and precis all the sessions of that Meeting. This has now been published and circulated to the membership. A further print run was commissioned by the Scottish Wheelchair and Seating Group. The Newsletter continues its successful development under the managerial control of Phil Swann and his team. Although the Newsletter is an expensive document to publish, it is an excellent vehicle for promoting the aims of the Group.

CONFERENCES

Dundee '97 has been mentioned already. Reports have appeared in the Newsletter and as a separate document. This was a highly successful meeting and has led to closer ties with the Scottish Group regarding further collaborations. The 1999 Conference for this Group has yet to be finalised; Bath and Cardiff are under consideration but as ever the Committee will welcome your suggestions. Your Committee is at the outline planning stage of a substantial joint conference for the Millennium or Y2K, as I believe the techies - those who understand Redwheel - would have it.

NATIONAL ISSUES

It is quite clear that the Benefits Agency is trying to reduce the provision of what usually seem to be entirely appropriate benefits to the population with disability whom we serve. Whilst this report should never be political tract - perish the thought - I believe we have duty of care which includes supporting those who have a right to benefits. The new Government has published its plans to dispense with commissioning by Health Authorities and setting up instead a much larger number of locality purchasing groups which will be strongly influenced by General Practitioners. We will have much to do to ensure the preservation of our funding. This is equally true for the resources allocated to EPIOC provision - a good thing - and to the Voucher Scheme, which I believe, is not such a good thing. The important point is that if these resources are not used, they will be withdrawn by the Treasury and thus lost to our population. You may be able to negotiate with your current Commissioners about appropriate issues.

CE MARKING AND THE MEDICAL DEVICE DIRECTIVE

This is a series of issues which, if they were not of such importance to our services, I would be inclined to satirise. This legislation which comes into effect in the UK in the near future has profound implication for our services and I encourage our engineering membership in particular to see the positive elements of the forthcoming changes lest it appears merely to be 'jobs for the boys'.

CONCLUSION

Finally, my thanks to all those who have helped in furthering the Group's aims in the last year. It is easy to omit thanks, which may be owed, and I trust that the membership will understand any unintentional oversights. I look forward to another year as your Chairman subject to the agreement of the new Committee, which you will elect shortly.

Robin Luff FRCS FRCP
Chairman Posture and Mobility Group for England and Wales

Constitution of the Posture and Mobility Group of England and Wales Version 98/0.2

1. Purpose

To promote improvement in and dissemination of knowledge about the posture and mobility needs of people with disabilities and about the equipment and services those needs require within a framework which recognises the rights and dignity of such people.

2. Aims and Objectives

2.1 To develop an interdisciplinary forum for continuing education, research and debate in the interests of the general public and of people with disabilities in particular.

2.2 To provide an umbrella organisation linking members of voluntary and statutory agencies, representatives of users' bodies, and representatives of manufacturers.

2.3 To maintain a register of members to enable efficient communication.

2.4 To encourage the establishment and maintenance of high standards of service delivery

3. Membership

Membership is open to all persons who:

3.1 have a professional, educational, research or commercial interest in the delivery of products or services meeting posture and mobility needs of people with disability;

3.2 are members of users' organisations; or societies judged appropriate by the Committee on behalf of the membership.

4. Individual membership confers:

4.1 a single non-transferable vote;

4.2 the right to be nominated to membership of the Committee;

4.3 receipt of the newsletter;

4.4 a copy of the conference proceedings;

4.5 a discount or benefit in kind (to be decided by the Committee) for conferences and meetings organised by the Posture and Mobility Group.

5. Committee

5.1 The Committee will comprise not more than ten members who may serve for a maximum continuous tenure of three years, ending with the third AGM following their election to the committee.

5.2 Committee members must stand down after this time but are eligible for re-election.

5.3 The Committee will elect the Chairman, Vice-chairman, honorary treasurer and membership secretary from the Committee membership. The Posture and Mobility Group seeks to encourage a mix of skills and disciplines on the Committee by nomination and the democratic process.

5.4 The three-year tenure of Committee members shall be extended in the case of holders of the offices within the Committee - Chairman, Secretary, Treasurer, Membership Secretary - to be three years from appointment to that office. Such members may thus serve for a continuous period of more than three years overall in the interests of continuity.

5.5 The Committee shall co-opt additional members as necessary for the business of the Posture and Mobility Group.

5.6 The Committee shall meet at least four times a year to conduct the business of the Posture and Mobility Group.

5.7 Five elected Committee members shall constitute a forum.

5.8 Nominations for election to the Committee shall be included with the Newsletter preceding the AGM. The Nomination should be seconded and

clearly state that the Nominee is willing to stand for election. Election shall be by simple majority. Single marked voting slips will be posted to all Members of the Society. Votes must be returned in person no later than 1 hour prior to the AGM or by post to arrive 5 days before the AGM.

6. Finance

6.1 An annual membership fee shall be paid by all individual members, the amount being that agreed by the Committee and endorsed by the Annual General Meeting.

6.2 Membership fees are to be paid by the 1st January for the forthcoming membership year.

6.3 Any change in membership fee will be agreed by the membership present at the Annual General Meeting.

6.4 Members will be asked to complete a standing order for payment of membership. The fee may be invoiced on request. The fee for invoicing shall be set by the Committee and reviewed annually.

6.5 The accounting year for membership shall be the calendar year, 1st January to 31st December. All membership subscriptions will thus become due on 1st January.

6.6 Any member failing to pay the requisite fee following one reminder by 28th February of the current membership year shall on that date lose the rights and privileges of membership and shall be required to re-apply for membership of the Posture and Mobility Group.

6.7 A statement of account of the financial affairs of the Posture and Mobility Group shall be made available for each financial year to each member.

7. Annual General Meeting

7.1 The Annual General Meeting shall take place during the National Conference of the Posture and Mobility Group.

7.2 The business of the Annual General meeting shall include:

7.2.a consideration of reports for the year;

7.2.b reviewing and, if appropriate, proposing revisions to the constitution:

7.2.b.1 any revision must be decided by debate and a card vote at the Annual General Meeting of the Group,

7.2.b.2 a simple majority shall be sufficient to approve the revision,

7.2.c deciding questions of general policy, other than constitutional issues, raised by the Committee or by members. Such questions must be forwarded to the Meetings Secretary to arrive at least six weeks before the date of the Annual General Meeting.

7.2.d approving membership fees for the coming year

7.2.e appointment of an approved accountant or accountants for the forthcoming year.

7.3 Ten percent of the membership shall constitute a quorum.

26 February 1998

Post Bag

Dear Phil,

I attended my first Posture and Mobility Group conference at Hull in April and was pleased to be able to present two papers. I found the two days stimulating and interesting. During the conference I became aware of how few services are able to offer an integrated service that allows assessment, prescription and provision of postural management equipment in all positions. I understand the remit of the wheelchair services is only to provide special seating linked to mobility. The inability to link this with postural support in other positions must lead to a fragmentation of the services leaving the provision of positioning equipment in lying and standing to the vagaries of local services. Children and young adults are particularly vulnerable as twenty four hour postural management programme is becoming increasingly recognised as a way of improving ability and reducing deformity. Only tackling posture management in the sitting position risks the work being undone by postures adopted in other positions.

The Posture & Mobility Group, as it names suggests, is the only organisation that exists to promote excellence in this field and I feel that it could have a particular role in influencing changes and promoting co-operation in the way wheelchair and local services work together to assess and provide equipment for individual clients.

I would be interested to hear the views of the PMG committee and the membership in regard to PMG taking on the role of a pressure group to work towards improving the provision of services and moving forward to a more integrated approach to postural management provision.

Yours sincerely,

Terry Pountney
Research Physiotherapist, Chailey Heritage Clinical Services

Standard Butt?

Peter Axleson's group at Beneficial Designs Inc of Santa Cruz, CA, have come up with a standard 'Butt' as the Americans refer to it. At RESNA '98, Allen Siekman described how he and his colleagues had developed their Seating Interface Tester (SIT) by taking a mold from a T6 spinal cord injured 35 year old male. To ensure the correct shape of the 'butt' the subject was suspended over the mold box in a pool of thin solution of alginate casting material. Thereby they avoided deformity of the soft tissues. The final SIT was created by using a model of a male pelvis with full femurs embedded in gel shaped by the mold. The final tests of SIT butt on a FSA pressure mapping sysytem produced results which were very similar to those produced by the original model. The team appreciated that this would need to be one of a series of models for different sizes, disabilities, sexes, ages, etc. However, they did establish that it was possible to create a model which reproduced (static) actuality realistically.

Notice Board

Date	Venue	Title	Contact
September 1998			
9 - 10	Wembley	Independent living show	tel. 01275 831 754 fax. 01275 892609
18 - 19	Oxford	CIGOP - Linda Beyon	tel/fax. 01244 0365 244/000 bleep 3012
October 1998			
26	South England	Helping Gravity Help You, given by	tel/fax. 01223 882105
28	Midlands	Thomas R Hetzel, ATP.	email: besrehab@thefree.net
29	North England		
November 1998			
19	Atlanta	19th Medtrade Conference and Exhibition	tel. +441536 710050 fax. +44 1536 418280 email. Medtrade99@aol.com
24	**Birmingham**	**RARE 98 at the Botanical Gardens**	**tel. 0171 737 4000 ext. 5282**
30	South England	Pressure Mapping and its Clinical Benefits	tel/fax. 01223 882105
		given by Bern C Taylor, PT, MCPA	email: besrehab@thefree.net
December 1998			
2	Midlands	Pressure Mapping and its Clinical Benefits	tel/fax. 01223 882105
3	North England	given by Bern C Taylor, PT, MCPA	email: besrehab@thefree.net
7 - 9	Amsterdam	2nd International Workshop 'Biomedical	tel. +31 (0)20 4448470/8530
		Aspects Of Manual Wheelchair Propulsion:	fax. +31 (0) 20 4448529
		The State Of The Art II	email. m-l-den-besten@fbw.vu.nl/
			b-oudejans@fbw.vu.nl
March 1999			
4 - 6	Orlando, Florida	Fifteenth International Seating Symposium	fax. 001 412 8257
			email. szczepanskill@msx.upmc.edu
April 1999			
?		**National Conference of the PMG**	**tel. 0171 737 4000 ext 5282.**
June 1999			
25-29	Calaforinia	RESNA	

Seating Standards

Over the last twelve months a working party (WP) has been meeting in the UK to promote an initiative to set up international standards for cushions and other devices used for seating and positioning. This WP is part of the Seating and Positioning Group of the British Healthcare Trades Association (BHTA - formerly BSTA), and is chaired by Ray Hodgkinson of Raymar. Membership of the WP includes representation from clinical, research, and industry interests. To date the WP has established the criteria which should be considered for appropriate standards, and classified them into half a dozen relevant groupings.

Meanwhile RESNA has been starting up a similar initiative in the States. At their annual meeting in June in Minneapolis, they agreed to work on a four part standard on wheelchair seating technology as volume 3 of Draft National Standard on Wheelchair Seating Devices. The sections and their chairs are to be:

Terms and Definitions (Kelly Waugh)
Pressure Management Devices (Tricia Karg)
Postural Support Devices (Anita Perr)
Seating Devices for use in Motor Vehicles (Gina Bertocci)

Jean Minkel is co-ordinating the activities of all three sections. The UK WP is aiming to co-ordinate its activities with those of the RESNA groups, as well as with other bodies in Europe, Japan, etc. which are currently working on seating standards.

For further information, please feel free to contact Ray Hodgkinson at Raymar tel. 01491 578 446 or Barend ter Haar at BES Rehab Ltd. tel 01223 882105, berrehab@thrfree.net. Editorial Team and Cover Info6 or Barend ter Haar at BES Rehab Ltd. tel 01223 882105, berrehab@thrfree.net.

If you would like to advertise in the PMG Newsletter contact Phil Swann – Editor for details.

On 21/09/98, Chailey Heritage Clinical Services will move into a new, purpose built building building alongside Chailey Heritage School. The new address will be Beggars Wood Road, North Chailey, Nr. Lewes, East Sussex, BN8 4JN. Once settled we will begin to organise seminars and meetings. Watch this space - and many others!

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Hard work this conference business!!

The next issue of the Newsletter will be in **January 1999**. The deadline for this issue is the **16th of December**. The aim of the Newsletter is to keep members in touch with current events in the world of posture and mobility and to provide the opportunity to share ideas and learn of new initiatives. Articles, should be between 500 and 2000 words, photos and/or cartoons are welcome as are jokes and mindbenders etc. Please send contributions printed or on disk.

The PMG Newsletter is published by the Posture and Mobility Group. The views expressed are those of individuals and do not necessarily reflect those of the Group as a whole.