

Spring/Summer 2014

# Syn'apse

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**Management of sleep disturbance in multiple sclerosis: a survey of current practice in the UK**

**From pitch to pool: aquatic physiotherapy in brain injury rehabilitation**

Sharing good practice: **Introducing the use of upper limb outcome measures within stroke care**

JOURNAL OF THE **ASSOCIATION OF CHARTERED PHYSIOTHERAPISTS IN NEUROLOGY**







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Cover image: MRI head scan by Domine (Fotolia)

### ACPIN'S AIMS

1. To promote and facilitate collaborative interaction between ACPIN members across all fields of practice including clinical, research and education.
2. To promote evidence-informed practice and continuing professional development of ACPIN members by assisting in the exchange and dissemination of knowledge and ideas within the area of neurology.
3. To provide encouragement and support for members to participate in good quality research (with a diversity of methodologies) and evaluation of practice at all levels.
4. To maintain and continue to develop a reciprocal communication process with the Chartered Society of Physiotherapy on all issues related to neurology.
5. To foster and encourage collaborative working between ACPIN, other professional groups, related organisations ie third sector, government departments and members of the public.

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# Forethought

## From the Chair

### Dr Gita Ramdharry

Senior Lecturer, St George's School of Rehabilitation Science, Faculty of Health and Social Care Sciences, St George's University, London, and Kingston University

### From the 2014 national conference

Two years have absolutely flown by and I have hugely enjoyed the varied nature of the role as Chair. I feel happy and confident to be passing the baton to Jakko Brouwers this year, who will bring very different experiences and skills to the job.

Our social media sites continue to be successful as a way of advertising CPD events and sharing information. We have 766 followers of our Facebook page and 445 followers of our Twitter feed. Many of the other professional networks now use Twitter regularly and there is a 'tweetchat' feed called @physiotalk which encourages live discussions of particular topics on a Monday evening. These discussions are archived and can be found on the physiotalk.co.uk website. ACPIN have also been using Webex as a platform for local CPD delivery using Jakko's expertise in this area. He has helped to set up Webex groups in Yorkshire and Northern Ireland. We are hoping to complement more of our CPD delivery with Webex to expand the possibilities of participation. Jakko's other role as Vice-chair is as the link person for NICE guideline work. ACPIN has registered as a stakeholder in several guideline development projects this year. We have supported some members to represent us at some scoping workshops and we will also contribute to the consultation of draft documents.

We have also contributed to some of the work of the CSP, updating the neurology section of the new manual handling guidelines; giving input to the *Physio works for stroke* document (thank you to Michelle Price) and *Physiotherapy works for Parkinson's disease* (Thank you to Bhanu Ramaswamy and Fiona Lindopp). Bhanu and Fiona are also very involved in the *European Guidelines for physiotherapists working with Parkinson's* and the CSP Skipp team are supporting this work. Our Welsh members have also been involved in compiling responses to the *Welsh Neuro Delivery Plan*. Also, our very

own Ralph Hammond became President of INPA, the International Neurological Physical Therapists Association which is a sub group of the WCPT. It is a collaboration of the neuro-physiotherapy interest groups from WCPT-recognised professional bodies. Cherry Kilbride is also on the committee and they are both involved in many aspects of work for INPA, with a particular focus on the WCPT conference in Singapore next year.

The joint ACPIN/COT SNPP splinting guidelines have recently gone to member consultation which closed on the 19th March. The team are starting to receive comments back from stakeholders (MD society, Headway, TiMS, Stroke Association, Different Strokes), in addition to ACPIN and COT SSSNP members. There will also be peer reviews by Therese Jackson, Prof Anand Pandyan, and Dr Mary Cramp. The team are meeting next week to start to revise the document in line with comments received and they are pleased to say that on the whole, it appears, the guidelines are being welcomed.

I'd like to remind people that ACPIN research bursaries of £1,000 continue to be available for members. So far this year, we have given out six. Application details are on the website. Also, a reminder that we launched the travel grants last year for people who are travelling to present research findings or work on specific projects abroad. We haven't had any applications to date. We also have a new costing structure for access to the membership. Most often this is people wanting to send research invitations and questionnaires to members. We only do this to members who have indicated that they wish to be contacted for research on their application form. This has also been extended to charges to commercial companies for advertising courses etc. Again, we only send commercial information to members who have ticked on their registration form that they are happy for this.

We like to give out prizes each year for the best *Syn'apse* articles. This year, we decided the two best were by Anneliese Brouwer and Ruth Witham. Congratulations to them. We also changed the way we look at posters and awarded three prizes for the abstracts presented at conference. Because of the number and variety of abstracts we received this year, we awarded two research and one service/practice development awards. Congratulations to our three prize winners.

We had a great conference and thank you to all of our sponsors, the Hilton events team for flawless organisation, Video Inn for the audio-visual support and Kevin Wade of kwgraphicdesign for the conference materials. Also, this year we used Eventbrite for the conference registration. We would like your feedback on how well this process worked. Thank you to Chris Manning and Jakko Brouwers for setting that up and dealing with registration plus Nikki Guck for liaising with our sponsors. Finally, it is always sad to say goodbye to invaluable members of the executive committee, but unfortunately we must bid farewell to Sandy Chambers. Sandy has served on the committee since 2007 and has worked particularly hard in setting up our membership system to allow online membership registration. This has been an extremely challenging role at times, so we thank Sandy for all that she has done. Despite switching her attention to moving back to the USA, she has continued to support Lorraine Azam who is taking on this role. We are extremely grateful and wish Sandy good luck with her move.

## Compliance, shared decision-making, old dogs and new tricks

### from the ACPIN President

#### Dr Fiona Jones

Reader in Rehabilitation, School of Rehabilitation Science, Faculty of Health and Social Care Sciences, St George's University, London, and Kingston University

**Bertrand Russell was a philosopher, mathematician and social critic who in 1948 delivered the inaugural Reith Lecture, an annual series of lectures still broadcast by the BBC. He was a social activist recognised for many great achievements and defending ideals such as 'freedom of thought', which underpins much of the Universal Declaration of Human Rights. A dip into the BBC archives or a book of quotations will easily lead you to Bertrand Russell, who, like other great writers and thinkers can distil a complex idea or proposition into a simple phrase, just enough to set you thinking on a slightly different route than when you set out. As Russell expresses, 'The greatest challenge to any thinker is stating the problem in a way that will allow a solution'.**

A work colleague recently quoted Russell to me about 'wise people being full of doubts' while discussing the concept of power-sharing and decision-making in neurorehabilitation. Who holds the answer to a problem? Is it the physiotherapist with their knowledge, expertise, experience and judgement or is it the individual who lives with their condition and the complexities it involves? Writers and thinkers about healthcare are also asking similar questions and now much of the policy research about how to support people to live well with a long-term condition involves the concept of shared decision-making. This suggests we have moved a long way from the concept of 'compliance', 'adherence' and latterly 'concordance', all of which seem to denote the possessor of knowledge is the professional. There is now greater appreciation that we as healthcare professionals may not always know the answer, although in many instances we still assume we do. The Health Foundation is an independent charity at the forefront of a programme of work to implement more person-centred healthcare services. They are initially focusing on shared decision-making and self-management support, which as they state 'requires a change in behaviour and mindset from healthcare professionals

and patients' ([personcentredcare.health.org.uk/about-us-0](http://personcentredcare.health.org.uk/about-us-0).) As more research builds in this area, it is becoming apparent that shared decision-making and self-management support are synonymous with each other, interpreted and needed in different ways by each patient, and require a culture change not just by individual professionals but by the organisation and team as a whole.

Going back to Russell. What is the solution to sharing power with patients? Aspirations, rhetoric and pathos are fine, but what does it look like and what does it sound like? We have competency checks for manual handling, but do we know if we are any good at shared decision-making, and does it matter? The Health Foundation has published evidence summaries on self-management support and shared decision-making which suggest it works, but not for everyone all of the time. So this doesn't yet give us a toolkit or route map as to the skills and techniques which work best. But we do know how powerful it can be to validate an individual's experiences and challenges of living with their long-term condition and create a shared agenda and plan. This was most eloquently expressed in a recent blog by a young woman with a neurological condition who wrote about a visit to

her GP who thankfully recognised that her pain management wasn't the most important thing for her at that time – she remembers 'The agenda for that appointment was person-centred, because we could focus on what was going to make the biggest difference to me. And that day, just sorting my medications wasn't going to do that'. [www.health.org.uk/blog/there-is-a-person-in-the-patient](http://www.health.org.uk/blog/there-is-a-person-in-the-patient)

Sharing decision-making will require more than the latest toolkit, or screening measure. It will require healthcare professionals to recognise that we don't have all the answers, but those answers may lie with the patient and their friends and families. This doesn't mean giving up our expertise, but using greater skills to tailor our knowledge and experience so that we can adapt our agenda with each patient and guide them to navigate through living with their long-term neurological condition. Our agenda,

timescale, and priorities may not be the same as our patients, and their perceived lack of motivation to adhere to treatments, could paradoxically be illustrative of a patient being very motivated – not to comply but to do their own thing! So it may in fact be a positive thing to change to a slightly different route than when we set out, I am sure we do this all the time, when we chat ideas through with colleagues, or share ideas with patients and their families. New research in all its forms will also help us to do this, but it can be a powerful testimony by one individual in a blog or a chat which brings ideas into sharp focus.

Finishing on a lighter note, and moving from Bertrand Russell to 2014, I am on Facebook but have very few friends- (don't really know why I have it, don't particularly like it) and I am on LinkedIn (but again not really sure why). But new tricks are indeed possible – I have now tweeted,

only single figures, but it's a start. Why bother? Well, in order to keep abreast of issues such as self-management and shared decision-making I follow opinion leaders including The Health Foundation and The Kings Fund, and because of this I found the great blog I mentioned. I know about things like 'hashtags' and that you can start a trend in any subject area. My 28 year-old nephew got me started and now I am off, so give it a go; it's not difficult and could be a great way of us all sharing and posting updates and ideas about different topics in neurorehabilitation.

By the time of publication ACPIN will have hosted the 2014 conference on 'Life and long-term conditions' and I am sure the subject of shared decision-making will be mentioned more than once – so check this out – [twitter.com/ACPIN\\_UK](https://twitter.com/ACPIN_UK)

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# Management of sleep disturbance in multiple sclerosis

a survey of current practice in the United Kingdom

**Multiple sclerosis (MS) is a chronic demyelinating disease of the central nervous system and is the most common disabling neurological disease in young adults (Murray 2006). The current lack of a cure means that symptom management to improve quality of life is the typical focus of treatment (Kesselring and Beer 2005). Usually this is undertaken by a multi-disciplinary team of health and social care professionals in partnership with people with MS.**

Sleep disturbance is reported regularly by people with MS; a recent review reporting that it is far more common than in the general population, with estimates ranging from 25% to 54% (Brass *et al* 2010). Sleep disturbance has been shown to adversely affect quality of life in persons with MS (Lobentanz *et al* 2004) (Caminero and Bartolomew 2011) and is related to an increased risk of morbidity. For example, heart disease, diabetes, obesity, depression, pain and fatigue have each been related to disorders of the sleep-wake cycle in MS (Clark *et al* 1992) (Merlino *et al* 2009) (Veauthier and Paul 2012) (Stanton *et al* 2006). The importance of assessing and managing sleep disturbance is therefore increasingly being acknowledged. Despite this it has been suggested that the frequency of sleep disturbance in people with MS is underestimated by clinicians (Caminero and Bartolomew 2011); with insufficient research available to inform clinical practice.

Sleep disorders arising during the course of MS may be secondary to numerous symptoms arising from the disease itself (for example, spasticity, spasms, restless leg syndrome, pain) or can be a primary problem (Fleming and Pollak 2005). By necessity, therefore, the assessment and management of this disorder is complex (Craig *et al* 2008), frequently requiring input from a range of team members, who utilise a variety of interventions that contain several interacting components. While a search of the literature highlighted growing evidence to support the clinical effectiveness of specific non-pharmacological treatments, either alone or in combination with drugs (Sateia and Nowell 2004) (Morin *et al* 1994), it failed to unearth any articles describing what constitutes routine practice by

nurses and allied health professionals working in this area either in the United Kingdom (UK) or internationally. In line with guidance from the Medical Research Council on evaluating complex interventions (Craig *et al* 2008), the aim of this survey therefore was to establish an initial understanding of current practice by UK-based nurses and allied health professionals involved in the care of people with MS.

## MATERIALS AND METHODS

This study gained ethical approval from Plymouth University Ethics Committee, Devon, UK.

### Research design

A descriptive, cross-sectional survey using convenience sampling.

### Sampling and recruitment

The target population was health care professionals in the UK who work with people with MS. Delegates attending the annual MS Trust Conference were chosen as the study sample since they were considered representative of the range of health professions routinely involved in MS management; and were likely to be motivated to complete the questionnaire, thus optimising the response rate. All were invited to take part; there were no exclusion criteria.

### The survey instrument

The literature search highlighted no relevant pre-existing survey questionnaire to establish current practice in the management of sleep disturbance. Consequently a questionnaire was developed, in line with established methods (Bowling 2000), as described below.

The initial stage of questionnaire development

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sought views, information and resources about the assessment and management of sleep disturbance (for example, assessment protocols and management regimes) from members of a national network of specialist MS therapists, via their web-based discussion forum ([www.therapistsinms.org.uk/members/forum](http://www.therapistsinms.org.uk/members/forum)). This information, together with that gained from the literature search, was used to develop an initial draft survey questionnaire. Members of the multi-disciplinary research team (n = 7), held a day-long meeting to review and refine this draft questionnaire; further subsequent iterations were undertaken by group members via e-mail until a version was developed which was considered suitable for piloting.

The draft questionnaire was piloted on 20 individuals, covering the range of health professionals intended for inclusion in the survey (nurses, occupational therapists, physiotherapists, psychologists, and speech and language therapists). The aim of the pilot was to establish the clarity and acceptability of the questionnaire items, and the face and content validity of the survey questionnaire (Bowling 2000). Specific feedback was sought in relation to ease of completion, wording and potential ambiguity or bias of questions, relevance and length of questionnaire, and whether there were any redundant or missing items. Using an iterative process, changes were made to the questionnaire in response to this feedback, and a second draft questionnaire was produced, which was re-piloted on a further five individuals. Following minor amendments to the wording of some

questions the final questionnaire was produced.

The final questionnaire, which had demonstrated to take no more than 15 minutes to complete, comprised 16 closed questions with categorical response options and one open-ended question for general comments. It was presented in four parts: the first part established background demographic details such as gender, professional role and work setting (six items); the second part established whether and how respondents assessed sleep disturbance (four items); part three explored methods of management of sleep disturbance (three items); and part four determined respondents self-ratings of levels of knowledge and confidence in managing sleep disturbance (two items). The questionnaire is available at: [www.therapistsinms.org.uk/downloads/Sleep\\_survey\\_questionnaire\\_example\\_FINAL\\_PDF\\_format.pdf](http://www.therapistsinms.org.uk/downloads/Sleep_survey_questionnaire_example_FINAL_PDF_format.pdf)

**Data collection**

All delegates were provided with the questionnaire in their delegate packs. They were requested to complete it and hand it into collection boxes during the three-day conference. Participation was voluntary and anonymous. Consent was assumed if the questionnaire was completed and handed in, as outlined in the accompanying participant information sheet.

**DATA ANALYSES**

Descriptive analysis of the data was performed using SPSS version 19.0 (SPSS Incorporated).

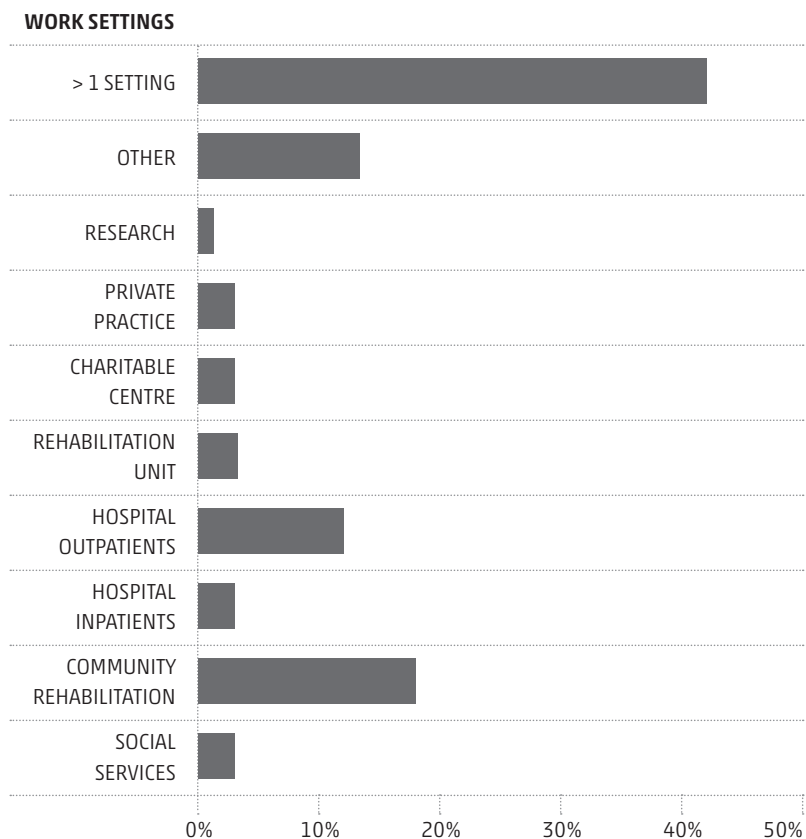
**RESULTS**

Of the 256 registered delegates (200 MS nurses and 56 allied health professionals), 181 delegates (71%) completed and returned the questionnaire. Missing data was very low; details for each individual item are described below.

**Sample characteristics**

Respondents (93% female, 168/181) reflected membership of the multidisciplinary MS team: 58% (103/179) were nurses, 21% (38/179) physiotherapists, 13% (24/179) occupational therapists, with the remaining 8% (15/179) comprising other team members including rehabilitation consultants, psychologists, speech and language therapists and academics.

Respondents worked across a wide range of health and social service settings (Figure 1). Typically, they worked as part of a multi-disciplinary team (74%, 131/177), and within an MS specific (58%, 101/174) or neurology specialist (29%, 50/174) environment. The considerable level of clinical experience in this sample is highlighted by the length of time since qualification: 77% (139/181) had been qualified for longer than 15 years, 8% (15/181) for eleven to fifteen years, 12% (22/181) for six to ten years, with just 3% (5/181) having qualified for five years or less. Notably, 44% (78/181) had been working specifically in the field of MS for more than ten years.



**FIGURE 1** Workplace settings of the respondents



### Assessment and evaluation

An overwhelming majority (86%, 152/178) considered sleep management to be part of their role, while 8% (15/178) did not, and 6% (11/178) were unsure.

When asked *how* they identified sleep disturbance with their clients only 3% (5/178) responded that they did not identify sleep disturbance as part of their assessment. Those assessing sleep disturbance used a variety of methods: 61% (105/173) included a specific question about sleep routinely in their initial client interview; 40% (69/173) gathered this information through direct questioning as part of a fatigue management programme; 68% (117/173) did so indirectly when questioning the client about other symptoms such as pain, spasticity or continence; and 28% (48/173) incorporated this within a mood assessment.

Respondents were asked *when* they identified sleep disturbance; the majority did so at initial assessment (70%, 128/177). When asked *how* they undertook this assessment, typically this was incorporated as part of their subjective history taking (49%, 89/177). While 13% (24/177) of people used a 'Patient Diary' to assess sleep disturbance, the majority of respondents (67%, 119/177) did not use a specific sleep assessment instrument as part of this process; with 35% (64/177) being unaware that such instruments existed. The standardised and validated sleep instruments used included global, patient-reported symptom questionnaires such as the: Epworth Sleepiness Scale (9%, 17/177), Visual Analogue Scale (4%, 7/177), Sleep questionnaire described in the *Birmingham Fatigue Management Manual* (2%, 4/177), and *Pittsburgh Sleep Diary* (1%, 2/177). No respondents at all reported using the following instruments: *Pittsburgh Sleep Quality Index*, *National Sleep Foundation Diary*, *Leeds Sleep Evaluation Questionnaire*, *Insomnia Symptom Questionnaire*, *Insomnia Impact Scale*, *Jenkins Sleep Evaluation Questionnaire*, *Functional Outcomes of Sleep Questionnaire*, *Medical Outcomes Study Sleep Scale*. These instruments have been described in a number of comprehensive reviews (Haywood *et al* 2012) (Buyusse *et al* 2006) (Moul *et al* 2004).

### Interventions

Table 1 (see page 8) details the interventions used to manage sleep disturbance and their frequency of use. The most frequently used interventions, with considerably more than half of the respondents using them either *often* or *always* were: general verbal advice (81%, 138/170), verbal advice tailored to the individual (74%, 125/167), incorporated within other symptom management (72%, 118/162) or within fatigue management/energy conservation programmes (61%, 99/163). In contrast, more than three quarters of respondents reported *never* or only *occasionally* using the following interventions: specialist sleep clinic (86%, 131/157),

cognitive behavioural therapy (85%, 134/157), coaching/ goal setting (84%, 132/158), specific sleep hygiene leaflet (82%, 125/153), mindfulness (81%, 130/162). When asked to briefly describe the use of other interventions by free text, the responses included: massage, lavender, reflexology, acupuncture and self-hypnosis.

When asked *how* interventions were provided, an overwhelming majority were provided on an individual face-to-face basis (91%, 116/127), although other formats were used, including: telephone (44%, 56/127), written information sheets (31%, 40/127), face-to-face group interventions (16%, 20/127) or web-based resources (8%, 10/127).

When asked about the perceived effectiveness of the interventions used, based on their own clinical experience (Table 2, see page 9), the interventions rated by more than 30% of people as *very effective* were: fatigue management (33%, 41/125), verbal advice tailored to the individual (32%, 44/143), specialist sleep clinic services (31%, 11/36) and cognitive behavioural therapy (30%, 14/46). Relatively few people had experience of the latter two interventions.

### Knowledge and confidence in managing sleep disturbance

When asked how *confident* the respondents were in their knowledge about sleep disturbance in MS, the majority were *somewhat confident* (63%, 109/173), with only a relatively few reporting to be *very confident* (9%, 16/173). A significant minority (28%, 48/173) were *not at all confident* in their knowledge. The results in relation to the respondents self-rated level of confidence in their own knowledge about the interventions available for managing sleep disturbance were similar: 5% (9/171) reported to be *very confident*, 60% (102/171) were *somewhat confident*, and 35% (60/171) were *not at all confident* with their level of knowledge.

Confidence in relation to assessment skills was generally lower. For example when questioned about confidence in *ability to undertake an assessment* of sleep disturbance almost half of the respondents (48%, 82/170) were *not at all confident*. Only 13 respondents (8%) were *very confident* in undertaking an assessment, with the remaining 75/170 (44%) being *somewhat confident*.

### Education and training

Most respondents (84%, 135/161) had not received specific in-service training or attended study courses in the area of sleep disturbance management. Typically the type of training received was of a general nature, with only 5% (8/161, in-service training) to 8% (13/155, study course) receiving MS specific training. Given the relatively low levels of confidence expressed in terms of knowledge, it is of interest that only half of the respondents (47%, 75/159) reported they had undertaken self-directed learning about the management of sleep disturbance. Unsurprisingly many responded that they

INTERVENTION	FREQUENCY OF USE				
	NEVER	OCCASIONALLY	OFTEN	ALWAYS	REFER TO SPECIALIST
General verbal advice	14/170 (8%)	15/170 (9%)	72/170 (42%)	66/170 (39%)	3/170 (2%)
General written advice	67/161 (42%)	47/161 (29%)	35/161 (22%)	10/161 (6%)	2/161 (1%)
Verbal advice tailored to the individual	21/167 (13%)	18/167 (11%)	64/167 (38%)	61/167 (36%)	3/167 (2%)
Written advice tailored to the individual	88/157 (56%)	41/157 (26%)	14/157 (9%)	10/157 (6%)	4/157 (3%)
As part of a general information leaflet (eg healthy lifestyles, fatigue management)	40/162 (25%)	30/162 (18%)	61/162 (38%)	26/162 (16%)	5/162 (3%)
A specific sleep hygiene advice leaflet	110/153 (72%)	15/153 (10%)	14/153 (9%)	6/153 (4%)	8/153 (5%)
Fatigue management/energy conservation	26/163 (16%)	24/163 (15%)	70/163 (43%)	29/163 (18%)	14/163 (8%)
Cognitive behavioural therapy for managing sleep	124/157 (79%)	10/157 (6%)	6/157 (4%)	2/157 (1%)	15/157 (10%)
Coaching/goal setting for sleep management	117/158 (74%)	15/158 (10%)	11/158 (7%)	5/158 (3%)	10/158 (6%)
Anxiety/depression management	49/162 (30%)	42/162 (26%)	41/162 (25%)	9/162 (6%)	21/162 (13%)
Relaxation	40/160 (25%)	49/160 (31%)	48/160 (30%)	15/160 (9%)	8/160 (5%)
Mindfulness	103/162 (64%)	27/162 (17%)	15/162 (9%)	0/162 (0%)	17/162 (10%)
Incorporated within other symptom management (eg spasticity, pain, bladder, posture)	14/162 (9%)	24/162 (15%)	83/162 (51%)	35/162 (21%)	6/162 (4%)
Exercise programme	49/167 (29%)	4/167 (20%)	50/167 (30%)	16/167 (10%)	18/167 (11%)
Prescribe medication	75/158 (47%)	24/158 (15%)	19/158 (12%)	6/158 (4%)	34/158 (22%)
Review medication	39/157 (25%)	15/157 (10%)	52/157 (33%)	29/157 (18%)	22/157 (14%)
Specialist sleep clinic	113/153 (74%)	18/153 (12%)	0/153 (0%)	1/153 (1%)	21/153 (13%)

**TABLE 1** Interventions used

would value further formal training. There did not appear to be a specific preference for one particular mode of education: in-service training (47%, 76/161), e-learning/web-based (54%, 87/162), and study day (53%, 86/153).

## DISCUSSION

To our knowledge this is the first survey that seeks to determine what constitutes routine practice of sleep disturbance management by nurses and allied health professionals working with people with MS, either in the UK or internationally. The response rate (71%) was high and since confidentiality of the responders' identities was respected, it could be assumed that the responders were honest in their responses.

Low response rates are common in surveys of health professionals (McCull *et al* 2001) (VanGeest and Johnson 2011), despite researchers using a range of methods to minimise this problem (for example making personal contact, improving the

quality of questionnaire design, providing incentives). High response rates are desirable because they increase the precision of parameter estimates and reduce the risk of non-response bias (McCull *et al* 2001). We therefore chose to undertake this survey of conference delegates, specifically to optimise our response rate. We recognise, however, that in doing so, the responses are based on the views of either predominantly MS specialists or those with an interest in MS. The results must be interpreted within this context. The same survey carried out with a sample of general health professionals may generate a different outcome. We would predict that non-specialist health professionals may have less awareness of sleep disturbance as a problem in MS, and perhaps even less confidence in assessing and providing appropriate management strategies with these individuals; this hypothesis would need to be tested.

The survey revealed that while the vast majority of these health professionals (86%) recognise

INTERVENTION	PERCEIVED EFFECTIVENESS OF THOSE WITH EXPERIENCE OF USING THE INTERVENTION				
	NO EXPERIENCE	VERY	SOMEWHAT	NOT AT ALL	UNSURE
General verbal advice	13/170 (8%)	14/157 (9%)	121/157 (77%)	1/157 (1%)	22/157 (13%)
General written advice	56/161 (34%)	11/105 (10%)	73/105 (70%)	7/105 (7%)	15/105 (13%)
Verbal advice tailored to the individual	24/167 (14%)	44/143 (32%)	83/143 (58%)	0/143 (0%)	14/143 (10%)
Written advice tailored to the individual	72/160 (45%)	22/88 (25%)	52/88 (60%)	4/88 (4%)	10/88 (11%)
As part of a general information leaflet (eg healthy lifestyles, fatigue management)	41/162 (25%)	24/121 (20%)	73/121 (60%)	6/121 (5%)	20/121 (15%)
A specific sleep hygiene advice leaflet	100/162 (62%)	13/62 (21%)	34/62 (55%)	4/62 (6%)	11/62 (18%)
Fatigue management/energy conservation	38/163 (23%)	41/125 (33%)	77/125 (62%)	0/125 (0%)	9/125 (5%)
Cognitive behavioural therapy for managing sleep	119/165 (72%)	14/46 (30%)	23/46 (50%)	1/46 (2%)	8/46 (18%)
Coaching/goal setting for sleep management	110/162 (68%)	9/52 (17%)	29/52 (56%)	3/52 (6%)	11/52 (21%)
Anxiety/depression management	53/165 (32%)	28/112 (25%)	70/112 (62%)	1/112 (1%)	13/112 (12%)
Relaxation	33/164 (20%)	36/131 (28%)	87/131 (66%)	0/131 (0%)	8/131 (6%)
Mindfulness	101/162 (62%)	12/61 (20%)	31/61 (19%)	2/61 (1%)	16/61 (10%)
Incorporated within other symptom management (eg spasticity, pain, bladder, posture)	24/161 (15%)	37/137 (27%)	79/137 (58%)	2/137 (1%)	19/137 (14%)
Exercise programme	45/161 (28%)	16/116 (14%)	85/116 (73%)	1/116 (1%)	14/116 (12%)
Prescribe medication	73/157 (46%)	9/84 (11%)	64/84 (76%)	4/84 (5%)	7/84 (8%)
Review medication	49/161 (30%)	17/112 (15%)	84/112 (75%)	2/112 (2%)	9/112 (8%)
Specialist sleep clinic	122/158 (77%)	11/36 (31%)	14/36 (38%)	1/36 (3%)	10/36 (28%)

**TABLE 2** Perceived effectiveness of interventions

that sleep management is part of their role, only a small minority (9%) considered themselves very confident in their knowledge of sleep disturbance and even fewer (5%) were very confident in their knowledge about its management. Nearly half of responders did not feel confident in assessing sleep and most wanted further training in this area. It is perhaps unsurprising that the respondents' confidence in their knowledge and skills was not high, given that most respondents (84%) had not received specific in-service training or attended study courses in the area of sleep disturbance management. We recognise however that self-rated perception of knowledge may not necessarily reflect actual knowledge (Radecki and Jaccard, 1995). For example, low confidence in these areas may not equate to low skill level, rather an enhanced understanding of the complexity of this issue in the MS population. Knowledge and skills can be gained in a variety of

ways other than formal study courses. It is disappointing that fewer than half of the respondents (47%) had undertaken self-directed learning in a clinical area which they considered to be part of their role and in which they expressed a lack of confidence in terms of their knowledge. This may indicate that while the problem is seen as significant, it is also a low priority for many of the respondents. Self-directed learning is considered essential to on-going professional development and to the delivery of high quality health care, particularly in today's rapidly changing environment where social, technological and medical changes mean that practitioners' skills and knowledge need to be continually updated (O'Shea 2003). We anticipate that by providing initial information about practitioner's knowledge in this area, the results of this survey will guide the development and provision of future education programmes in this area.



Delivery of interventions used multiple formats including the provision of written information and provision of web-based resources, group education and advice given via the telephone. Almost half of respondents (44%) delivered interventions via the telephone, which reflects the increasing use of innovative methods, such as the telephone, in current practice by MS health professionals. This is encouraging given the evidence which supports the effectiveness of these new treatment methods in related areas such as the management of fatigue (O'Shea 2003) and cognitive problems (Cosio *et al* 2011). Whether the delivery of interventions in these formats is effective in managing sleep disturbance in people with MS is currently unproven and is a potential area for further research.

The vast majority of clinicians utilised a range of interventions to help manage sleep disturbance in their patients, which is in line with the literature which recommends that tailored packages of care, rather than single interventions are most likely to be effective (Lichstein and Riedel 1994). Of the interventions used, the most frequently provided was general (81%) and individual verbal advice (74%). It is encouraging that advice is being commonly given since surveys of people with MS highlight the high value they place on being provided with relevant advice about symptom management in a manner that is tailored to their individual needs (Somerset *et al* 2001). However, important questions remain as to whether the verbal advice given is implemented by patients, and how effective it is in improving their ability to manage sleep disturbance. Verbal advice alone, for instance, may be problematic in a population in which cognitive problems, particularly in relation to memory, are commonly reported (Bobholz and Rao 2003). General written information sheets about sleep hygiene were also commonly provided (31%). While these are of demonstrated benefit, there is recent evidence that a self-help book, which utilised a cognitive behavioural approach, was more effective in changing sleep behaviour in insomniacs, than written sleep hygiene advice (Bjorvantin *et al* 2011). Keeping up to date with the development of new interventions such as this can be very challenging for clinicians, particularly in complex conditions in which multiple symptoms occur. It is possible that the generally low level of confidence, in terms of knowledge of interventions, is reflected by this reality. This lack of confidence may however have an advantage since it has been shown that individuals are more likely to systematically search out information on a topic area that they feel they are less knowledgeable about (Radecki and Jaccard 1995).

There is a paucity of literature which specifically evaluates the effectiveness of cognitive behavioural therapy, coaching/goal setting, mindfulness or specialist sleep clinic interventions for managing sleep disturbance in people with MS. It is possible that this may partly

explain why a relatively small percentage of the clinicians referred patients on for these interventions. There is, however, a growing body of evidence to support the use of these interventions both within the healthy population (Montgomery and Dennis 2003) (Caldwell *et al* 2010) and in other patient groups (Kierlin 2008), which may hold promise for people with MS; further research in this area is needed.

This survey has several limitations. Firstly it is recognised that this is a biased sample, based on the views of either predominantly MS specialists or those with an interest in MS, since all respondents were attending a national conference for professionals working with people with MS. The results must be interpreted within this context. Secondly, the survey allowed little scope for the collection of qualitative data from respondents, which limits the depth of data gained about the responders' knowledge, skills and confidence in managing this aspect of patient care. Qualitative studies would allow verification of the survey results; and enhance our understanding of clinicians' usual practice in the management of sleep disturbance in people with MS. Thirdly, MS nurses formed the larger proportion of respondents in this survey. While this may reflect the proportion of professional groups working to support people with MS, a number of the treatments involved, such as fatigue management programmes, physical activity programmes and cognitive behavioural therapy, are not traditional nurse-led roles and this may affect the study findings.

The results of this survey help elucidate our understanding of the current management of sleep disturbance by health professionals' working with people with MS. The survey identifies that few health professionals use formal tools for assessment, and that they lack confidence in their own skills and knowledge about available assessment tools and modes of intervention. We suggest that qualitative research is needed to explore the views of health professionals working with people with MS, as well as individuals with MS who experience sleep disturbance. Alongside this there is a need to evaluate the range of non-pharmacological interventions which are available for use.

## CONCLUSION

This survey provides an initial understanding of current practice in the management of sleep disturbance, by experienced MS nurses and therapists in the United Kingdom. It demonstrates that the vast majority of the clinicians completing the survey considered the management of sleep disturbance to be part of their role. The results suggest their knowledge about managing sleep disturbance, particularly related to assessment instruments, is limited. Further exploration is required to verify these findings across different settings and countries, and from the perspective of people with MS.

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# From pitch to pool

Aquatic physiotherapy in brain injury rehabilitation

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**In the current economic climate, there has been recent debate about the cost-effectiveness of hydrotherapy pools (Campbell 2013). Despite the apparent clinical effectiveness of aquatic physiotherapy, there is very little evidence to support its use in brain injury rehabilitation and the quality of the studies available is limited by non-randomisation, small sample sizes and lack of long-term follow-up (Geytenbeek 2008).**

There is supporting evidence from one small-scale controlled study (Driver *et al* 2004) that evaluated the effect of an aquatic programme on fitness parameters, including strength, in individuals with a brain injury. This showed that fitness and functional ability were improved in the aquatic therapy group.

In light of the scarcity of evidence specific to brain injury, it is necessary to draw from wider sources. Donoghue *et al* (2011) report that there is increasing interest in the use of aquatic-based exercise for plyometric training. This is because the pool environment provides both physiological and psychological benefits, has similar performance effects as land-based training, and may be useful in rehabilitation and injury prevention. Plyometric training is exercise in which muscles contract to exert maximum force in a rapid or explosive way with the goal of increasing both speed and power, for example, when repeatedly jumping. The emerging evidence supporting aquatic-based exercise, alongside case reports using aquatic exercise principles in non-neurological patients, may help to strengthen the argument for aquatic physiotherapy in brain injury rehabilitation. The following case report illustrates the use of aquatic physiotherapy in the rehabilitation of a professional sports player following a severe traumatic brain injury.

## HISTORY OF PRESENT CONDITION

Cameron<sup>1</sup> is a 24-year-old man who suffered a severe traumatic brain injury and lung contusions in a road traffic accident. His GCS was 3/15 at the scene. A CT head scan showed

intraventricular and subarachnoid haemorrhages, contusions, diffuse axonal injury and scattered petechial haemorrhages. He was admitted to the Intensive Care Unit and ventilated. Initially he suffered with severe autonomic dysregulation (causing diaphoresis and severe fluctuations in heart rate and temperature). This significantly limited early postural management. He required a tracheostomy, urinary catheter and PEG tube which were all subsequently removed.

Cameron was transferred to Frenchay Brain Injury Rehabilitation Centre six weeks post injury. At this stage he displayed sustained opisthotonic posturing; a state of severe extensor spasticity causing hyperextension of the head, neck, spine and lower limbs. Cameron received specialist multidisciplinary rehabilitation, which included aquatic physiotherapy from four months. At seven months he had bilateral percutaneous achilles tendon lengthening surgery to correct severe ankle equinus deformity. This case report details Cameron's aquatic physiotherapy programme from when it resumed at 8 months post injury, in accordance with post-operative guidance, once all surgical wounds were healed. Cameron's main goal was to complete his local half-marathon.

## SOCIAL HISTORY

Professional rugby player with supportive family, friends and sports colleagues.

## MEDICATION

- Baclofen 30mg tds
- Tizanidine 1mg bd
- Clexane

1. The patient has consented to use of his details in this case report but his name has been changed for anonymity.



Joint	Movement	Left			Right		
		Passive	Active	Muscle Power	Passive	Active	Muscle Power
Hip	Extension	10°	10°	3	10°	10°	4
	Flexion	95°	75°	3	125°	130°	4
	Abduction	45°	45°	3	45°	45°	4
	Adduction	10°	10°	4	10°	10°	5
	Lateral Rotation	45°	45°	4	45°	45°	4
	Medial Rotation	20°	20°	3	45°	45°	4
Knee	Extension	0°	0°	4	0°	0°	4
	Flexion	110°	100°	3	140°	140°	4
Ankle	Plantarflexion	15°	15°	3	30°	25°	3
	Dorsiflexion	0°	-5°	4	5°	5°	5

**TABLE 1** Range of movement and muscle power (Oxford Grading Scale)

## ASSESSMENT FINDINGS

At eight months post injury Cameron presented with full active range of movement but mild weakness in his right lower limb. He had reduced range of movement and significant weakness in his left lower limb. He demonstrated normal sensation to light-touch and intact proprioception.

### Impairments

- Reduced range of movement (active and passive) and reduced muscle power in left hip flexion, left hip medial rotation, left knee flexion, bilateral ankle plantarflexion and left ankle dorsiflexion (*Table 1*).
- Decreased co-ordination (reduced speed and accuracy) throughout left side.
- Increased extensor tone in lower limbs on effort (left more than right).
- Decreased speed of information processing.

### Activities

- Assistance of one for sit to stand.
- Maximum assistance of two, providing proximal support, to mobilise 20m.
- Unable to walk up and down stairs.
- Unable to run or jump.

### Participation

- Unable to access community gym due to balance and mobility difficulties.
- Unable to participate in sport.
- Unable to return to paid employment.

On assessment there was a greater active range than passive range of right hip flexion. One possible explanation for this anomaly is that while the passive range was limited by increased muscle tone in the right hip extensors, this increased tone was reciprocally inhibited by activation of the hip flexors allowing greater active range of hip flexion.

A problem list was developed and goals were set collaboratively (*Table 2*).

## TREATMENT PROFILE:

Cameron's post-surgery aquatic physiotherapy programme was delivered in two phases. The first phase (week 1 to week 6) focused on mobilisation, strengthening, sit-to-stand and gait. The second phase (six weeks to three months) concentrated on plyometric exercises to increase propulsion for gait and to work towards running and jumping. During both phases Cameron participated in 45 minutes of aquatic physiotherapy once a week.

### Buoyancy-assisted mobilisation of left hip using contract-relax technique to increase PROM into flexion.

Start position see *Figure 1*. Push woggle downwards for six seconds, extending left hip against resistance of woggle. Relax hip extensors for ten

Problem List	Goals
Decreased passive range of movement (PROM) (95°) and active range of movement (AROM) (75°) in left hip flexion	<b>1</b> Increase hip flexion PROM and AROM by 10° in 4/52.
Decreased PROM (20°) in left hip medial rotation.	<b>2</b> Increase medial rotation PROM by 10° in 4/52.
Decreased muscle power around the left hip (extensors 3/5, flexors 3/5, abductors 3/5, adductors 4/5, medial rotators 3/5).	<b>3</b> Increase muscle power in left hip by one point on the Oxford Grading Scale in 6/52.
Requires assistance of one for sit to stand due to decreased co-ordination throughout left side.	<b>4</b> Move between sitting and standing independently in 4/52.
Requires maximum assistance of 2, providing proximal support, to mobilise 20m.	<b>5</b> Mobilise 40m with moderate assistance of 2 providing distal support in 6/52.
Enters pool using chair hoist.	<b>6</b> Enter pool via steps using rail with assistance of 2 in 6/52.
Unable to run or jump.	<b>7</b> Jog on the spot in the pool for 30 seconds within 3/12.

**TABLE 2** Problem list and goals



FIGURE 1



FIGURE 2

seconds and allow buoyancy to assist mobilisation into flexion (Feland 2004). Progressed by placing two woggles under knee. This increased buoyancy resistance during the contraction phase and buoyancy assistance during the relaxation phase<sup>2</sup>.

**Buoyancy-assisted mobilisation of left hip using contract-relax technique to increase PROM into medial rotation.**

Start position see *Figure 2*. Hip and knee must remain at 90° throughout exercise. Allow left foot to come out to side so left hip medially rotates. Push down against resistance of armband for six seconds but do not allow hip to rotate laterally beyond neutral. Relax for ten seconds, allowing buoyancy to assist mobilisation of hip into medial rotation. Progressed by increasing the amount of air in the armband.

**Buoyancy-resisted hip extensions for left hip extensor strengthening.**

Start position see *Figure 3*. Flex left knee to 90°. For concentric strengthening push left knee down against resistance of float. For eccentric, allow hip to return to start position slower than speed of buoyancy. Progressed by increasing length of lever (extended knee) and increasing buoyancy resistance (moved float distally to ankle).

**Increasing AROM of left hip flexion and strengthening of left hip flexors; buoyancy resisted in outer to mid-range and buoyancy assisted mid to inner-range.**

Start position see *Figure 4*. For concentric strengthening pull left knee downwards and towards the wall against resistance of the float (on distal left thigh) until hip is at 90° then allow buoyancy to assist mid to inner-range flexion. Return hip to 90° of flexion and for eccentric strengthening allow the hip to return to start position slower than the speed of buoyancy. Progressed by increasing number of repetitions.

**Left hip abductor and adductor stabilisations for strengthening (buoyancy counterbalanced, using turbulent drag).**

Supine, supported by rehabilitation technician at trunk, small float on left ankle so leg remains at surface of water. For isometric training, the therapist alternately pushes (hands on abductor aspect) and then pulls (hands on adductor aspect) right leg, instructing the patient to hold the left leg position still. First progressed by increasing speed and therefore drag resistance. Further progressed to isotonic strengthening using reversals; the therapist instructs patient to actively abduct the left leg when they push and adduct when they pull.

**Strengthening left hip medial rotators; buoyancy resisted outer to mid-range and buoyancy assisted mid to inner-range.**

Start position see *Figure 2*. Allow left foot to cross midline so the left hip laterally rotates. Push down against resistance of the armband to mid-range and then allow buoyancy of the armband to assist medial rotation of hip as far as possible.

**Fast reciprocal cycling of lower limbs (speed resisted) for generalised lower limb strengthening and co-ordination, to improve sit to stand.**

Supine, supported by therapist to decrease excessive metacentric rotation. Fast reciprocal cycling of lower limbs. Progressed by increasing duration.

**Bilateral hip and knee flexion/extension utilising patient-created turbulence for generalised lower limb strengthening, to improve sit to stand.**

Supine, supported with inflatable neck collar. Therapist holds patient's ankles in fixed position (not feet due to recent ankle surgery); patient bilaterally flexes and extends legs continuously. Progressed by reducing streamlining, taking elbows out to side to increase surface area and therefore resistance.

2. All photos use a model to protect anonymity.

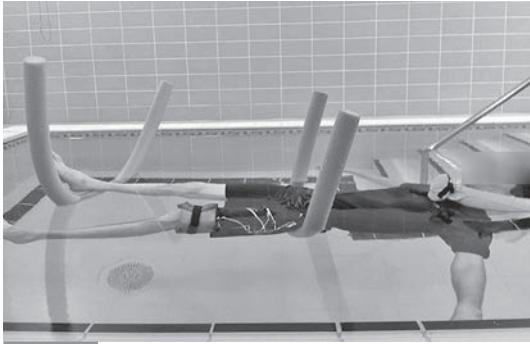


FIGURE 3

### Water supported gait re-education.

Walking with therapist created turbulence around the lateral aspect of the left hip during stance to encourage weight transfer and increase duration of left stance phase.

### Plyometric Exercises

For all exercises stand holding the pool rail for support.

- Jumping jacks.
- Alternately jumping one foot in front and the other foot behind simultaneously.
- Jumping on the spot with feet together.
- Jogging on the spot.

Each exercise started with single jumps and progressed to continuous repetitions of each exercise. They were further progressed by reducing upper limb support.

### OUTCOMES

See Table 3.

### REFLECTION ON PRACTICE

In Cameron's case, aquatic physiotherapy was considered to be the most effective way to carry out joint mobilisation and muscle strengthening of the left hip, with the aim of improving functional ability during sit to stand, gait and walking down steps. It was also used to introduce exercises for increasing propulsion during walking and jogging. Cameron was concurrently carrying out land-based physiotherapy. This makes it difficult to know exactly how much aquatic physiotherapy contributed to his progress. However, the land-based sessions focused on functional training, while pool sessions worked on mobilisation, strength and propulsion. Therefore, it is likely that aquatic physiotherapy significantly contributed to the achievement of his goals. Cameron's treatment profile was restricted by the size and depth of the pool. For example, a longer pool and variety of depths would have been beneficial to enable deep water running and for progression of gait re-education. Instead, the exercises were adapted to maximise progress within the limitations of the pool. Goal 2 was not achieved, probably due to the prolonged time over which soft tissue shortening had occurred. It is likely that Cameron would have needed a longer period of stretching to gain increased passive range, and pool mobilisations



FIGURE 4

were not frequent or prolonged enough to do this. Cameron would have benefited from more frequent aquatic physiotherapy sessions, but this was prevented by time restraints. Goal 3 was only partly achieved and, on reflection, the adductors could have been worked more intensively from the start of the programme by using isotonic reversals. This may have improved the outcome.

Research has shown that muscle strengthening is as effective in water as on dry land, while reducing pain during exercise (Petrick 2001).

Goal	Outcome	Comments
1	Achieved in 4/52	Left hip flexion PROM 105° and AROM 90°.
2	Not achieved	No change in PROM into medial rotation at left hip.
3	Part achieved	Improved muscle power in left hip extensors (4/5), flexors (4/5), abductors (4/5) and medial rotators (4/5). Although adductors appeared stronger on testing, there was no increase on the Oxford Grading Scale.
4	Achieved in 4/52	Able to move between sitting and standing independently.
5	Achieved in 6/52	Able to mobilise 40m with moderate assistance of two providing distal support. Alternatively, also able to walk 20m with four wheeled rollator and assistance of one.
6	Achieved in 6/52	Entered the pool using the steps with assistance of two.
7	Achieved in 3/12	Able to jog on the spot in the pool for 30 seconds and complete five consecutive jumps on the spot with feet together.

TABLE 3 Outcome after three months



Franchimont *et al* (1983) claim that where muscle atrophy has occurred due to immobilisation, direct vasodilation with heating stimulates muscle growth. This suggests that muscle strengthening is optimised in warm water. Hall *et al* (1990) also highlight that warm water promotes muscle relaxation. For Cameron, this muscle relaxation was useful in limiting unwanted extensor tone when carrying out effortful exercises and in allowing effective joint mobilisation. Petrofsky (2002) effectively demonstrated that muscle action when walking in water is similar to that on dry land and therefore useful for gait re-training, as in Cameron's case.

In 2002 Geytenbeek reported that neurological populations were under-investigated in hydrotherapy and a recent search suggests that this has not changed significantly in the last ten years. However, she also commented that there is clinical evidence of moderate quality to support the effectiveness of hydrotherapy for improving joint mobility and muscle strength. This is consistent with the outcomes in Cameron's case.

One of the reasons for using aquatic physiotherapy with Cameron was to maximise participation by carrying out exercises in an enjoyable environment (Harrison 2010). Driver (2009) showed that aquatic physical activity intervention can positively influence mood following traumatic brain injury. Aquatic physiotherapy supported Cameron's mood and emotional well-being by giving him a greater sense of achievement and independence than on dry land. To the treating physiotherapist, it was clear that while Cameron was working to improve joint range and muscle power, he was simultaneously working on control and selectivity of movement. The hydrostatic pressure and viscosity that slows movement in water allowed him time to process proprioceptive feedback and control the quality of his movements.

In rehabilitation, it can be challenging to make the transition from gait training to high impact activities such as running and jumping, but evidence supports use of water-based exercise for early plyometric work (Donoghue *et al* 2011). Cameron's main goal was to complete his local half-marathon; therefore it was essential to improve his propulsion during gait. Donoghue *et al* (2011) recognise that in water buoyancy controls the downward movement of the body, which reduces impact forces and joint loading, while assisting the upward concentric phase of a jump. The pool was chosen for early plyometric work with Cameron to minimise the risk of post-operative achilles tendon rupture and reduce manual handling risks, until plyometric exercises could be safely carried out on dry-land.

## SUMMARY

Through using aquatic physiotherapy, Cameron's physical goals were addressed in an environment that optimised his mood and well-being. As a result of his dedication and determination,

Cameron successfully completed his local half-marathon earlier this year. Some NHS Trusts have considered closing their hydrotherapy pools because they claim that they are not used enough to justify the running costs. However, more innovative hospitals have started to rent their pools or offer a range of private sessions, in addition to their core services, to ensure financial viability (Campbell 2013). Perhaps this case report will encourage more physiotherapists to jump in at the deep end and strive to keep our hydrotherapy pools open for the benefit of our patients.

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# Management of Parkinson's using a Pilates programme

**Parkinson's is a degenerative neurological disorder that occurs in 1 in 500 people in the UK with prevalence slightly higher in men than women. Usual onset is after the age of 50 although early onset Parkinson's is sometimes diagnosed under the age of 40 (Parkinson's UK 2013). The disease process affects the dopamine-producing neurones of the substantia nigra within the basal ganglia which project to the striatum.**

The basal ganglia are responsible for: pre-movement planning and preparation, initiation of movement, sequencing and timing of movement, maintaining cortically selected movement, habit building and shifting of motor and cognitive sets. They are anatomically linked to the limbic system so depletion of dopamine will not only affect motor function but non-motor and psychological function too. Physiotherapists are mainly concerned with the effects of motor symptoms but must take into account possible problems with emotional response, mood, retaining new information, recognition of names and faces and autonomic dysfunction. Other possible non-motor symptoms that can be encountered are sleep and sensory disturbances (Aragon *et al* 2007).

Motor symptoms can include bradykinesia, rigidity of muscles, tremor and decreased postural control mechanisms. The bradykinesia and muscle rigidity often leads to a flexed body posture, sometimes with lateral flexion and decreased mobility of the trunk. Consequently there may be secondary muscle weakness and tightness in other areas.

## FUNCTIONAL IMPLICATIONS

### Balance

Decreased trunk mobility and poor postural mechanisms may affect balance as can decreased sensory processing within the basal ganglia. Together, these factors increase the risk of falls.

### Walking

Stride length, trunk rotation, arm swing and walking speed are reduced. Gait can become shuffling and festinating. Loss of internal

cueing mechanism of automatic movements such as walking means clients with Parkinson's encounter problems with freezing and inability to initiate movement, particularly on meeting obstacles or doorways. Dual tasking when walking can become difficult.

### Fine motor activities

Writing and fastening buttons become increasingly hard as reaching and grasping are affected.

### Transfers

These will become difficult due to motor symptoms. (Keus S *et al* 2004)

A combination of non-motor and motor symptoms can lead to the person with Parkinson's becoming more sedentary, consequently increasing the risk of falls and to problems with constipation and decreased cardiovascular efficiency. The prevalence of osteoporosis is also higher in people with Parkinson's which can be positively affected by exercise. Reduced bone mineral density in this population may be due to several factors such as decreased activity, decreased muscle strength, low body weight and vitamin D deficiency (Speelman A *et al* 2011).

## PHYSIOTHERAPY, EXERCISE AND PARKINSON'S

The KNGF (Koninklijk Nederlands Genootschap voor Fysiotherapie) Guidelines for Physiotherapy in Parkinson's Disease published in 2004 by Keus *et al* are based on scientific research and make therapeutic recommendations for physiotherapists so that they can provide optimum treatment to Parkinson's patients. The guidelines suggest different goals of therapy for each stage

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Stage	Symptoms	Management
1	Mild, unilateral symptoms which are not disabling.	Early (H&Y 1-2.5) Prevention of inactivity, prevention of fear of moving or falling and to improve physical capacity.
2	Bilateral involvement. No balance impairment. Possible kyphotic posture, slowness and speech problems. Postural reflexes intact.	
3	Significant bradykinesia, moderate to severe symptoms, postural instability, walking impaired but still possible with help. ADLs independent.	Mid (H&Y 2-4) Aim to maintain and improve activities such as transfers, mobility and reaching/grasping. Therapy should include work on balance and body posture as well as continuing as for early stage.
4	Severe symptoms, rigidity, bradykinesia, still walking though impaired.	
5	The patient is fully dependant with no walking or standing. Fully disabled, full nursing care needed.	Late (H&Y 5) Continues as for the mid phase but should also provide maintenance of vital functions and prevention of pressure sores and contractures.

**TABLE 1** Keus S *et al* 2004

of the disease as classified by Hoehn and Yahr (1967) and set out in *Table 1*.

Over the last few years there have been a number of studies looking at exercise and Parkinson's. Morris *et al* (2010) describes several studies that included treadmill training, Tai Chi, graded intensity training and musculoskeletal exercise, all of which demonstrated improvement. Morris *et al* concluded that people with mild to moderate Parkinson's can benefit from interventions that incorporate flexibility, lower limb strengthening and cardiovascular work. This is important in preventing secondary musculo-skeletal complications, improving balance, gait and function and also to prevent or reverse declines associated with the ageing process. To sustain benefits, individuals should exercise several times each week incorporating it into their daily routine. They should be assessed at least annually by a physiotherapist in the early stages and more often in later stages.

Speelman *et al* (2011) discussed a meta-analysis of several studies looking at the effects of exercise and physiotherapy on motor disability concluding that exercise can improve physical function, strength, balance, posture and gait.

A randomised, controlled trial looking at Tai chi and Parkinson's was published by Li *et al* (2012) and concluded that this balance-based exercise method appears to improve postural control and functional capacity and reduces falls in patients with mild to moderate Parkinson's. The NICE guidelines for Parkinson's also suggest that The Alexander technique may be useful to patients (NICE 2006).

There is positive anecdotal information regarding exercise methods such as the Alexander technique, Tai Chi, Yoga and Pilates.

These posture-rich techniques all use cognition to promote posture and body awareness (Parkinson's UK 2013).

## PILATES AND PARKINSON'S

Pilates was created by Joseph Pilates in the 1920s and its benefits are acknowledged worldwide. This technique comprises of a large number of exercises that concentrate on strength (particularly of the core or deep stabilising muscles such as transversus abdominus and multifidus), flexibility, balance, co-ordination, correct breathing and stress relief, all of which have been deemed important in the management of Parkinson's (Keus *et al* 2004, Royer *et al* 2007).

Pilates has been recognised by physiotherapists as beneficial to several rehabilitation populations. The Australian Physiotherapy and Pilates Institute (APPI) have designed a modified Pilates programme described as "A form of dynamic stabilisation retraining that reconditions the body from the central core to prevent the recurrence of, and treat a range of, postural, musculoskeletal and neurological conditions".

In the area of neuro-Pilates the aim is: "...to retrain low threshold activity of local muscles to increase stability, develop postural control and improve alignment, improve strength, improve balance reactions, improve proprioception, regain extensibility of and decrease over-active global muscles, improve body awareness and visual-spatial co-ordination, improve gait" (Withers *et al* 2009).

Pilates instructors are updating their qualifications and specialising in rehabilitation populations such as Parkinson's as more and more anecdotal and research-based evidence becomes apparent (Hudson 2013).

Royer and Waldmann (2007) suggest that Pilates for patients with Parkinson's should include: (a) spine mobility exercises especially through extension, lateral flexion and rotation, (b) scapular patterning prior to upper limb exercises integrated with spine movement, (c) hip mobility especially through extension, rotation, adduction and abduction, (d) then integrated into gait with progressions to maximize the client's balance and co-ordination abilities and (e) applications to daily activities or sport.

## Pilates is based on eight principles

### Concentration

During a Pilates session the client should be mindful of each exercise. With decreased automatic control of movement encountered with Parkinson's, this more cognitive approach can be helpful.

### Breathing

Breathing control is an integral part of Pilates and may help improve respiratory function that is decreased in Parkinson's due to postural changes. Breathing control allows early activation of transversus abdominus which increases

local muscle stability and improves postural control (Hodges *et al* 1999).

### Centering

The centre is the “powerhouse” from which the arms and legs are moved. A strong core allows efficient movement and greater local stability which improves postural control.

### Control

Improved muscle control can be achieved as the patient progresses, and lead to better movement quality.

### Precision

The patient aims to perform the exercises with precision leading to greater conscious and kinaesthetic control. ‘Kinaesthetic cueing’ occurs when the patient focuses on how a movement feels and how it relates to the body (Royer *et al* 2007). This precision can be very useful when automatic control is decreased.

### Flowing movements

Pilates exercises are fluid, smooth and continuous. This may have positive effects on bradykinesia and decreased range of movement due to rigidity.

### Isolation

Mindfulness of each exercise allows the client and therapist to recognise incorrect movements so they can then isolate them and make corrections.

### Routine

Pilates forms part of a weekly routine.

## COGNITIVE AND CUEING STRATEGIES

With the disturbance of internal cueing mechanisms and decreased automatic control of movement, alternative cueing and cognitive techniques can be used, dividing tasks into single components (Keus S *et al* 2004). Using these during Pilates may help to improve movement, and as the disease progresses the client may be familiar with these techniques when he or she needs to use them for transfers and gait. There are several different intrinsic and extrinsic cues that can help and three examples pertinent to Pilates are listed below.

### Mental rehearsal

The client prepares for the task/exercise by mentally rehearsing it before they carry it out. This primes the body so it is ready to perform more effectively.

### Visualisation

Visualisation and imagery can improve positioning and alignment and can be useful to Parkinson’s clients who may use such strategies to combat the lack of automatic control.

### Verbal cues (external cue)

Words such as ‘flowing’, ‘gentle’, ‘smoothly’ will supplement visualisation methods and can help

to reduce global muscle over-recruitment as well as the intention tremors which can delay or stop an intended motion (Royer *et al* 2007).

## PATIENT CASE STUDY

### History

In February 2011, R presented to his GP with a tremor of the right hand and was diagnosed with early stage Parkinson’s. No medication was indicated. In September 2011 R self-referred for Pilates to increase flexibility in stiff joints and muscles, maintain his mobility and balance, and be as pro-active as possible to increase his sense of well-being.

R is married and is a retired accountant. He is very active, spending a lot of time outdoors tending to his two donkeys and working in his large garden.

### Physical assessment

R can walk several miles with no aid, drives and is independent in all personal care and transfers. He reports no problems with balance or falls. A full objective assessment was carried out, and a problem list and Pilates-based treatment plan were devised.

### Initial problems (September 2011)

1. Tremor right hand.
2. Decreased range of right shoulder flexion (145 degrees) thought to be due to general muscle weakness and tightness. Right hand reaches 20cm lower than left hand when running fingers up wall.
3. Decreased hip rotation bilaterally (half ROM) due to tightness of hip adductors and weakness of the gluteal muscles.
4. Decreased trunk control on right side during prone swimming exercise. This was manifested as decreased ability to transfer weight and stabilise through the right side of his trunk meaning he could not lift his left arm off the floor.
5. Tightness of the right hamstrings. Decreased end range knee extension (-15 degrees).
6. Decreased ankle dorsiflexion and plantar flexion due to joint stiffness. Right=5 degrees dorsiflexion and 30 degrees plantar flexion. Left= 10 degrees dorsiflexion to 40 degrees plantar flexion. In child pose exercise R could not bring his bottom back on his heels due to ankle discomfort and stiffness.
7. Decreased trunk rotation during gait.
8. Decreased cervical spine ROM, all movements with protracted posture.

### Goals

Individual goals were devised that were appropriate to R but were also mindful of the general goals set out on the UK Quick Reference Card 4 (QRC4) *Treatment Strategies* (Parkinson’s UK 2009), which are adapted from the *KNGF Guidelines* (Keus *et al* 2004). These are summarised in *Table 1*.

The therapist and R decided on goals that he wished to achieve making them as measurable as possible as for SMART goals (Porter S 2013).



The GAS-light was used as a valid tool by which R's progress could be measured and provided an individual set of goals unique to R. The GAS requires the therapist to predict as accurately as possible the expected outcome. In the full GAS model each score from -2 to +2 will have a specific goal description as compared to the GAS-light where only the expected outcome is specified (which scores zero). Simple statements are then used such as 'much worse' (-2), 'a little worse' (-1), 'a little better' (+1), 'much better' (+2) (Turner-Stokes L 2009). Below are four key goals that had the GAS-light applied to them:

1. Improve right shoulder elevation through flexion, especially when running hands up wall.
2. Improve ability to lift left arm up off floor during prone swimming ie improve right trunk stability.
3. Decrease stiffness of right knee and reduce flexion deformity.
4. Improve ankle ROM; R particularly wanted to perform child pose comfortably, with his bottom back on his heels.

R was highly motivated with a great desire to be able to perform the exercises as correctly as he could, achieving positions that were challenging to him. These goals were pertinent to R and the therapist as they demonstrated a physical improvement as well as measuring objective markers. For the purpose of the study the two measurements for the GAS-light were taken at the start and end of the ten month programme, although reassessment of objective and subjective markers was continuous throughout. No balance or functional outcome measure (eg Berg) were used as R was high-functioning and a ceiling effect would have occurred.

### Treatment

A Pilates programme was devised to work on improving range of movement throughout the body, targeting any specific decreased flexibility. It also worked on core strength, postural control, co-ordination and mind-body awareness. Exercises were changed regularly to ensure they never became too automatic. They were progressed as appropriate using gravity, props, such as the foam roller or gym ball, and Pilates machines, such as the reformer and cadillac, which use springs to assist or resist movement. Standing and balance re-education exercises were included to ensure principles of Pilates were always translated into everyday function. The exercises shown in *Table 2* were appropriate to R's problems and related to the treatment strategies laid out on the *QRC4 Treatment Strategies* (Parkinson's UK 2009).

### Results

Final results using the GAS-light as recorded at reassessment in July 2012. The GAS equation was applied to the scores and results are below:

$$\text{GAS score} = \frac{50 + 10\sum(w_i x_i)}{\sqrt{(0.7\sum w_i^2) + 0.3(\sum w_i)^2}}$$

- Baseline GAS T-score: 31.9
- Achieved GAS T-score 64.5

Results (see *Table 3*) show that R achieved a higher score than was expected. ie >50. As explained in the variance column it was felt that R was particularly motivated and determined to achieve goals that he found difficult. This would be taken into account when deciding his expected outcomes for his next set of goals.

### Patient feedback

- Improvement in flexibility and balance.
- Less discomfort during functional outdoor tasks (such as mending his sit-on mower) and able to complete them in a shorter time.
- No longer freezes when walking although this only happened occasionally.
- Improved sense of well-being: feeling more positive that he has found something he can do to help himself that works.

### DISCUSSION

This study illustrates how Pilates may have the potential to benefit Parkinson's patients by improving flexibility and strength, and maintaining functional ability and balance.

Improvements in joint flexibility were seen with related goals being achieved. It is hypothesised that these improvements were due to a regular Pilates programme that became part of R's weekly routine, and without it he may have become less flexible, and balance and function may have decreased. Each client will present with different problems and the varied repertoire of Pilates means programmes can be tailor-made. It is also possible that the cognitive nature of the Pilates method allows the client to become familiar and practiced with cueing techniques.

Although this is only one case study, the improvements seen and felt by the client suggest that a Pilates programme monitored by a physiotherapist could be of benefit to people diagnosed with Parkinson's. It may not be realistic or financially viable for a client to see a private physiotherapist weekly, on a long-term basis, and this amount of input would not be available within an NHS physiotherapy department.

But perhaps, ideally after initial physiotherapy assessment, clients could benefit from weekly Pilates sessions with an instructor who has appropriate training in managing Parkinson's clients and who has links with a physiotherapist. This could be much more achievable and cost-effective.

### Limitations

- Verbal feedback was received from R but a quality of life measure such as the *Parkinson's Disease Questionnaire* (PDQ-39) as suggested in the UK QRC 1: *Diagnostic Process* (2009) might be useful in providing greater validation.
- The GAS-light was deemed adequate for this single case study but for studies with larger client numbers the full GAS model should be used.
- This is a single case study: more case studies need to be done.

Pilates Exercise	Aims particular to R	Relevance to guidelines (QRC4 2009)
Breathing exercises.	1, 4	Cognitive strategies, aerobic capacity, muscle strength training, (breathing control will initiate early activity of transversus abdominus), relaxation.
Deep neck flexor isolation, neck rotations supine.	8, 9	Trunk (neck) mobility, improves posture, will aid visual input.
Static abdominals, small pelvic tilts, shoulder bridge, shoulder bridge with arm movements, straight and oblique abdominal curls.	4, 7	Cognitive movement strategies, relaxed, co-ordinated movements, muscle strength, trunk and joint mobility.
Hip twist, clam.	3	As above.
Scissors, all levels.	4	As above.
Single leg stretch, dying bugs.	4, 2, 5, 6	As above, lengthening of hamstrings.
Chicken wings, dumb waiter, arm circles, thread the needle, arm openings side lying. <i>Foam roller can be used to combats thoracic spine flexion during chicken wings exercise.</i>	2	Joint mobility and trunk.
Bugs, four-point and prone swimming.	2, 4, 5, 6	Relaxed, co-ordinated movement (complexity increases so more challenging), dual task, muscle strengthening, joint mobility, reaching.
Arm extension in sitting, dumb waiter.	4	Posture awareness, visual cue if using a mirror, joint mobility, strength training.
Cat stretch, child pose.		Relaxation, joint mobility.
Spine twist. <i>Use gym ball or stand to challenge balance. Can also be done in standing.</i>	7, 10	Strength training, joint mobility, trunk mobility.
Weight transference/balance exercises, stepping all directions. eight pilates principles applied.	10	Practise of appropriate tasks to identify (potential) balance loss. Maintain balance, train strength. Practise walking.
R also did a number of exercises in prone lying to inhibit flexion patterns and encourage extension eg prone hamstrings, diamond press, arrow, prone swimming.	9, 4, 8	Relaxed, co-ordinated movement, training muscle strength, joint mobility, posture.

Refer to [www.sarahsessaphysio.co.uk](http://www.sarahsessaphysio.co.uk) for explanation of exercises.

Verbal cues and feedback were used throughout the treatment sessions as well as imagery and mental rehearsal.

**TABLE 2** Treatment

- Comparative studies (with greater client numbers) between other structured Parkinson's exercise programmes and Pilates need to be undertaken to determine whether one approach is more beneficial than another.
- Studies to look at the usefulness of Pilates in the mid and late stages of Parkinson's should be conducted.
- Group sessions need to be investigated as this may be more accessible for many. Patients may also feel more supported and motivated within a group setting.

## CONCLUSION

Specialist and individualised Pilates sessions for those with Parkinson's could provide this population with a means by which they can maintain independence and be symptom-free for longer. This might improve quality of life for them and their families. R presented with bradykinesia, tremor and muscle stiffness. Through Pilates he found his flexibility, strength and function improved and he had a greater sense of well-being. He also learned cognitive and cueing strategies that may be useful in the later stages of the disease. His balance was very good on initial assessment but his Pilates programme

Goal	Patient stated goal	SMART goal	Baseline score	Achieved	Final score	Variance
						<i>Describe achievement if differs from expected and give reasons</i>
1	Improve shoulder mobility and decrease stiffness.	Improve right shoulder elevation through flexion. When running hands up wall: right hand to be only 10cm or less lower than the left hand. Active flexion through elevation to be at least 160 degrees.	-1	<b>Yes</b> R had full right shoulder elevation through flexion. On reaching up the wall both hands reached the same height.	+2	R's better than expected outcome; may be due to the fact he was highly motivated and determined and practised daily at home.
2	Perform prone swimming exercise.	Improve ability to lift left arm up off floor during prone swimming ie improve right trunk stability and take weight over to this side more easily.	-1	<b>Yes</b> R could now lift his left arm up off the floor.	+1	Although he found this difficult and the movement was not smooth it was still better than expected.
3	Decrease stiffness of right knee.	Reduce flexion deformity to less than 10 degrees.	-1	<b>Yes</b> R had a flexion deformity of 5 degrees at final assessment so it was improved but not absent.	0	
4	Perform child pose.	Improve both ankle ROM. R particularly wanted to perform child pose comfortably, with his bottom almost completely back on his heels.	-1	Yes R's ankle ROM improved: except on right plantarflexion which remained the same. R=10 degrees d.flexion, L= 15 degrees d.flexion and 50 degrees p.flexion.	+1	He could now get his bottom back completely on his heels.

TABLE 3 Results

was tailored to maintain this. R's symptoms are common in the early stages of Parkinson's and such a programme could be of benefit to others. This should be investigated further.

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# Sharing good practice

## Introducing the use of upper limb outcome measures within stroke care

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### The driving force

**The upper limb has an important role within every day functional activities (Shumway-Cook and Woollacott 2007). Hemiparesis of the upper limb is a common but undesirable consequence of stroke (Stoykov and Corocos 2009, Yavuzer *et al* 2008). It has been reported that half of all stroke survivors are left with major functional problems with their hands and arms. Stroke is the third largest cause of death and disability in the United Kingdom, with over 300,000 people in England living with moderate to severe disability (National Audit Office 2005). Kwakkel *et al* (2003) suggests that six months after injury severe motor deficits remain in 30% to 66% of stroke survivors upper limbs. Loss of this function and increased upper limb disability can therefore have a major impact on a person's independence. Basic everyday tasks such as washing and dressing, feeding and grooming can become a challenge, thus affecting quality of life (Jorgensen *et al* 1999), and can lead to a major social-economic burden on communities (Platz *et al* 2005). The upper limb is therefore a major focus of stroke rehabilitation.**

There are a variety of treatment interventions for therapists to incorporate into stroke rehabilitation to reduce impairment, improve function and increase independence. Techniques such as functional electrical stimulation, mirror therapy, constraint induced therapy, biofeedback, robotics, proprioceptive neuromuscular facilitation and motor learning are being used widely both clinically and in research environments. In a review of upper limb management on our stroke unit it was identified that we wanted to explore and implement more evidence-based upper limb treatment techniques and enhance the patients' experience of upper limb rehabilitation. However it quickly became apparent that evaluating the effectiveness of these techniques was not going to be easy!

Outcome measures are required in both research and clinical practice to determine the effectiveness of rehabilitation interventions (Ashford *et al* 2008, Unsworth 2008). Furthermore, clinical and professional guidelines state that standardised measurement tools should be used in rehabilitation (CSP 2005, College of Occupational Therapists 2007). The experience of our stroke unit

therapy staff was that in clinical practice outcome measures can often be confusing and that there is very little guidance for selecting appropriate measures. In the current climate within the National Health Service there will be increased pressure to provide numerical data of the effectiveness of treatment intervention and the cost benefit of providing it within a service (Van de Winckel *et al* 2007). With all this to consider the search for an upper limb outcome measure began.

### The problem

The clinical presentation of a stroke patient's upper limb can vary dramatically. Altered sensation, reduced strength, lack of co-ordination, reduced dexterity, reduced motor control, altered tone, limited hand shaping and grip strength are just some of the possible problems following a stroke. In my clinical experience patients can present with one or more of these problems to a greater or lesser extent, therefore impacting very differently on their ability to function. Common outcome measures do not necessarily reflect the patient's ability within everyday functional tasks. They do not account for the varying level of

ability particularly at the lower end of the potential range, demonstrating little or no variation, creating a floor effect.

With every patient presenting a different clinical picture and having individual goals, how easy is it to select an appropriate measure? How easy is it to use these measures in stroke rehabilitation? How meaningful are these measures to patients, and are they demonstrating the degree of improvement relevant to patient need?

Within our stroke unit, therapists were often very happy and confident with completing global outcome measures such as the Bartel Index (Wade and Collin 1988) that provide a general assessment of functional independence, but this alone is often not sensitive to changes (Duncan 1997) such as those as a result of focal upper limb intervention which can be important to both patient and carer.

When reviewing the literature for evidence-based upper limb interventions it became increasingly frustrating to find that different outcome measures had been used in research to evaluate the effectiveness of the treatment intervention on the upper limb, which made comparison of trials and overall outcome extremely difficult and inconsistent to apply into practice.

On reflection of our unit's practice in measurement of upper limb function, we found it was common practice for therapists to establish joint SMART goals with the patient to help guide rehabilitation and monitor progression. Changes in upper limb ability and function were noted but often narratively by therapists and stroke patients alike while performing a functional relevant task or observed when working towards a specific goal. The numerical evidence of a valid and reliable outcome measure was often lacking. This led me to ask why.

### The tried and tested

To improve our evaluation of upper limb treatment interventions as a therapy

team we piloted three upper limb measurement tools. The aim was to become more familiar with the measurement tools so as to encourage integration during goal planning with patients, and to try and establish what was preventing us from using them routinely within upper limb rehabilitation. Firstly we looked at the seven Brunnstrom stages of motor recovery (Sawner and Lavigne 1970), but this scoring system was quickly discounted before implementation due to the theoretical assumptions of the technique being based on 1960s research with confusing terminology. It also provided no functional element and was therefore seen as meaningless to patients.

Subsequently the Fugl-Meyer Assessment (FMA) upper limb extremity section (Fugl-Meyer *et al* 1975) was reviewed. This scale is commonly found in research articles and used by therapists to evaluate stroke related motor impairment, and is considered to be a comprehensive well-designed tool. Despite this, our reflection found that although it covered important upper limb elements such as range of movement, sensation, co-ordination and grip, it had no true functional application. In addition it was lengthy for the therapist to complete during treatment sessions, the lower level patient would struggle to score at all and it appeared to lack sensitivity to change.

Finally the Rivermead upper limb motor assessment (Lincoln and Leadbetter, 1979) was trialled. Initially there was enthusiasm as there seemed to be the functional component that was missing from the previous two measures, but this was to the expense of the patient with minimal or no active movement in their arm. One required functional activity to complete the first level, meaning it left no grounds for scoring. Although function was a major feature, elements such as pat-a-cake came across as a little pointless for the patients to complete, not really a function they could see themselves requiring in the modern world today. All outcome measures attempted were challenging for the cognitive-impaired stroke patient. With most research excluding these patients in their trials, it does not always reflect the clinical picture faced by therapists, and again exposes the gulf between clinical practice and research.

### What the literature says

Two systematic reviews on upper limb outcome measures for neurological patients were found. Ashford *et al* (2008)

aimed to identify valid and reliable outcome measures in the hemiplegic arm in stroke or head injury patients that were reflective of 'real life' function. More recently Connell and Tyson (2012) reviewed the psychometric properties and clinical utility of upper limb measurement tools to provide recommendation for clinical practice in people with neurological conditions.

Interestingly, rather than just look at the psychometric properties, Ashford *et al* (2008) wanted to find measures that reflected day-to-day performance in a person's normal environment, as opposed to observations under test conditions, which are often seen within research trials. Connell and Tyson (2012) focused on the clinical utility ie how practical and cost-effective the measuring tools were to use in the clinical setting. Both these factors are extremely important for the busy therapist and patient.

Disappointingly Ashford (2008) concluded there is no single comprehensive measure that addresses both active and passive real life function in the hemiplegic arm. Six measures met the review criteria, but this included four versions of the Motor Activity Log, with overall conclusions that the measure selected to evaluate clinical effectiveness will depend on the patient's level of ability and their goals for treatment. Connell and Tyson (2012) found that out of a total of 31 upper limb measures only two, Box and Block (Mathiowetz *et al* 1985) and Action Research Arm Test (ARAT) (Lyle 1981), fulfilled psychometric criteria, as well as the feasibility to use in clinical practice. No measures demonstrated how much change in score would be needed to show improvement in a patient's upper limb performance. There would appear to be a gulf between what is best practice and the reality of the clinical setting.

Not one to give up undeterred, I wanted in some small way to address this gulf in our clinical area and came up with the following objectives:

- 1 To establish the opinion of stroke physiotherapists and occupational therapists on the limitations of current upper limb outcome measures and what they feel would be useful criteria/elements to be included in an upper limb outcome measure, which they would find feasible and worthwhile to use in clinical practice with patient with strokes
- 2 To establish the opinion of patients with stroke who have an upper limb disability on upper limb importance, function and measure of improvement.

### Method

The following three questions were posed to a small team of occupational and physiotherapists of varying grades working within stroke rehabilitation at Dudley Group of Hospitals:

- 1 What makes a good outcome measure?
- 2 What limitations are you finding with current available upper limb measurement tools?
- 3 What is important information for you to obtain from an upper limb assessment tool? (Results in *Table 1*)

During our stroke unit's weekly upper limb exercise class, which contained patients of varying levels of impairment and disability, the following five questions were asked.

- 1 What activities/tasks involving your arm do you feel are important to you?
- 2 What part of the arm movement do you feel is the most important to gaining function?
- 3 What do you feel is the key action/element which is missing in your arm, hindering its ability to function?
- 4 What would be an indication of improvement in arm function for you?
- 5 What would be a measure (if any) of arm function? (Results in *Table 2*)

### What did I learn from the process?

It would seem fellow therapy colleagues are experiencing similar difficulties in the identification of upper limb outcome measures to use with stroke patients. Time and availability of resources are clearly recognised as a limitation to current measures, as highlighted by Connell and Tyson (2012) who excluded 12 upper limb outcome measures on this alone.

Hand grip, ability to pick objects up and sensation appear to be important criteria and measure of improvement for the patient, so should be considered as areas that an upper limb outcome measure should assess. Functional assessment within a task would appear to be important to the therapist and patient. A wide range of activities were identified by the patients in *Table 2*, varying from everyday essential tasks such as personal hygiene and having a drink to higher level complex tasks of driving a car and using tools such as screw drivers. With the array of feedback in *Table 2* it would seem impossible for a single outcome measure to meet the needs of all patients as their goals and focus are inevitably going to be different, and with technology in the world changing at a rapid rate, patients' needs will be changing continually.

### 1 What makes a good outcome measure?

- Quick
- Idiot proof
- Standardised
- Little resources required
- Able to re-test easily
- Easy to follow for therapist and patient

### 2 What limitations are you finding with current available outcome measures?

- Not enough time to complete
- Don't include functional assessment
- Not suitable for lower level ability
- Not sensitive to change
- Nothing available for cognitive-impaired patients

### 3 What is important information for you to obtain from an upper limb assessment?

- ROM both passive and active
- Grasp (maybe elements of the GRASP programme)
- Functional ability (drinking, feeding, buttons)
- Grip strength
- Sensation
- Pain

TABLE 1

Interestingly it was noted that the upper limb was not always important to the patient with more focus wanted on walking with the quote "if I get my leg going it will help my arm". This I feel highlights the importance of therapist – patient communication in patient-centred goal planning.

It seems current outcome measures don't meet the needs of the individual patient, and the issue of finding one outcome measure that addresses the active and passive upper limb remains a problem. This has led me to believe that we, as a team, now need to focus on the needs of the patient. Maybe reverting to using the Goal Attainment Scale (GAS) is the only way of achieving this. The Goal Attainment Scale was initially introduced by Kiruek and Sherman (1968) for assessing outcomes in the mental health setting and has since been modified for use in the care of the elderly, and in cognitive rehabilitation. GAS is a method of scoring the extent to which the patient's individual goals are achieved, providing a meaningful outcome measure for rehabilitation. The reported benefits of GAS

### 1 What activities/tasks involving your arm do you feel are important to you?

- Feeding
- Cleaning
- Using computer mouse
- Grasping objects
- Knitting
- Baking
- Mowing the lawn
- Walking the dog
- Toileting
- Walking
- Washing/personal hygiene
- Pushing the shopping trolley
- Pouring a drink
- Writing
- Driving the car
- Climbing stairs
- Using a screwdriver/DIY
- Using my mobile phone/texting
- 'To help the other arm'
- Dressing
- 'If I get my leg going it will help my arm'
- 'Everything'

### 2 What part of arm movement do you feel is the most important to getting function?

- **Whole of the arm**
- Shoulder
- Wrist
- **Hand**
- **Hand control**
- Touch and feel objects
- **Hand grip and manipulation**

TABLE 2 Items in **bold** were responses on more than one occasion

are that it encourages patient involvement and there is growing evidence of sensitivity over other standard measures (Gordon *et al* 1999).

In conclusion it appears there is no single upper limb outcome measure suitable for all patients. There still appears to be a gulf between research and clinical practice. I feel I have come a long way in gaining a greater understanding of the patients' needs regarding their upper limb rehabilitation and certainly do not want to dismiss the use of traditional outcome measures, but this work highlights that the therapist needs to select a tool that measures what is relevant to the individual. Work is ongoing within this area and Tyson and Connell (2012) continue to look at the possibility of creating an upper limb outcome measure tool box to aid clinicians.

### 3 What do you feel is the key action/element which is missing in your arm, hindering its ability to function?

- Hand movement
- Hand grip
- Being able to control the hand and arm
- Sensation
- Tiredness
- ROM and strength

### 4 What would be an indication of improvement in arm function to you?

- Being able to feel it/normal sensation
- Seeing it move (visual feedback)
- Being able to do tasks
- Being able to open and close my hand

### 5 What would be a measure (if any) of arm function?

- When using it in function
- Picking objects up
- Sensitivity of hand
- Feedback from therapist
- How far I could stretch arm
- Reduction in pain
- Grip strength

### How has it changed our service?

As a team there is now more structure around the assessment and treatment planning for the stroke patients' upper limb. We routinely discuss upper limb goals with patients and record them in a GAS where appropriate. We have the confidence to use the tried and tested upper limb outcome measures if we feel it will add value to the patient's rehabilitation. Future work for us is to investigate the use of alternative models of tiredness scales, and to consider the regular use of the visual analogue scale for pain and sensation in the patient with no active movement in the upper limb, where traditional outcome measures appear inappropriate.

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## Improving health and well-being

### Exercise classes for people with MS

**Dawn Harrison** Grad Dip Phys MCSP Neurophysiotherapist MS Society Northern Ireland

**Although there are no specific guidelines for people with MS, the guideline for healthy adults is 150 mins of exercise every week, which can be broken into small chunks. It is stated 'there is now strong evidence to show that physical activity benefits many aspects of health'. (Chief Medical Officers 2011)**

Research has shown that people with MS are more likely to suffer from cardiovascular disease (Bronnun-Hensen 2004), so increased exercise can be very beneficial. There is no evidence that participation in exercise results in increased fatigue or relapses for people with MS. In fact a recent study funded by the MS Society

found that short periods of moderate intensity exercise can improve fatigue levels and quality of life in people with MS (Carter *et al* 2014).

A series of exercise classes for people with MS have been set up across Northern Ireland in partnership with the MS Society and Active Communities, Disability Sport NI.

"There is no evidence that participation in exercise results in increased fatigue or relapses for people with MS."

#### Rationale

These classes were set up by Dawn Harrison (neurophysiotherapist MS Society NI) after several requests by members who wanted to access exercise programmes but had been unable to use the classes offered at local leisure services. Several reasons were given for





Dawn Harrison (centre) with participants and gym instructor during an exercise group.

not being able to access classes ranging from classes being too aerobic, people not being able to get on and off the floor and instructors not understanding the fluctuating nature of MS. Members also stated that they had difficulty motivating themselves to do home exercises alone but wanted to maintain the benefits they felt they had achieved after a period of physiotherapy.

### Planning

Before the classes were set up, I met with members of the MS Society branches to discuss what exercise they wanted to participate in. Meetings were then arranged with instructors to discuss specific problems or challenges that people with MS may experience; for example, increased tone, fatigue and fluctuations in their condition from one week to the next. Once classes were set up, staff within the health services were informed so they could refer clients to the class as appropriate.

The exercise classes were then planned in partnership with Active Communities, with the emphasis being on posture and the way the exercises were carried out. The classes include exercises for all areas of the body with activities such as sitting to standing, walking, shoulder elevation, sidestepping and abdominal exercises. These exercises require some basic equipment i.e. chairs, theraband, light weights, steps and cones. Some of the classes are very mixed-mobility groups so some of the exercises need to be tailored to the clients needs. The fitness instructors run the classes with support from the physiotherapist. Initially I attended the first one

or two sessions and then would attend every few months, or if the instructor or a member highlighted a problem. The classes are run at the local leisure centres thereby allowing people with MS to access local leisure facilities with support.

### Results

Prior to the introduction of the classes, most of the participants were not participating in any form of exercise. In fact, many stated that they had not exercised for several years.

Outcome measures were recorded before the first exercise session and were repeated on completion of a six-week exercise programme. These were: 5m walk, functional reach and the Multiple Sclerosis Impact Scale (MSIS). The MSIS is a tool that measures the patient's views of the impact of their MS over the previous two weeks. The questionnaire has 29 questions, 20 of which relate to physical activities and nine of which measure the psychological impact of MS. (Hobart *et al* 2001). All participants who completed all the measures showed improvements in both walking speed and functional reach, with the more functionally-limited members improving the most. In the six weeks there was no change in MSIS scores.

### Feedback

Members report several improvements following the classes including weight loss, feeling motivated to carry out home exercise programmes, reduction in falls and improved balance. They also report a great social atmosphere at the classes and

"All participants who completed all the measures showed improvements in both walking speed and functional reach, with the more functionally limited members improving the most."

now many of the groups meet for coffee afterwards.

### My learning

I have been surprised at the levels of improvement even in a short period of time and especially for those with severe mobility difficulties. For example, a few participants who use wheelchairs have reported better balance and quality of life following exercise focusing on abdominals. Some have reported that the results have led to greater independence, for example, being able to hold their own house keys.

### Ongoing success

There is now long-term provision of weekly exercise classes for people with MS in six areas throughout NI. Fitness instructors run the classes with only occasional support from a physiotherapist as required.

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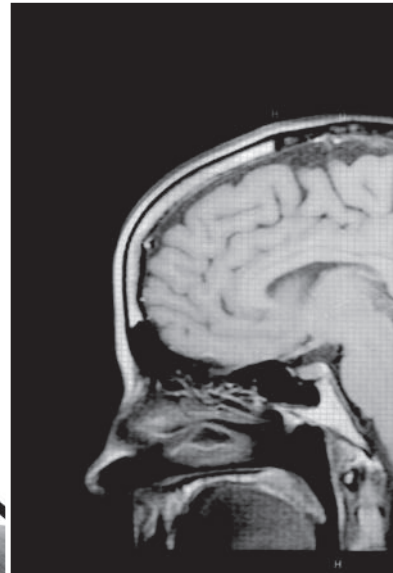
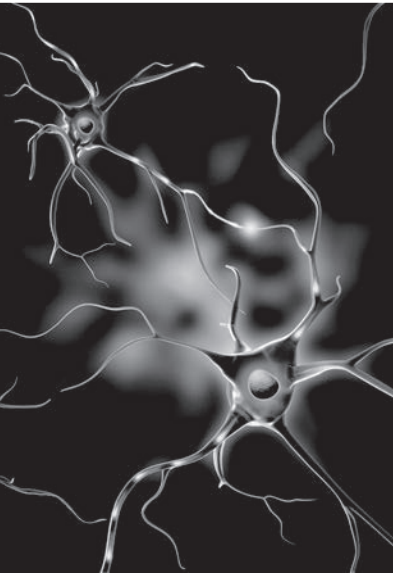
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# Focus on

## A summary of hydrotherapy in stroke rehabilitation

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**There are many reasons to use hydrotherapy post stroke. The support of the water allows those with severe weakness or balance problems to stand and mobilise easier and with more independence than they would on land (Jackson 1997). This reduced dependence on physical assistance, which would otherwise be provided by additional therapists or mechanical aids, frees the therapist to facilitate more distally, allowing the patient to recruit activity more proximally (Chon *et al* 2009). The consequences of losing balance are reduced and allow the patient to be challenged to the limits of their balance abilities, which can build confidence (Carruthers and Hood 2004) and allows early independent movement, which can also have a positive effect on motivation and exercise adherence (Wankel 1993).**

Immersion exposes desensitised body parts to stimuli including water temperature, hydrostatic pressure and water movement, which facilitate sensory and perceptual interactions needed for improved co-ordination and spatial orientation (Vargas 2004). The therapist can also utilise the properties of movement in water such as buoyancy, drag and flotation to challenge the patient in ways that are not possible on land (Lambeck 2007). The physiological effects of immersion such as a reduction in sympathetic nervous system activity (Epstein 1976) may also convey therapeutic benefits. As stated by Newman, (2009): "Water is the perfect environment for patients who are not quite ready or able to perform land-based exercise programs".

### Review of the literature

Electronic searches by title or keyword of Ovid Online, NHS Wales Full text journals, Embase, Ovid Medline, AMED, SAGE, Ingenta Connect, International Journal of Therapy and Rehabilitation online, ScienceDirect and Wiley journals were conducted. Search terms used are shown in Table 1. References from relevant articles were reviewed and appropriate articles identified. Nine relevant studies were identified (see Table 2).

Han *et al* (2013) compared proprioceptive exercises completed underwater versus on land, as an addition to normal therapy treatment, in 62 patients who had suffered a stroke at least six months

previously. Treatments were completed for 40 minutes, three times a week over six weeks. They found that underwater exercise led to greater improvement in joint position, sense and balance (measured by an electronic motion analysis system) than land exercises.

Park *et al* (2012) compared underwater and overground treadmill walking in 20 patients who were at least six months post-CVA. Treatment was four times a week for 30 minutes over six weeks. They found an improved gait pattern in the underwater group (measured with a computerised gait analysis system), shown by increased weight bearing through the affected foot and larger joint angles exhibited in gait, as compared with overground treadmill walking.

Mehrholtz *et al* (2011) conducted a Cochrane review of hydrotherapy for improving activities of daily living (ADL) post stroke. Four trials were eligible

for inclusion, comprising 94 patients. Conclusions were that water-based exercise significantly improved ADL (measured by the Short Form-36) and muscle strength. However, significant differences were not found in walking speed and postural control (as measured by Berg balance scale). No differences were found in aerobic fitness or attrition rates. The authors also discuss the difficulty in comparing existing hydrotherapy research due to the generally poor description of techniques used and widely variable methodologies.

Dos Santos *et al* (2011) looked at the functional mobility of ten stroke patients over the course of twelve hydrotherapy sessions that included stretching, muscle strengthening, balance and walking training. The Timed Up and Go (TUAG) outcome measure was used before and after each session to assess the immediate effects and short-term carryover of the treatment on mobility. Results were also compared from the first to last session to identify longer-term change. All patients reduced their TUAG time (first versus last session) suggesting improvements in functional mobility. In addition, seven out of the ten improved their mean TUAG time (taken after each session), suggesting hydrotherapy is associated with short-term improvement in functional mobility. However, methodological issues prevent any meaningful conclusion. The focus on short as well as long-term effects of hydrotherapy is an approach that deserves further focus.

Park and Roh (2010) looked at the effect of water versus land-based balance

Aqua* (* = Truncated)	Exercise	CVA
Hydro*	Therapy	CVE
Water-based	training	Cerebro vascular Accident
Hydro-kinesi	treatment	Cerebro vascular event
Thalassotherapy	Rehab*	Neuro*
Watsu (Shiatsu principles applied in water)		Stroke
Water		

**TABLE 1** Variety & Combinations of search terms used

exercises completed 35 minutes per day, six times a week for six weeks on postural sway (using a computerised force platform) in 46 post-CVA patients. Both groups improved their balance, with the water group demonstrating improved balance with eyes closed. The balance outcome measures used assessed static balance, measured by centre of pressure sway path length; although dynamic balance is arguably more important functionally for these patients. The intensity of treatments suggests a dose-response relationship with hydrotherapy, while specific balance-challenging exercises may represent a specificity effect.

Paizan *et al* (2009) looked at the addition of hydrotherapy undertaken prior to conventional 'kinesiotherapy' (*Physiotherapy*). Their hypothesis was that patients receiving hydrotherapy prior to their 'land' session would gain more benefit. 152 patients were used who were treated three times a week for six months with the hydrotherapy consisting of exercises based on Halliwick and Bad Ragaz. The outcome measure used here was the improvement in Barthel score per month of treatment, which was shown to be greater with the patients receiving additional

hydrotherapy. The authors suggest that the addition of hydrotherapy to an ongoing treatment programme may increase the effectiveness of the physiotherapy treatment.

Noh *et al* (2008) compared eight weeks (three times per week) hydrotherapy with conventional therapy in 20 subjects post-CVA. Water therapy was based on Halliwick and Ai Chi principles. The water-based exercise group showed a significantly greater improvement in Berg balance score and ability to weight transfer than the conventional therapy group, with similar improvements in gait and lower limb strength. The relatively long time since stroke (mean of 2.8 years for the water group and 1.6 years for the control group), suggests that hydrotherapy may confer benefit to a chronic stroke population.

Chu *et al* (2004) compared eight weeks of targeted heart rate training (3 x 30 minutes a week) on land versus in water in twelve subjects (> one year post CVA). The water group showed a 22% increase in VO<sub>2</sub> max along with improved gait speed and lower limb strength, when compared with the land group, but no difference in balance (as measured by Berg balance score).

"Hydrotherapy may confer benefit at all stages post stroke, possibly helping overcome plateaued status in established strokes and impacting on related factors such as medication intake, balance and functional ability."

Kesiktas *et al* (2004) compared the addition of 20 minutes of underwater exercises three times per week to conventional therapy only, on spasticity and function in 20 spinal cord injury (SCI) patients. Outcome measures included spasm severity, Functional Independence Measure (FIM) score, Ashworth Scale and oral Baclofen intake. The hydrotherapy group showed a statistically significant decrease in spasm severity and oral Baclofen intake compared to the control group. Both groups improved their FIM

Study	Subjects	Hydrotherapy intervention	Outcome
Han <i>et al</i> (2013)	62 post-CVA (>6 months)	Proprioceptive exercises (in addition to usual Rx)	↑ Joint position sense ↑ Balance (versus land group)
Park <i>et al</i> (2012)	20 post-CVA (>6 months)	30' underwater treadmill walking, four times per week over six weeks	↑ Gait pattern ↑ Weight bearing on affected leg
Dos Santos <i>et al</i> (2011)	10 post CVA patients	12 sessions including stretching, strengthening and balance exercise, and walking training	↑ TUAG time
Mehrholtz <i>et al</i> (2011)	96 patients	<i>Cochrane review</i>	↑ ADL and muscle strength No change in balance/gait speed
Park and Roh (2010)	46 post-CVA patients	35' balance exercises, six times per week over six weeks	↑ Static balance versus land group
Paizan <i>et al</i> (2009)	152 post-CVA patients	Halliwick and Bad Ragaz (immediately prior to conventional therapy)	↑ Change in Barthel score per month of treatment
Noh <i>et al</i> (2008)	20 post-CVA patients (>1 year)	Halliwick and Ai Chi, three times weekly over eight weeks	↑ Balance (Berg) ↑ Ability to transfer weight
Chu (2004)	12 post CVA patients (>1 year)	Exercise at targeted heart rates for 3 x 30' over eight weeks	↑ VO <sub>2</sub> max ↑ Gait Speed ↑ Lower limb strength
Kesiktas (2004)	20 SCI patients	20' underwater exercises, three times per week (in addition to usual treatment)	↓ Spasm severity ↓ Oral baclofen intake ↑ FIM score
Zamparao and Pagliano (1998)	CVA, MS and SCI patients (1998)	CROM, co-ordination exercises, walking and swimming, 45' daily over two weeks	↓ Energy cost of walking

**TABLE 2** Literature review: summary of interventions and outcomes



scores, with a larger increase in the hydro group. This a unique study in that it looks at the effect of the intervention on medication intake. Physical spasticity management is applicable to stroke and other neurological conditions and reduction in medication could limit side effects and reduce expenditure which is another area worth further study.

Zamparo and Pagliano (1998) looked at the energy cost of level walking before and after 45 min daily hydrotherapy for two weeks in patients with chronic spastic paresis from stroke, multiple sclerosis (MS) or SCI. Treatment included active and passive range of motion exercises, co-ordination exercises and water immersion walking along, with free swimming if able. All patients decreased their energy cost of walking (as measured by expired gas analysis). This effect was speed dependent; those with a slower self-selected speed showed the greatest benefits from the therapy. The focus on changes in function, related to a specific symptom common to different causative pathologies, is unique and worthy of further study. It is also one of the first studies that looks at hydrotherapy as a short-term intensive treatment programme to improve plateaued functional status.

### Discussion

The literature reviewed shows that hydrotherapy can improve proprioception, balance, gait quality, efficiency and speed, weight bearing ability of a hemiparetic leg, functional mobility, VO<sub>2</sub> max, leg strength, activities of daily living and can reduce spasm severity and oral Baclofen intake. Advantages of hydrotherapy over land-based treatment may include easier and lower load handling for the therapists (Paizan et al 2009), increased sensory input for the patient, experience of more independent movement than on land and the ability to challenge balance in a relatively safe environment where the consequences of a loss of balance are less severe. Though far from conclusive, current research indicates that hydrotherapy may be beneficial as a short-term intensive treatment, as an adjunct to usual therapy or as an alternative to land based therapy.

Current research is sparse with many limitations and methodological issues, such as low subject numbers and poor description of techniques, that makes comparison of studies difficult. Specific techniques used, alongside the skill of the therapist, are likely to impact on the benefit conferred from treatment. Treatments and outcome measures used

should closely reflect the goals of the treatment, whether specific strengthening, balance or functional abilities, and also be sensitive enough to detect changes in those particular variables.

### Conclusion

Existing evidence is positive and suggestive that the benefits of hydrotherapy are highly specific to the type of treatment. Hydrotherapy may confer benefit at all stages post stroke, possibly helping overcome plateaued status in established strokes and impacting on related factors such as medication intake, balance and functional ability. Future research should look at the longer-term carryover as well as the cost-reducing potential of hydrotherapy treatment, for example, in reduced medication intake, reduction in risk factors, changes in mobility levels and potential savings in social care expenditure. Optimal intensity, duration and type of hydrotherapy treatment need to be identified through further well-designed research studies.

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# Non-clinical CPD

## attending Physiotherapy UK 2013

**Esther van der Hoek** Clinical specialist physiotherapist Aneurin Bevan University Health Board

In October 2013, I was given the opportunity of attending the two day Physiotherapy UK conference at the ICC in Birmingham. It was the first time I had been to the CSP's flagship event since qualifying as a physiotherapist in 1996. I was looking forward to attending, as many colleagues, including my husband, also a physiotherapist, had attended previous events and had told me how good it was. So I went to see what it was all about for myself. The ICC is in the centre of Birmingham and was quite easy to get to by train.

I went to the conference with the aim of:

- Learning something new to introduce into my clinical practice
- Getting an overview of the wider issues affecting the NHS and physiotherapy services across the UK
- Networking with colleagues from my own health board and meeting old and new friends
- Looking at the trade stands

- Experiencing a great piece of learning to make a valuable contribution to my CPD record, especially with the possibility of having to present it in the 2014 HPCP audit, should I get picked.

Over the two days I attended many sessions, including the Founders lecture by Dr Emma Stokes and the debate on the Francis report. I went to lectures from the neurology, musculoskeletal and rehabilitation strands and learnt a great deal. By the end of the conference I had a greater understanding of the process of development of the NICE guidelines and strategies for implementing them into clinical practice. I could see what was affecting the physiotherapy community across the UK, including the outcomes of the Francis report, seven-day working, advances in technology, implementation of research and evidenced-based practice. I also learnt a great deal from the 'exercise strategies to improve shoulder function' lecture by Professor Karen Ginn and the 'foot function in relation to common gait

dysfunction and symptomology' by Paul Harradine. Both were evidence-based and provided practical knowledge and skills that I have since been able to implement into my everyday clinical practice.

I visited a great number of the stands including the CSP stand that was promoting Physiotherapy Works, the evidenced-based briefings demonstrating the effectiveness of physiotherapy. There were stands representing orthotics products, clinical interest groups, disease management, such as the Parkinson's Disease Society and the Charcot Marie Tooth Society, and stands promoting advances in technology.

I would definitely recommend that every physiotherapist should attend the Physiotherapy UK conference at least once in their career. It was a fabulous opportunity to network with colleagues, pick up the odd pen and *Post-it* notepad, essentials in every department, and to see what is being achieved and showcased within our profession.

## The life of a PhD student

**From a discussion at a national ACPIN research workshop in early 2012, it was felt that entering into post-graduate research can be very daunting with no one knowing entirely what to expect. It was decided to follow two PHD students on their epic journey through the highs and lows that they will inevitably experience, to assist anybody who is thinking of pursuing the research avenue themselves.**

### How time flies!

In my previous blog I wrote that I was keenly anticipating the end of recruitment to the clinical trial – using Botulinum toxin or placebo injections to the forearm flexors combined with electrical stimulation to the forearm extensors to improve function very early following stroke. The trial has been running since January 2012 and I have managed just two single week breaks in that time, so I suppose I was hopeful that I would be less busy when recruitment was completed. This was realistically never going to be the case.

I also wrote how I was spending a lot of time attempting to get the trial up and running at other centres. Unfortunately this was never achieved. The bureaucracy and a lack of commitment from

a member of the research team meant this proved to be too difficult. So I closed recruitment in December having recruited 120 patients to the trial, of which 97 were randomised to the clinical trial. I was really hoping to get to randomise 100 patients but this was not to be either. Another step too far!

I have managed to get continued funding until October 2014 so that I have time to write up and analyse the results. This became necessary as we had initially planned to finish recruitment in September 2013 – a delay in finishing recruitment leads to a delay in unblinding and subsequent data analysis.

So what am I doing now? I am back to trying to get the *Cochrane Review* completed. I first mentioned this in the

"I have been reminded that some things are in your control and some things are out of your control."

Winter 2012 of *Syn'apse* – how time flies! The aim was to have this done by January 2014 but the clinical trial had to take precedence so *Cochrane* took a back seat. It is somewhat frustrating as this will only form a tiny part of my PhD thesis but takes up a phenomenal amount of time.

Data is also being put together and transferred in electronic format so that when unblinding of the trial takes place in May this year I will be able to get

straight into the analysis phase. I have an *Excel* spreadsheet with over 30,000 cells in it. That is something that is better not to think too hard about and just keep working on.

I am obviously unable to analyse the data in any way that could potentially unblind me but we have been able to interrogate some of the baseline measurements and investigate the variations in those who recovered arm function quickly and those who did not recover following stroke. I have been accepted to present some of this data as a poster at the World Congress of NeuroRehabilitation in Istanbul in April. I am also expecting to help at a presentation that my Professor is giving on one of the days. This is certainly one of those boosts that I have discussed previously that keeps my morale and work rate up. I am sure I will let you know how that goes in any future blogs.

So to summarise the last six months – I have been reminded that some things are in your control and some things are out of your control. There have been many frustrations out of my control (not managing to randomise 100 having got so close, was particularly exasperating) – but I have continued to enjoy achieving the micro and mini milestones that I set for myself, and were firmly in my control.

## Opportunity!

**“The opportunity of a lifetime must be seized during the lifetime of the opportunity.”**  
(Leonard Ravenhill)

As my PhD journey draws to a close, I have found myself reflecting on the many opportunities that I've had along the way. Some opportunities were seized, others slipped away. I am reminded of a very famous quote from Mark Twain that said “I was seldom able to see an opportunity until it had ceased to be one.” That would sum up my experience at the beginning of my PhD. At this point along the journey I was focused on one thing and one thing only – getting the PhD. As such, I was not looking for anything that was called an opportunity, unless it was directly related to what I was doing. That is, directly related to achieving the PhD. In fact, if there was something that was not directly linked to my research I would not even consider it and would classify it as a distraction. Well, I have learnt that ‘perceived distractions’ can also be positive. I had tunnel vision; sometimes that might be necessary in life, but sometimes it is worth being more open-minded and looking around. In this blog I will share two key opportunities that came my way; one directly linked to my PhD the other indirectly. Nevertheless, both proved very rewarding.

### Teaching

The nature and the terms and conditions of my PhD programme meant that teaching was attached to my role. This was an expected opportunity for me. I have found teaching a welcome break that afforded me the opportunity to think about something else other than my research. Interacting with future physiotherapists and sharing not only my involvement in research, but also attempting to bridge the gap between research and clinical practice using my experiences as a clinician has been rewarding.

However, one thing that I did not expect was the amount of support that was available to PhD students who are involved in teaching. Firstly, you are supported by the other lecturers who you work closely with on a particular module. Secondly, the university supports you on a wider scale. For example, all PhD students who are involved in teaching are supported through what is called the Graduate Learning and Teaching Programme. This programme provides an opportunity to learn about the key principles that underpin learning and development in higher education, and practical tips about how to manage your tutorials to gain the most

from your teaching sessions. For me, when this programme came about, I initially saw it as a distraction and did not wish to be involved. However, after consideration I decided to sign up to find out more about it. I was happy I did because as a result I have gained an additional qualification that could open up the door for me to lecture at any higher education institution in the UK, should this be the route I desire to pursue post PhD.

### Conferences

Another opportunity PhD students can find very rewarding is presenting at conferences. You decide whether you wish to present a poster or you may be asked to do an oral presentation. I have found these opportunities quite scary but rewarding at the same time. Presenting your research at a conference will open it up to public scrutiny and is not an easy exercise but can be very valuable. Since my first public presentation, the others have not been too difficult. I have found that the more you speak about your research, the more clarity you gain about the message you wish to communicate to your audience. Poster presentations are good for that reason. Some conferences require you to present what is on your poster in three to five minutes. If you can communicate with your peers in such a limited timeframe, it means you are clear about your topic area. I have found that this is easier in conferences amongst like-minded professionals. Presenting your research to other professionals outside the health field provides other challenges but can be equally rewarding. It involves adapting your style to suit the audience, avoiding the use of medical jargon.

Overall, despite being focused on one thing at the beginning of my journey, now I have realised the reward of seizing opportunities as they come along, whether they are directly or indirectly linked to my PhD. I have also learnt that opportunities do not always come along when it is convenient, and they don't shout “**I am an opportunity, seize me!**”, but most times they can be very rewarding. So, if you are thinking of doing a PhD be open-minded and keep an eye out for opportunities as you travel through your journey.

# LIFE & LONG-TERM CONDITIONS

ACPIN NATIONAL  
CONFERENCE & AGM  
NORTHAMPTON HILTON  
22 MARCH 2014

## Lecture abstracts

### Enhancing physical activity after stroke: opportunities and challenges

**Frederike van Wijck** Professor in Neurological Rehabilitation, Institute for Applied Health Research and the School for Health and Life Sciences, Glasgow Caledonian University, Glasgow

**There is a growing interest in physical activity as part of managing long-term neurological conditions, with the largest body of evidence pertaining to stroke. More recently, evidence is also emerging about sedentary behaviour after stroke. There are clear opportunities for health care and exercise professionals to improve health and quality of life after stroke by enhancing physical activity and reducing sedentary behaviour – but what are the challenges to making this happen?**

The aim of this talk is to present an overview of recent developments in the field of physical activity after stroke, and to discuss emerging opportunities for health care professionals to contribute to the development of a pathway for physical activity after stroke.

We will begin the session with an overview of physical activity and sedentary behaviour after stroke and the impact these behaviours have on activities of daily living, independence and community re-integration. We will then discuss the most recent evidence for exercise and fitness training after stroke in terms of its safety, clinical effectiveness and psychosocial impact.

This body of evidence has informed clinical guidelines and government policies within the UK and across the world. These recommend – unless there are contraindications – that physical activity be part of a more active lifestyle after stroke.

Based on these policies and evidence, Exercise after Stroke Services are being developed throughout the UK. However to optimise the benefits of these services, barriers in the uptake and maintenance of physical activity need to be carefully considered.

In the final part of the session, we will explore our emerging understanding of barriers and motivators to physical activity after stroke, and discuss how we may use this in practice to promote a more active lifestyle after stroke.

**Dr Frederike van Wijck** qualified as a physiotherapist and movement scientist in The Netherlands and is currently Professor in Neurological Rehabilitation at the Institute for Applied Health Research at Glasgow Caledonian University. Her research focuses on functional recovery after stroke. Her work on physical activity after stroke, developed together with

Prof Gillian Mead at the University of Edinburgh and her team, comprises systematic reviews on the effects and experiences of physical activity after stroke, as well as studies on the measurement of physical activity, impact of goal setting and the design and evaluation of physical activity for stroke survivors who are non-ambulatory. She has also been involved in the design and validation of the first UK 'Exercise and Fitness Training after Stroke' course and the development of best practice guidelines for community-based exercise and fitness training after stroke. She is an author/editor of two books, both published by Elsevier: with Professor Gillian Mead, she co-edited the book *Exercise and Fitness Training after Stroke: a handbook for evidence-based practice* and together with Dr Douglas McBean, she co-edited the textbook *Applied Neurosciences for the Allied Health Professions*. Frederike is a member of the Cochrane Stroke Editorial Group and research lead and founding member of the Scottish Stroke Allied Health Professions Forum.



# Long-term implications of CP and spasticity in childhood

**Stephanie Cawker** Clinical Specialist Physiotherapist Neurodisabilities, Wolfson Neurodisability Service, Great Ormond Street Hospital, London

**This lecture will discuss the musculo-skeletal implications of the negative and positive effects of upper motor lesions in people with cerebral palsy and impact of ageing.**

It will predominantly cover issues for people who are classified as Gross Motor Classification System 1-3 (those who use walking for their main form of mobility in childhood) and are more likely to access physiotherapy through their local GP services rather than specialist movement disorder services.

Childhood therapy options and life-long expectations will be considered.

## Recommended reading

GMFCS Expanded and Revised (2007) [www.canchild.ca](http://www.canchild.ca)

*NICE guidelines for Spasticity management in Children and young people with non-progressive upper motor neurone injury* (2012) [www.nice.org.uk/CG145](http://www.nice.org.uk/CG145)

**Stephanie Cawker** is a Clinical Specialist Physiotherapist working in paediatric neurodisability, and an extended scope practitioner Botulinum toxin (BTX) injector. She has worked at Great Ormond Street Hospital since 2000 as part of the multidisciplinary neurodisability service, and co-ordinates the movement disorders service. Previously she worked for Tower Hamlets and The Royal London NHS Trusts

as a community physiotherapist and as part of the neuro-orthopaedic assessment service, including work in the gait analysis laboratory and transition clinics. Stephanie has been a long-standing member of Association of Paediatric Chartered Physiotherapists (APCP), and has held roles at regional and national level. She was a member of the APCP 'Botulinum Toxin guidance' development group in 2008, and one of the physiotherapy representatives on the National Institute for Clinical Excellence (England & Wales) guideline development group - Spasticity management in children and young people with non-progressive brain disorders in 2012.

# Living with traumatic brain injury

**Dr Petra Mäkelä** BSc MBChB MSc MRCP(UK) King's College Hospital NHS Foundation Trust, London

**John Ling** Clinical Nurse Specialist, King's College Hospital NHS Foundation Trust, London

**Traumatic brain injury (TBI) represents a heterogeneous condition for which access to rehabilitation is generally restricted to those with more severe injury, and services beyond the acute hospital setting remain patchy. Following TBI, individuals face uncertain challenges during their transition from healthcare to the community, which often continue to unfold over many years.**

Focusing on 'the person in the patient', the presentation will consider the ways in which TBI can affect individuals' long-term well-being and participation. Narratives from people living with TBI will be used to explore challenges faced and strategies used, including aspects of self-identity, family, relationships, and employment.

Although patient experience is often considered through its 'functional' components (such as how symptoms are managed) and 'transactional' features (such as where and when an appointment is held), less attention is paid to the 'relational' aspects of significance to the person (in which they are 'cared about' through ongoing relationships; Murrells et al 2013). Examples of continuity of relational support will be considered through the role of a Clinical Nurse Specialist in Brain Injuries, crossing acute and community contexts, and Headway, a brain injury charity providing social rehabilitation and peer support opportunities.

People who return to employment or study after TBI are considered to have achieved 'a good outcome', yet over half report significant difficulty and psychological stress (Dawson et al 2004). Perceived self-efficacy has been found to be strongly related to subjective quality of life after TBI (Cicerone and Azulay 2007) and can be influenced through interventions that allow the person to experience success and mastery. The potential for interdisciplinary support of self-management, to enhance self-efficacy after TBI, will be explored.

## References

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**Dr Petra Mäkelä** is currently undertaking a Darzi Fellowship at King's College Hospital NHS Foundation Trust. She is focusing on service development in the traumatic brain injury pathway, within the Major Trauma Centre and across the regional trauma network. Petra has completed specialist training in rehabilitation medicine and stroke medicine, in London. She has also undertaken training in adult psychiatry and has completed a masters degree in cognitive neuropsychology. She has worked within inpatient and community neurorehabilitation services in the UK, Australia and New Zealand. She is interested in initiatives for developing self-management support for people with neurological conditions.

## Long-term neurological conditions

self-referral, self-management or funding for yourself

**Dr Sara Demain** Lecturer in Physiotherapy, University of Southampton

**Self-management is recognised as the cornerstone of living with a long-term condition, yet there is considerable debate about what self-management means and how much support is needed to help people self-manage.**

This presentation calls on data from several qualitative studies to highlight how people with neurological conditions experience self-management and the barriers they face to managing their own health and well-being.

The presentation aims to challenge perceptions about self-management and generate debate about how physiotherapists can better support people living with long-term neurological conditions.

**Dr Sara Demain** is unusual in being a physiotherapist with a PhD grounded in social science which gives her a unique perspective on the use and evaluation of rehabilitation technologies. Her research has had a direct impact on Stroke Association and Chartered Society of Physiotherapy policies regarding the provision of physiotherapy after hospital discharge and informed guidance on best practice in exercise provision after stroke. She uses a range of qualitative and quantitative methods and methodologies to explore both the physical and sociological aspects of rehabilitation technologies. Sara is particularly interested in rehabilitation engagement and self-management in neurological condition, exploring how therapy services and individual therapists can provide therapies which people can do, and want to do.

## WORKSHOPS

### 1 Transition from paediatric to adult services

**The workshop will look at the transition process for young people with long-term conditions within health, as well as outside the health sphere.**

**Stephanie Cawker**

Clinical Specialist Physiotherapist  
Neurodisabilities, Wolfson Neurodisability Service, Great Ormond Street Hospital, London

Stephanie is a Clinical Specialist Physiotherapist working in paediatric neurodisability, and an extended scope practitioner Botulinum toxin (BTX) injector. She has worked at Great Ormond Street Hospital since 2000 as part of the multidisciplinary neurodisability service, and co-ordinates the Movement disorders service. Previously she worked for Tower Hamlets and The Royal London NHS Trusts as a community physiotherapist and as part of the neuro-orthopaedic assessment service, including work in the gait analysis laboratory and transition clinics. Stephanie has been a long-standing member of Association of Paediatric Chartered Physiotherapists (APCP), and has held roles at regional and national level. She was a member of the APCP 'Botulinum Toxin guidance' development group in 2008, and one of the physiotherapy representatives on the National Institute for Clinical Excellence (England & Wales) guideline development group - Spasticity management in children and young people with non-progressive brain disorders in 2012.

**Andy Hiscock** MCSP

Neuromuscular Care Advisor for the East of England, Addenbrooke's Hospital, Cambridge

After eight years working in a variety of clinical areas, Andy spent three years as a research physiotherapist in London working with both children and adults with neuromuscular conditions. Since November 2012 he has been working for the East of England Neuromuscular Care Advisory Service based at Addenbrooke's Hospital in Cambridge. This role supports children and adults with neuromuscular conditions across all aspects of health and social care, as well as supporting education and health professionals involved in each case.

**John Ling** is the Clinical Nurse Specialist for the neurovascular and brain injury services at King's College Hospital. He is also a trustee of Headway (South East London/North West Kent). He trained as a nurse at Brighton University and subsequently completed an MSc in Physiology at the University of London. His main clinical background is in critical care, also having worked previously at Queen Square. He now runs a brain injury follow-up clinic providing advice and support to patients and families. John also co-ordinates the neurovascular service at King's which manages pathologies such as subarachnoid haemorrhage and arterio-venous malformations. He provides a Transcranial Doppler service to screen for cerebral vasospasm after SAH.

## 2 Life after stroke

**This workshop will give a guided tour of national resources available from the Stroke Association, interactive sessions on 'my physiotherapy journey through NHS' and 'on the other side' life after services. Maria will be joined by three volunteers from the Stroke Association.**

The workshop will finish with a questions and answers session.

### **Maria De George**

Regional Information Officer, Stroke Association

Maria has over ten years experience working in the field of stroke and has held two positions with The Stroke Association. Her current position means she has regular contact with those affected by stroke, through stroke clubs and awareness events, and is fully aware of the challenges that stroke brings. She is responsible for strategic community development and networks regularly with health and social care professionals and commissioners across the region.

## 3 End of life care

**Thinking and talking about end of life care is as much about living as dying. Health care professionals sometimes feel a sense of impotence and hopelessness when supporting people at the end of their life; however physiotherapists really can make a difference.**

This workshop will explore how planning ahead and maintaining independence can promote well-being, dignity and comfort for people nearing end of life. It can elicit a sense of control and help to allay fears and concerns. We will look specifically at some of the resources available from the MND Association which may help with this process.

### **Rachel Boothman**

Regional Care Development Adviser, Motor Neurone Disease Association

After several years working in journalism and then supporting students with special educational needs, Rachel qualified as an occupational therapist from the University of Northampton in 2002. She has worked in the NHS in both physical and mental health settings. For the past five years she has worked in the charity sector as a Regional Care Development Adviser with the Motor Neurone Disease Association. This role involves advising around management of complex cases, educating health and social care professionals, supporting and supervising volunteer visitors and influencing a wide range of stakeholders to improve standards of care.

### **Louise Rickenbach**

Regional Care Development Adviser, Motor Neurone Disease Association

A physiotherapist by background, Louise developed an interest in Motor Neurone Disease while working in community and palliative care settings. She volunteered as an Association Visitor for the MND Association for four years, alongside working as a physiotherapist, before coming into post last year, as the Regional Care Development Adviser for the MND Association in the south central area.

# AGM 2014

## Minutes

The meeting opened at 12.00 pm

### **1. Welcome and introduction to the executive committee**

Committee members present:

Gita Ramdharry, Jakko Brouwers, Adine Adonis, Jane Petty, Lisa Knight, Ralph Hammond, Chris Manning, Nikki Guck, Fran Brander

### **2. Apologies**

- Lorraine Azam (congratulations on the birth of her new baby boy)
- Lisa Bunn who has temporarily stood down as co-research officer while on maternity leave
- Jenny Barber

### **3. Minutes of 2013**

Minutes published in the Spring/Summer 2013 edition of *Syn'apse*. Unanimously accepted as an accurate account

### **4. President's address**

Dr Fiona Jones

### **5. Chair's address**

Dr Gita Ramdharry (This can be found on pages 2 and 3 of this edition of *Syn'apse*)

### **6. Treasurer's report**

Chris Manning

Vote to retain the current accountants:

*Proposer:* Helle Sampson

*Seconder:* Jakko Brouwers

Carried unanimously

Full copies of the ACPIN accounts are available on request via [treasurer@acpin.net](mailto:treasurer@acpin.net)

## President's address

### Dr Fiona Jones

Reader in Rehabilitation, School of Rehabilitation Science, Faculty of Health and Social Care Sciences, St George's University, London, and Kingston University

### 7. Election of Executive Committee members

- Gita Ramdharry stepped down as chair from now, following two years service as chair. Jakko Brouwers, as vice chair, automatically transfers into the honorary chair position. Adine Adonis was unanimously voted in as vice chair
- Voting of the executive committee:
  - Jane Petty was unanimously re-elected as research officer  
*Proposer:* Andrea Stennett  
*Secunder:* Lisa Knight
  - Gita Ramdharry was unanimously voted in as honorary secretary  
*Proposer:* Cherry Kilbride  
*Secunder:* Anne Rodger
  - Lorraine Azam was unanimously elected as membership secretary  
*Proposer:* Andrea Shipley  
*Secunder:* Jane Petty
  - New committee members unanimously voted in:
    - Joe Buttell  
*Proposer:* Anne Rodger  
*Secunder:* Jo Tuckey
    - Melanie Falk  
*Proposer:* Jakko Brouwers  
*Secunder:* Helle Sampson)

### 8. AOB

None

**As usual I was given a very short time for my address, probably a good thing, as I have a tendency to ramble! So I chose to concentrate on an area which can be a common topic of debate among neurophysiotherapists: 'goal-setting'. But rather than talk about the evidence base, and the relative strengths and weaknesses of our current approaches such as SMART and GAS, I showed a short film which clarified goal-setting from a patient's point of view.**

Jim was in his early 50s when he had his stroke, and worked for the police. He has now retired from work but runs his local Different Stroke group, and knows a thing or two about goal-setting. Since his stroke he has retrained as a counsellor, and now supports young adults through education, helping them work through problems and to develop their own solutions. He also provides support and advice for the members of his group and is the 'go to' person for many worries and anxieties experienced by people when living life again after stroke.

You probably did have to be there to hear Jim's viewpoint and reflections on goals, but he sent a powerful message about who should be in charge. He did this by recounting a really positive experience he had with a neurophysiotherapist, who in his words 'never made him feel as if he wasn't in control'. She was also prepared to support him to try a challenge which was risky (an outdoor

assault course!) but after a fall gently guided him to understand ways of reducing his risk, never saying no.

Jim feels that some of the efforts made by rehabilitation teams to identify whether goals are being met or not (ticking the box for audit purposes), may in themselves be stifling the creative and therapeutic aspects that can be gained through supporting a person to set goals. He also made the point that, whatever happens, if he identifies a goal, it should be his decision, and his alone, to decide when not to try any more.

I hope that powerful commentaries and reflections from people like Jim, who really know, can help us towards a really good debate on goal-setting at some time in the future, before we are in danger of losing touch with the real reason for doing it. I am looking forward to the chance to debate these and other related issues in the coming year.

## Treasurer's report

### Chris Manning

**I will now present a summary of the financial accounts for national ACPIN for the year end 31st December 2013.**

The total income (*Figure 1*) was £95,960. This was a decrease on last year's income and was mainly due to a decrease in income from the March conference, and a decrease in membership income.

Expenditure (*Figure 2*) for 2013 was less than 2012. This was mainly because last year includes £10,000 for the splinting guidelines. Other costs have small variations between years, but nothing significant.

*Figure 3* divides the course income and expenditure up to the conference that ACPIN held this time last year, March 2013. The conference was planned to run at a

	2013	2012
	£	£
Course Fees	21,148	26,133
Membership	68,160	69,015
Capitation	5,552	3,890
Database and Syn'apse	1034	1,343
Bank Interest	66	63
<b>Total</b>	<b>95,960</b>	<b>100,444</b>

**FIGURE 1** Income



loss, with low course fees in order to put some money back into the membership. You will see that the course was run at a significant loss.

The balance sheet (Figure 4) on the 31st December 2013 showed a small surplus of £9,274 and we carry forward reserves of £162,410 into 2014.

We are constantly looking at ways we can use this money for the benefit of the membership, and conference fees remain low. Membership fees will remain unchanged for the tenth year. We awarded several research bursaries in 2013 and the amount available for each project has been raised to £1,000. Do consider this if you are undertaking research. Next year we will run a two-day conference and a loss is anticipated on this. The splinting guidelines, produced in association with the College of Occupational Therapists will be published in 2014 and this is expected to incur substantial costs.

	2013	2012
	£	£
Conference	37,884	40,595
Synapse	11,784	11,196
Travel	7,677	8,427
Administration	6,621	6,731
Research	3,850	545
Capitation	11,450	13,045
Computer Costs	368	188
UK Stroke Forum	-	372
Splint Guidelines	-	10,000
Accnts, bank, gifts, sundry	3,842	3,158
<b>Total</b>	<b>83,476</b>	<b>£94,257</b>

FIGURE 2 Expenditure

	2013	2012
	£	£
March conference	21,148	37,884
<b>Reserves brought forward</b>		<b>153,135</b>
<b>Surplus/(deficit)</b>		<b>9,274</b>
<b>Reserves carried forward</b>		<b>162,410</b>

FIGURE 3 Courses

	£
Reserves brought forward	153,135
Surplus/(deficit)	9,274
<b>Reserves carried forward</b>	<b>162,410</b>

FIGURE 4 Reserves

**Copies of Accounts 2013**

Full copies of the ACPIN accounts for 2013 are available on request.

**Vote for Accountants**

Vote to retain the current accountants for 2014: Langers, 8-10 Gately Road, Cheadle, Cheshire, SK8 1PY.

## Delegate's report

Claire Guy

**Once again, the ACPIN conference provided a stimulating platform for informed discussion and sharing of up-to-date contemporary thinking in the areas of managing and living with longer-term neurological conditions.**

Frederike Van Wijck explored the topic of enhancing physical activity after stroke, with the challenges of gaining functional skills improvement and yet people often still remain sedentary. Structured programmes do promote improved mood and self-esteem, and peer support is important, but the barriers are still fear, fatigue, depression and lack of knowledge. Physiotherapists are well placed to provide the seamless support after the acute phase to encourage, motivate, integrate and facilitate activity, but also use skills and knowledge to drive policy change.

This theme underpinned much of the conference, stimulating thoughts and ideas as other speakers' contributions added to the wider picture addressing other diagnostic groups. Stephanie Cawker used her wealth of paediatric experience to stimulate thinking in the adult neurophysio when talking about transition of services for people with CP as they move into adulthood. This was carried through later in one of the interactive workshop sessions.

It is always thought-provoking to hear a user perspective and Dr Petra Makela

and John Ling integrated this well into their talk: living with traumatic brain injury. Their discussion highlighted the 'person within the patient' with two video clips showing different approaches taken by women following TBI, as they re-entered a social and work environment. Contextual factors of individual identity and relationship following injury are key to outcome. This highlights where neuro physiotherapists can be well placed to navigate people through a maze of challenges they face when they move out of a protected rehab environment.

This led very well into the subject of self-management, with Dr Sara Demain, who provided a wealth of information and seven principles to tap into.

Another topic that was discussed throughout the day was risk, and how moving forward and trying new things always involves risk. If you are interested in this, look at Dave Padgen's (Stumbling Dave) homepage and a quote by Al Alaverez on risk. Dave is a speaker and adventurer with CP. Fiona Jones also addressed this in her president's address on goal-setting and the importance of

each person setting challenging goals for themselves.

The workshops worked well, with the opportunity for more interactive discussion on specific areas. The stands also provided appropriate information. Once again, the conference provided a great opportunity to network and catch up with the ACPIN community, which is thriving, visible and pro-active. Thanks went to Gita for a very productive term as chair and a welcome to Jakko in his new role. Another successful conference.

# News

UKABIF launches manifesto to improve services for children and young people with acquired brain injury

**“There is a general lack of understanding about the effects of Acquired Brain Injury (ABI) in children and young people, and a lack of awareness that over time ABI is a developing disability. Current care planning and service provision is woefully inadequate”, said Professor Michael Barnes, Chair of the United Kingdom Acquired Brain Injury Forum (UKABIF) at the November launch of the UKABIF Manifesto *Life after brain injury? A way forward.***

The charity is calling for a National Audit of brain injury incidence and rehabilitation not only for children and young people, but also for adults. As Professor Barnes pointed out: “How can you plan rehabilitation services if you don't have accurate data about the incidence and prevalence of ABI?”.

This is the second Manifesto to be launched by UKABIF as part of its Campaign to highlight the need for improvements in the provision of services for people with ABI. The Manifesto outlines the importance of considering ABI as a chronic health condition with associated ongoing symptoms and emphasises that current care planning and service provision is inadequate. Education services also play a crucial role in the care pathway but personnel have limited knowledge of ABI. In addition, practical, easy access to information

is required for children, young people, their families and all professionals involved in their care and support.

Speaking at the launch Maureen Le Marinel, President of UNISON, Britain's biggest trade union with members in the public services and the essential utilities, talked about Katie, her niece, who was knocked down by a car and suffered an ABI. “UNISON is supporting the UKABIF campaign because I've seen at first hand just how devastating an ABI in a young person can be. Although our NHS was brilliant, there was a lack of information, service integration and co-ordination. And although the whole family is pivotal in the rehabilitation of the child, they are often not considered such a key part of the process.”

Lord Ramsbotham, Chair of the Criminal Justice and Acquired Brain Injury Interest Group, commented that there



The United Kingdom  
Acquired Brain Injury Forum

can be major consequences if children and young people are not monitored long-term – a study published in 2010 highlighted that almost 50% of young male offenders had a traumatic brain injury at some stage in their lives; a significantly higher prevalence than that expected in society as a whole. “ABI must be managed early to avoid long-term disability, and monitored long-term for problems arising post-injury”, said Lord Ramsbotham.

“ABI is a leading cause of death and disability”, concluded Professor Barnes, “our manifesto presents four key recommendations which we hope health professionals, purchasers and providers of services will support and implement. By working together we can improve services and ensure the best possible outcomes.”

WFNR Franz Gerstenbrand award now open for entries

**To support Brain Awareness Week (10–16 March 2014), the World Federation for Neurorehabilitation (WFNR) has announced that the WFNR Franz Gerstenbrand Award is open for entries from clinicians, researchers and allied health professionals to recognise and reward a neurorehabilitation project that has benefitted patients.**

“This is the second year of our Award and we've announced it during Brain Awareness Week not only to highlight our work in neurorehabilitation, but also to demonstrate our support for the global campaign to increase public awareness of the progress and benefits of brain research”, said Stephanie Clarke, WFNR President.

Named after Professor Franz Gerstenbrand, in recognition of his continuous contributions to neurorehabilitation, the Award is worth £3000 and open to WFNR members and non-members worldwide. Entries can come from any aspect of neurorehabilitation and examples include a patient or clinic management initiative, research project,

**WFNR**  
**World Federation for**  
**NeuroRehabilitation**

best practice development or the use of a new technological development. The annual, single prize will be awarded as either a travel bursary to a clinical conference, professional development course or research project.

For further details on how to apply for the award visit: [www.wfnr.co.uk](http://www.wfnr.co.uk)

## Exercise in multiple sclerosis (EXIMS)

**This MS Society funded study investigated the effects of a practically implemented exercise programme, designed to facilitate sustained behaviour change, on self-directed exercise behaviour and important health outcomes in people with MS (PwMS), with up to nine months of follow-up.**

### Methods

120 PwMS (EDSS range 1.0-6.5) were randomised to a twelve-week pragmatic exercise intervention (EXIMS) plus usual care, or usual care only. EXIMS comprised a tapered programme of aerobic exercise, strength and balance training, with two supervised plus one prescribed home exercise session during weeks one to six, and one supervised plus two prescribed home exercise sessions during weeks seven to twelve. Supervised exercise incorporated cognitive-behavioural techniques to promote long-term exercise behaviour change. The primary outcome

was self-reported exercise behaviour (Godin Leisure Time Exercise Questionnaire – GLTEQ) at three months. Secondary outcomes included fatigue and health-related quality of life (HRQoL).

The home sessions were geared towards the mobility and symptoms of each participant. Participants were encouraged to seek out opportunities to exercise, either in the home or in the local community (eg healthy living centres, health walks, fitness centres, swimming pools etc), based on their individual needs and preferences.

The overall results demonstrated an

increase in GLTEQ self-reported exercise in the intervention group versus usual care after three months, with a non-significant increase still apparent at nine months. Reductions in physical, cognitive, psychosocial and total fatigue favouring the exercise group were also observed after three months. Many HRQoL domains showed improvements in favour of the exercise group after three months with improvements in emotional well-being, social function and overall quality of life being sustained for nine months.

As a result of this the MS Society will be rolling out a 'Get Active' programme, looking at models of delivery of local exercise and activities for people with MS. They will be working with leisure and activity providers delivering 'MS Awareness' sessions to improve the opportunities for people with MS to get active locally.

## Defining the value of AHPs with expertise in multiple sclerosis

**Katy Dix and Howard Green**

**This report, published in November 2013 by the MS Trust, focuses on the range of highly skilled, knowledgeable and experienced allied health professionals who support people with MS.**

It states how vital it is that the MS AHPs are able to demonstrate their value to a wider audience. The reforms to the NHS, rising financial pressures and the need to deliver significant savings with no compromise in quality means that MS services need to make themselves visible to commissioners and show the difference they make.

The MS Trust commissioned this work, building on the 2012 report; *Defining the value of MS specialist nurses*, to advance the understanding about the opportunities and challenges in showing the real impact of AHPs with expertise in MS. Compared with the nurses, these challenges may be even greater, particularly given the wide variation in service configuration, the diversity of roles, types of employer, levels of expertise and in evidence of outcome.

This report makes a series of important, practical recommendations for commissioners designing and allocating resources for MS services, for MS AHPs working on the front line in a changing and challenging environment, and to the

national organisations with an interest in protecting and developing services for people with MS.

### Recommendations

Commissioners should ensure that:

- Any MS service that they commission includes MS expertise in occupational therapy and physiotherapy and that they have access to the MS expertise if required.
- There are sufficient AHPs with expertise in MS to enable people diagnosed with MS to have direct access to clinicians to obtain MS-specific information and advice about when and where to refer on.
- They commission explicitly for high standards of inter-agency communication from MS services.
- All MS service teams have access to neuropsychologist support for people with MS.
- MS services are commissioned according to the widest definition of value

for money recognising the long-term financial value to the NHS of maximising people's day-to-day living functions.

- Commissioners should consider adopting the model for long-term conditions within the *Year of Care*<sup>1</sup> which contains a practical guide to commissioning and delivery of untraditional services to support self-management.
- Whilst challenging MS services to demonstrate service outcomes, effects, and outputs, ensure that MS services are not disadvantaged by the fact that supporting people through a long-term degenerative condition means they may not be able to quantify the benefits as easily as other types of service.

### Recommendations for Allied Health Professionals

AHPs with expertise in MS should:

- Further raise awareness of their services amongst GPs and other professionals.
- Formally provide open access to advice for professionals providing services to people with MS.
- Choose at least a few measures from the National Outcomes Framework 36 and adopt or adapt them to measure their service.
- Survey service users and carers systematically.
- Audit their services to identify strengths and weaknesses, and plan and act on the results.
- Participate in research.

1. *Year of Care* Report of findings from the pilot programme, Diabetes UK, Department of Health, The Health Foundation and Diabetes UK2011

# UK International Emergency Trauma Register

## UKIETR is a new opportunity for UK-based physiotherapists interested in working during natural disasters.

**Pete Skelton** Rehabilitation Project Manager, Handicap International

Historically, the inclusion of physiotherapists and occupational therapists during disasters and emergencies has been viewed as a luxury. However, recent research and best practice guidance, in particular following the 2010 Haiti earthquake, has placed rehabilitation professionals at the forefront of the emergency response.

“Early rehabilitation can greatly increase survival and enhance the quality of life for injured survivors.”

*Humanitarian Charter and Minimum Standards in Humanitarian Response* Third Edition 2011 The Sphere Project [www.sphereproject.org](http://www.sphereproject.org)

Emergency rehabilitation begins as early as possible after a disaster and involves the prevention of disabling or life-threatening complications while maximising an individual's function. Rehabilitation professionals are also often the best placed to ensure the inclusion of people with disabilities in an emergency response, and to consider the long-term needs and social inclusion of those affected. However, until recently there was a lack of a centralised register of appropriately skilled and prepared rehabilitation professionals, both in the UK and internationally, and professionals are often unable to take short notice annual leave to take part in an emergency deployment.

In response to these issues, Handicap

International have started a two-year project in partnership with UK-Med to fully integrate rehabilitation professionals into the UK International Emergency Trauma Register (UKIETR). The UKIETR is funded by the Department for International Development (DFID) to enable the rapid deployment of trained UK-based health professionals to sudden onset disasters. When needed, a specialist field hospital is provided by Merlin and Save the Children.

The principle of the register is that it is inclusive and so all UK-registered physiotherapists and occupational therapists with an interest in working in emergencies are welcome. Handicap International are also working with professional networks, including ACPIN, to develop high quality clinical humanitarian training. As register members attend these free specialist trainings and additional training offered by UK-Med, they will become eligible to be placed 'on-call' for emergency deployment. Critically, as this on-call period is known in advance, employers can plan for a staff member's potential deployment. Also, significantly, funding for deployed staff will be provided by DFID directly to their employer, meaning

# HANDICAP INTERNATIONAL



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that employers benefit from their staff's training and experience, but do not lose out financially in the event of them being deployed. UKIETR members can take part in the register knowing their post will be covered, and that they do not need to take annual leave in order to deploy.

### What to do if you are interested?

- Interested physiotherapists and occupational therapists can join the register at [www.uk-med.org](http://www.uk-med.org) or contact [peter.skelton@hi-uk.org](mailto:peter.skelton@hi-uk.org) for more information.
- UK-Med will offer UKIETR members pre-departure training, as well as UK and International field-based training to prepare them for the realities of work in sudden onset disasters.
- Appropriately-skilled therapists on the register will then be invited by Handicap International to undergo specialist emergency training to prepare them for deployment. Participants will also be offered additional 'gap-filling' training in selected clinical fields where they may lack core skills.
- Once fully trained, participants will be placed 'on call' for a two to three week deployment as part of a multi-disciplinary surgical team.

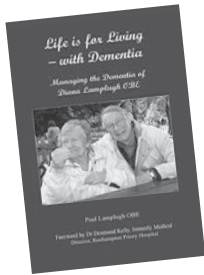




# Reviews

Reviews of research articles, books, courses and equipment in *Syn'apse* are offered by regional ACPIN groups or individuals in response to requests from the ACPIN committee. In the spirit of an extension of the ERA (evaluating research articles) project, they are offered as information for members and as an opportunity for some members to hone their reviewing skills. Editing is kept to a minimum and the reviews reflect the opinions of the authors only. We give the authors of the original book or paper the opportunity to respond. We hope these reviews will encourage members to read the original article and not simply take the views of the reviewers at face value.

## Life is for Living – with Dementia. Managing the Dementia of Diana Lamplugh OBE



*Paul Lamplugh OBE*

This heart-warming booklet describes the experience of one couple's life as multiple strokes and dementia changes Diana's life immeasurably.

Diana had set up the Suzy Lamplugh Trust and was an ardent campaigner for personal safety before her health deteriorated. It has been written by her husband who viewed the many trials that faced them over the eight year period as "some of the most important years of our marriage". What strikes the reader is the positivity of the book, how Paul strived for Diana's life to be fun and social, even when Diane was not able to converse, or became agitated. Particularly poignant was how he cherished the occasions where, as he describes, she was briefly connected, responding to a situation with wit and humour. Carers of people with stroke or dementia may appreciate some of the shared experience and insight, but this moving account would give valuable insights to therapists working with people with cognitive deficit. If you would like to purchase the booklet, please send £5, to cover printing costs, to Paul Lamplugh, 14 East Sheen Avenue, London SW14 8AS.

## Balance rehabilitation: translating research into clinical practice

Course reviewed by **Ramakrishna Gundapudi**

Specialist Neuro Physiotherapist, Holy Cross Hospital, Haslemere, Surrey

**This was an advanced level course for instructors on balance rehabilitation taught by Anne Shumway-Cook and Marjorie Woollacott, two prominent researchers in the world of neurophysiotherapy, held in Copenhagen during June 2013.**

Prior to this, I had attended a basic level course on balance rehabilitation taught by the same instructors here in the UK. Both courses opened my eyes to the availability of research evidence in the area of balance rehabilitation, and helped me to organise information on balance rehabilitation in a logical, structured way and use it to benefit my patients with impaired balance in more specific and targeted ways.

The information presented suggests that balance rehabilitation is complex and requires a framework that is consistent with current research on the neural control of normal and impaired balance control. The 'systems framework' presented suggests that balance is not a unitary concept but is complex and multidimensional. Multiple factors including deficits in motor, sensory and cognitive systems contribute to impairments in steady state (the ability to maintain balance), reactive (the ability to recover balance) and proactive (the ability to activate balance prior to a voluntary movement) balance control. All are influenced by environmental conditions. Impaired balance leads to loss of functional independence, reduced participation and increased risk of falls. Because of this complexity, no single test or treatment will be sufficient to understand and treat all the factors contributing to impaired balance. It naturally follows that we require multiple tests, measures and treatment strategies to address balance problems in our patients. A systems framework enables therapists to organise clinical strategies for the assessment and treatment of balance into a comprehensive and cohesive system that is consistent with current research on evidence-based balance rehabilitation. This framework also integrates very well into the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) model.

The framework presented in this course challenged my thinking and helped me

to refine my practice, making it more comprehensive and at the same time more specific. The framework enabled me to explore each aspect of assessment and treatment in depth, to link my clinical strategies to the research evidence, and to structure my clinical practices logically around the systems framework.

Each of the three days of the course explored one of the physiological factors (motor, sensory and cognitive) contributing to normal and impaired balance. Each day examined clinical strategies for assessing that aspect of balance control, and the research evidence supporting treatment of that aspect of balance. Each day included a lot of practical elements including assessment labs, video case studies, small-group treatment planning and discussions. The practical elements of the course gave me insight into how to select the most appropriate clinical measure with a greater understanding of what information each clinical test provides, and an understanding of the evidence supporting my treatment strategies.

At first I was overwhelmed at the amount of research presented, and felt that it was too much, but as the course progressed I realised that if we are to move our profession forward and justify our assessment and treatment choices, we need to have a good understanding of the research behind what we do in clinical practice. In addition, the research studies presented had direct implications for my own clinical practice and helped me learn new treatment techniques that I could implement.

The course inspired as well as equipped me with the necessary knowledge and skills to teach the basic three-day balance rehabilitation course. I am happy to share this knowledge with regional ACPINs or departments if interested.

# Resources

## Articles in other journals

### Archives of Physical Medicine and Rehabilitation

#### Volume 94:11

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Nakase-Richardson R, McNamee S, Howe LL, Massengale J, Peterson M, Barnett SD, Harris O, McCarthy M, Tran J, Scott S, Cifu DX *Descriptive characteristics and rehabilitation outcomes in active duty military personnel and veterans with disorders of consciousness with combat- and noncombat-related brain injury* pp1861-1869.

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# Regional reports

## East Anglia

### Tabitha Mathers

The East Anglia membership stands at a fairly healthy 150. The committee has representatives from the Cambridge, Ipswich, Norwich and Colchester areas and would welcome incomers from any area currently unrepresented.

In the autumn, we offered a 'book giveaway' to support physiotherapy neurological services in the region. Individuals were encouraged to apply to purchase a recommended neurological text book which was then supplied by the EA committee. Unsurprisingly, it was very popular and many departments benefitted.

The various courses arranged over the last six months have included the Addenbrookes day on connective tissue and fascia, in the autumn. Helen Lindfield returned in March for an enlightening look at motor relearning and recovery of function, at Ipswich.

The AGM at Addenbrookes, in May, is set to include a focus on musculo-skeletal assessment and treatment of the shoulder girdle and cervico-thoracic spine with application to neuropathology.

There are plans to hold a course on functional disorders and also Parkinson's Disease, in the autumn.

The committee are always keen to hear from the membership regarding ideas for training and any other neuro-related issues. I am currently unable to contact some members as their email addresses are unrecognised. If you haven't received any communication for a while please contact me at eastanglia@acpin.net and I will try to sort it out.

## London

### Andrea Shipley

London ACPIN continues to expand, with events still well attended.

In the latter half of 2013 we had our cheese and wine evening (September) with a presentation by Catriona Neville and Venessa Venables from Queen Victoria Hospital. They gave us a very enlightening talk about the MDT management of facial palsy from lower motor neurone deficits.

It was great to hear from colleagues who have such experience in an area that many of us have had little opportunity to be involved in. The evening was oversubscribed with most of the refreshments gratefully received and heartily consumed!

In October, we were lucky enough to host a study day on goal-setting in rehabilitation, presented by the renowned expert in this area, Dr William Leveck, from New Zealand. This day was the first of what we hope will be an annual event shared with our occupational therapy colleagues from SSNP. The day was very popular with all MDT members and a vast amount of knowledge on the complex subject of goal-setting was shared and well received with enthusiastic audience participation.

Sadly this year we have to say goodbye to one of our long-standing and trusty committee members, Ulreke Hammerbeck. Ulreke goes to pastures new up in the North West. Our loss will be someone else's gain, no doubt. May we take this opportunity to say a big thank you and all the best in Manchester. Whilst we are all sorry to see Ulreke leave us, we are delighted to welcome a new committee member, Glenn Nielsen, who will double our male representation!

So let's see what we have in store for you this year. Our programme is a little less flamboyant in 2014, but still filled with lectures and study days/mornings to tempt even the most self-sufficient CPDers.

On February 22nd we had a very popular study morning on disorders of the Basal Ganglia. Unfortunately, one of the presenters had to cancel on the day due to sickness, although thankfully this did not reduce the enjoyment of the morning. We were still able to hear an impressive overview of the normal functioning of the Basal Ganglia by John Rothwell with an introduction to disorders. This was followed by an enlightening presentation on atypical Parkinson-type conditions, including physiotherapy management from Fiona Lindop. Finally Monica Busse expanded our knowledge on the latest developments around Huntington's Disease and the evidence informing therapy approaches.

June 14th will bring us a half-day focused on Traumatic Brain Injury:

'Hospital to home: the bigger picture', with a broader overview including physiotherapy in the acute stage, cognition, exercise participation and return to work.

An additional event this year will take place on Friday 4th July (5.30pm) when we are scheduled to partner with UCL and hear a lecture from Steve Wolf.

This year our evening lecture will be from a physiotherapist who has been involved in one of the first massive rehab trials, AVERT. The lecture will take place on September 11th; however, due to limited venue availability, we will have to reduce our post-lecture cheese and wine to a brief wine and nibbles reception.

On October 25th we are planning to have another joint MDT event with our OT colleagues, and perhaps others. The details of this event are currently being finalised.

Our research update will take place in November this year, scheduled for the morning of 15th.

All this and a new (and hopefully easier) way of applying and paying for the courses online - all of which remain at very reasonable rates for ACPIN members.

Thanks for your time and ongoing interest. We look forward to seeing you in 2014.

## Manchester

### Stuart McDarby

We are looking forward to an exciting 2014 and have been pleased to welcome new committee members Angela and Cathy, which has led to a restructure in our roles and responsibilities.

We have been sad to lose the services of Helen, our treasurer and valued team member, and we thank her for her contributions to developing the Manchester committee. All the best for the future, Helen!

We have put together a thought-provoking and diverse programme for 2014, and our members are invited to watch out for a combination of lectures and study days in March, May, September and November.

In March we welcomed Claire Downs for an evening lecture on peripheral nerve injury, to accompany our AGM. This is followed in May by a study day with

Gemma Alder around Pusher behaviour and neglect.

Looking further ahead we have events planned around the shoulder (combining MSK perspectives into neurological rehab) and a hydrotherapy study day.

As with all our events, details will be sent out via email, and Manchester members are advised to keep an eye out for details closer to the time.

Without wishing to sound repetitive, we are always grateful for the support of our members and any ideas for topics, speakers and venues are welcome.

All the best for 2014!

## Northern

### Kelly Winter

Happy New Year! There have been some changes within Northern ACPIN committee over the last few months. Our thanks to Lara Malone and Anne Wood, who have stepped down from the committee and leave their roles as chair and regional representative.

The 'Best in Practice' series of evening lectures has continued into the new year. Advances in FES with demonstrations of available equipment and a seminar on Neuro-Oncology were the topics covered in October and November's events. In January, a valuable session on speech and language techniques to aid therapy was well attended and positively received.

We continue to welcome any members who want to join the Northern ACPIN committee and urge anyone interested to contact us via email (Northern@ACPIN.net) or catch one of the committee members following any upcoming events. We also encourage suggestions for ideas regarding speakers, courses or venues as we come to plan development opportunities for the future. As of January 2014, our regional representative has changed to Kelly Winter, so please get in touch with any additional queries or suggestions. Thanks for your continued support!

## Northern Ireland

### Dr Jacqueline Crosbie

The 2013-14 ACPIN programme for Northern Ireland has been running from October 2013. This year we reverted to the usual time of the evening lectures at 7:30pm. We hadn't seen any big change in the numbers attending when we tried the 6:00pm start time. We have also reduced the number of evening lectures

to five and will hold two other events in the year, one of which will be a study day and, hopefully, a Webex facilitated event. We opened the year in October 2013, with a session on the management of spasticity using Botox and splinting. Siobhan McGuinness, a physiotherapist from the Regional Acquired Brain Injury Unit, spoke about her work in the spasticity clinic and the development of this service for people with problems relating to spasticity management here in NI.

In November 2013 we held a study day on Parkinson's Disease, and this was a huge success. Many thanks to Fiona Lindop for facilitating an excellent update on the pathology and how the condition affects people, along with the most recent research and guidelines on how physiotherapists can help manage the problems caused by this condition. The day also benefitted from an excellent talk and presentation from the local PD UK group, and in hearing from a service user. This lady had a fabulous personality and attitude to her life and how it has been affected by Parkinson's. Her key strategy for management lay with exercise and maintaining her physical abilities, so she was a great advocate for physical therapy.

In February 2014 there was a presentation from a local charity, Northern Ireland Chest, Heart and Stroke. They have been running a research project called Moving On. This has been aimed at providing exercise classes for people with stroke. It has been very successful and one of the team will present some of the results from the study. A Webex facilitated event was planned for March 2014 and we will finish this year's programme with a session by Gemma Latham, a physiotherapist involved in end of life care. Many of her patients and service users have neurological problems and she and the team provide this type of service in the community here in NI.

This year at the National ACPIN Conference Sarah McConnell represented the NI committee in March 2014.

## Oxford

### Claire Guy

Welcome to all members for the spring edition and thank you so much for your continued support. I hope we are providing a programme you are interested in, but please let us know any ideas you have, email - oxford@acpin.net

We had a successful two-day problem-solving course on Ataxia run by Sue Armstrong, always a success and great

to have Sue leading the course. In the autumn there were successful evening sessions on neuroimaging, upper limb spasticity and an informative discussion exploring functional physical outcomes at different levels of Spinal Cord Injury (SCI).

This year a varied programme has been planned. In February Drew Dodd's talk was 'Problem Solving in Lower Limb Orthotics', and at the AGM there was an opportunity to see a number of different FES products for lower and upper limb. There will also be evening sessions to hear more about the Oxford Trauma Rehab Network and how therapists can integrate with this service, along with an active demonstration of the Ekso Bionics exoskeleton to assist gait following SCI and stroke. We will be welcoming Georgie Friend back from Canada to talk about her experiences of completing a therapeutic rehabilitation qualification, and how it can be integrated into practice in the UK. We have two new, enthusiastic clinical specialists in the region, who I am sure we will be using in the future for our evening talks. We welcomed new, keen committee members at the AGM and we are set for a healthy programme.

The committee is strong, with good local interest from therapists able to support the regular and varied evening programme - please contact us with ideas. Thanks to members for your support and commitment. Kim Radford will be taking over the regional representative for 2014/15.

Do check your flyers, *Frontline* or contact any of the committee for further information. With thanks again to you all.

## South Trent

### Kate Caldwell

We have run a number of events in the past year. In July a Spasticity management update by Dr Pandyan from Keele University was very well attended and sparked good debate. Alex Morely conducted a low tone course in November in Mansfield, which was well received particularly by less-experienced therapists. More recently, in Nottingham, we held an evening lecture with feedback from two research therapists involved in studies with a Wii glove and stem cell therapy.

In March, Jenny Williams led a clinical reasoning study day in Leicester, which was excellent, and we have booked her again for another course! We have plans for more events in 2014, so keep your eye out for advertising for the following events: UL biomechanics and assessment

with Martin Scott (Clinical specialist shoulder unit at Nottingham) in May, Journal Club on the upper limb and Paul Johnson (Bobath tutor) in October. Other topics we are exploring include cervical artery dysfunction and cognition. If there are any other ideas or topics you wish to have a course or lecture about, we are always pleased to hear from our members.

Finally, the South Trent committee has representatives from across the region; however, we are eager to have more members join us. The date of our next meeting is Monday 16th June so please do contact us if you are interested in coming along and we can give you details of time and place. Our email address is southtrent@acpin.net. We look forward to hearing from you.

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## South West

### Nic Turner

South West ACPIN's membership continues to be strong, and attendance at events consistent. Our main committee (based around Bristol) is at full capacity, and we continue to have committee sub-groups in Devon and Cornwall who are always interested in having new members, so if anybody is interested please get in touch.

I, as regional representative, am still settling into the role, so would like to take this opportunity to thank everybody for their patience and support, particularly my fellow committee colleagues and our previous representative Helen Madden during this transition.

We had our regional AGM in March, with keynote speaker Dr Ralph Hammond sharing his experience of his own doctoral journey as well as providing an interesting insight into neurological research initiatives in the South West.

In October 2013 we invited Paul Johnson, Bobath tutor, to run a one-day practical course on locomotion, and in the evening he kindly agreed to give a presentation on the Bobath concept with its place in contemporary neuro-rehabilitation. The presentation was very well attended, with over 80 therapists, lecturers and students coming along from across the region.

We have more courses lined up for the future, but these are still in the early stages of planning. These include a two-day vestibular rehabilitation course, a BBTA problem-solving weekend on the upper limb, a constraint-induced movement therapy course, and hopefully a one-day practical course on proprioceptive neuromuscular facilitation. We always welcome more ideas for courses, so please contact

me if anything comes to mind. We are also interested to hear about any potential venues for future courses.

At the time of writing, Cornwall sub-group are planning to run an event with the MS Society, and Devon sub-group organised a course on the Pusher Syndrome in early March.

Thank you all for your on-going support for ACPIN in your region.

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## Surrey and Borders

### Emma Jones

Surrey and Borders have seen a change to the committee over the last few months with the addition of new members and a couple of long-standing members stepping down. However, we are still looking for new members to support the running of the region and this will continue over the next few months. The posts of regional representative, secretary, chair and treasurer remain the same for another year.

2014 has started well with our AGM and evening lecture presented on an MSc Project exploring the experiences of stroke survivors during the transition from hospital to home with an Early Supported Discharge Team. This evening was positively received. The format for this year has slightly changed with two practical courses being arranged for April and June. In April we ran a course on functional rehabilitation for the upper limb with Helen Linfield and in June we will run a course on balance retraining with Krishna Gundapundi. We are looking forward to the variation this will bring to the annual programme with evening lectures to see out the rest of the year.

On-going events will be forwarded to Surrey and Borders ACPIN members by email. They also may be advertised in *Frontline*, on the iCSP website and on Facebook and Twitter, so keep your eyes peeled!

Please do not hesitate to contact me with any queries or suggestions for future programmes on [surrey@acpin.net](mailto:surrey@acpin.net). We look forward to seeing you all at future events!

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## Sussex

### Gemma Alder

Welcome to any new and existing members. Thank you to all ACPIN members that have continued to support the running of Sussex ACPIN. The Sussex committee would like to thank speakers and

attendees from recent successful events.

In September we will host a lecture on neuro-adapted Tai Chi with Ros Smith at the Princess Royal Hospital, Haywards Heath.

For further information on events please take a look at the ACPIN website, Facebook page or alternatively you can email [sussex@acpin.net](mailto:sussex@acpin.net)

As always your thoughts and ideas are important to us; they really aid us in shaping the course format for the following year. Please feel free to contact myself or any of the committee members to share your ideas.

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## Wales

### Adele Griffiths

Wales ACPIN would like to welcome all new members and thank all existing members for their continued support. At our AGM in February, we welcomed two new committee members and are particularly pleased to have strengthened our West Wales representation.

Recent events included a Christmas Social evening with a Technological Advances in Rehabilitation presentation and an FES bike patient demonstration.

2014 started with a January Webex event to debate the Welsh government consultation document: *Together for Health - Neurological Conditions Delivery Plan* producing comments that have been submitted to the Welsh Government.

In February the Wales ACPIN annual winter training event took place in Port Talbot. This year we hosted a study day on 'Transition from Paediatric to Adult services'. The speakers were Dr Francis Gibbon, consultant paediatric neurologist from Cardiff; Dr David Abankwa, consultant in neurerehabilitation in Swansea; Sarah Clements, All Wales Specialist Physiotherapist in palliative care, and Matt, a Swansea University student studying history. Matt has Duchenne Muscular Dystrophy and took questions from the audience about his experiences of transition and the challenges of university life. An entertaining speaker, Matt was able to give that personal view on the study day that always lifts such occasions from interesting to outstanding. The day concluded with small group work on transition at any stage of life. Plans were made for a follow-up Webex with one of our paediatric colleagues on Person Centred Planning used by her MDT to facilitate transition.

The rest of the programme for 2014 includes:

- June: Welsh Stroke conference stand.

- July: Webex – an opportunity for discussion of recently published guidelines
  - September: Private practice evening lecture
  - October 11th-12th: Hydrotherapy in neurology course at Camarthen. The tutor is Jackie Pattman.
  - November: Webex – *NICE Guidelines* debate
  - December: Christmas evening lecture and social event
- Wales ACPIN email address is [Wales@acpin.net](mailto:Wales@acpin.net) – please use this for future correspondence.

## Wessex

### Lindsay O'Connor

As always since the last update there have been a few important changes to the regional committee to be aware of. Nicola Perkins has temporarily stepped down as chair to go on maternity leave following the safe arrival of her baby girl; our thanks to Nicki for all her hard work as chair and we look forward to having you back in the future. Kat Chambers will also be stepping down as treasurer following the AGM, but will remain on the committee; thank you to Kat for all your hard work and excellent organisation skills. Alice Wilson has kindly volunteered to take on the role of chair. Alice has been an active committee member and we are very happy she is taking on this new role. We would also like to welcome back Alahna Barratt to the committee, following maternity leave.

As always we welcome new members from all areas of the region and with all levels of experience who want to join the committee. We are particularly interested to know if any of you would like to take on the role of treasurer. Please do not hesitate to get in touch if this is something you might be interested in and we can provide further information on what it involves.

At the end of last year we ran two successful events. The first was a two-day course on 'Dynamic movement screening and functional exercise' which was well attended with excellent feedback; we hope to build on this course later in the year, with further details to follow. Our last event of the year was a study morning 'Exploring the management of the minimally conscious patient' with speakers from a range of professional backgrounds; again the event was well attended and we hope to continue to provide a range of two-day, study morning and evening lectures throughout the year.

Following a slow start we are currently planning the programme for the coming year and welcome any input from members on course content and location. We have several exciting events in the pipeline, including: neuro-pharmacology, motivational interviewing, neuromuscular disease and hydrotherapy for neurological patients. If you are interested in holding a course in your local area and think you might be able to help with finding a venue please get in touch as we are really keen to provide events across the region, particularly in the West.

A repeat plea but please could you make sure you update your contact details so we have the right email and postal address, and encourage any colleagues who you know are ACPIN members to do the same. Unfortunately there are always several undelivered emails each time we send out information which means you may be missing out.

As always we welcome ideas from our members on events and courses you would like us to organise, or any other comments and suggestions.

## West Midlands

### Cameron Lindsay

Our last event of 2013 was a huge success with over 150 people attending a set of lectures on functional disorders. The event was widely publicised in local hospitals and we invited commissioners to attend the event at Birmingham University. The event attracted more than ten different health professions and many various specialities, not just neurology. The committee received some excellent feedback from various people, thanking them for putting on this specific event and highlighting the issues.

Subsequent to the event, members of ACPIN have helped form a multi-disciplinary working party to discuss and hopefully establish a pathway or business case to develop local services for Functional Patients. From this first meeting it was agreed a mapping event was necessary and this was organised for the 19th March.

Our 2014 course programme is coming together; however, dates have not been set in stone, as I write this. Our AGM was held after a lecture from Jackie Shanley (Coventry University) on 9th April on vision and perception.

We also planned lectures on 13th May from Sports psychology and translating the evidence to rehabilitation and a lecture on vestibular rehabilitation

in June. We are also planning a *Sharing Good Practice* event where departments around the region will highlight and share good practice. This is likely to be our winter event so its exact nature is yet to be confirmed, but we will be presenting prizes for the best.

As always, please feel free to contact the committee anytime with ideas on events or feedback.

## Yorkshire

### Karen Hull

2013 was another busy year for Yorkshire ACPIN. We very much appreciate that CPD is of major importance to all practising physiotherapists, and that, sadly, many Trusts are cutting back on funding for courses. Consequently, we have tried to keep our courses as topical, relevant and local as possible, and with a mixture of full-day, half-day and evening courses throughout the year.

We do our best to listen to our members' suggestions regarding courses and lectures, speakers and venues. We have responded to your request to widen the range of venues by putting on courses at York, Goole, Harrogate, Wakefield, Dewsbury and Airedale as well as at various venues in Leeds and Bradford over the last year.

Our varied lecture programme has included a spasticity study day which was combined with our 2013 AGM, two movement science courses with Paulette Van Vliet, an FES study day, a CIMT study day and a Bobath master class with Mary Lynch Ellington. We held evening lectures on a variety of subjects including behavioural ophthalmology, 'Best Practice in Botulinum therapy', K-Taping, evidence based practice, legal issues relating to the Mental Capacity Act and 'establishing good 24-hour management of patients by improving carer skills'. We have had some great courses with excellent speakers.

We are looking forward to a joint study day with the MS Trust in September and a range of other courses. We are open to suggestions from members and if you have any ideas of topics or speakers please get in touch.

Finally, we would like to record our thanks to our outgoing chair, Christine Robbins who has been a superb co-ordinator of our efforts for the past five years. Jade Donnelly will be taking over the reins as chair. As ever, many hands make light work, so if anyone would like to join the committee please do not hesitate to contact us at [Yorkshire@acpin.net](mailto:Yorkshire@acpin.net)



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May 2014

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## Syn'apse

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