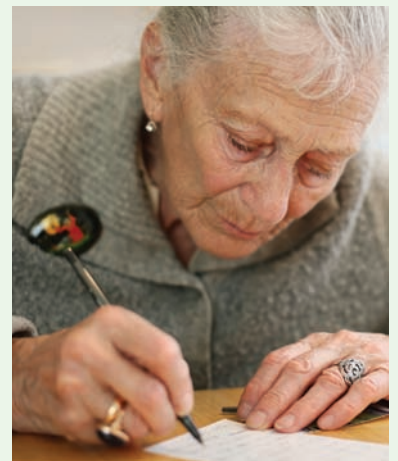
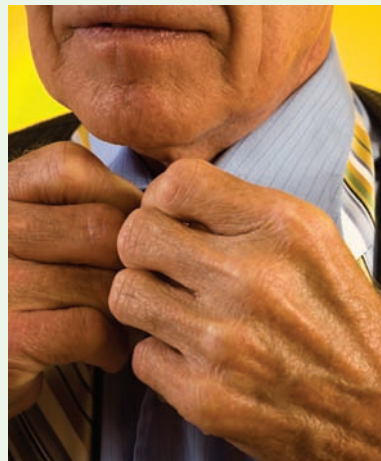


For everyone concerned with stroke rehabilitation

Next Steps for Bridges

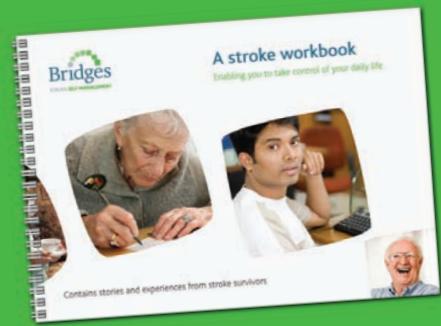


When the UK stroke strategy was launched in 2007, it was one of the first times self-management had been mentioned in the context of stroke. The strategy highlighted the "scope to expand the range of 'self-management' activities available for people with stroke". Since the inception of our individualised stroke self-management programme in 2008, followed by our name change and redesign of the stroke workbook in 2010 we have been working to address this aim.

After completing a pilot randomised controlled trial in Belfast, surveying our Bridges workshop participants, and analysis of over 100 case reflections carried out by practitioners using the programme we have gained invaluable and rich feedback. We have learnt from the experiences of practitioners, stroke survivors and their families using the programme. They have told us they would like an additional story of someone who has had a more severe stroke and a wheelchair user in the workbook, they like the new goal setting pages but would like extra sheets for more targets, and that it would be good to have the workbook in different formats e.g. audio or web based version. They also told us it would be useful to have a smaller accompanying workbook that could be given out to carers.

At the UK Stroke forum in 2010 a panel of People with Aphasia and Dr Kate Swinburn from Connect highlighted aspects of good goal setting for the audience. One suggestion was that they did not like the word 'goal' and maybe we should call the process 'things I want to do'. Well, at the top of our 'to do' list is the work to develop information for carers about how they can support self-management skills. This work has now started and we have made links with local carers groups who will be working with us on this new project. If anyone has an experience where the support of a carer has been critical to the success of using the workbook we would like to hear from you. Please contact Fiona Jones on 020 8725 0319, email: F.Jones@sgul.kingston.ac.uk

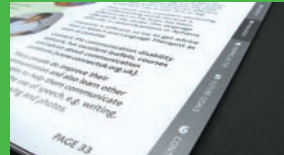
Supporting self-management: Another active ingredient?



Self-management programmes based on Social Cognition Theory such as the Bridges programme aim to enhance self-efficacy through tasks such as supported goal setting, and encouraging reflection on progress using the stroke workbook as an interactive tool.

Findings from our qualitative studies and analysis of case reflections have also highlighted the vital role played by carers in the process of engaging individuals in using the stroke workbook. Social factors such as family and carers are an influencing factor for self-efficacy, as are any interactions that help an individual to gain feedback on their performance and acknowledgement of successes.

Reflections by practitioners have supported this key ingredient for success, but also highlight that the way carers engage can be very different. Like most aspects of the programme we cannot be prescriptive about what works for each individual person and their supporter. Below are a few comments from practitioners' case reflections;



- Although the carer was keen for their partner to use the workbook and saw the benefit, their enthusiasm meant that they also took control of the process
- Carers enjoyed reading the stories about different individuals and got encouragement
- Helped the individual and their carer to reflect on how far they had come since having their stroke, and helped them stay motivated
- I needed to introduce the workbook very slowly, to let the individual and his partner have time to look at each section themselves before moving on
- The person was unable to write so it was suggested they write the targets with their carer, but this needed lots of encouragement, and regular support to focus on their small achievements

We aim to have produced a 'Guidance for carers' booklet by 2012, and will let you know of our progress in the next newsletter and through our website.

Spotlight on the Bridges advisory group – Sue and Graham Davidson

Our Bridges advisory group is expanding and we are delighted that Sue and Graham Davidson joined us for their first meeting earlier this year. It has been four years since Graham's stroke, and the advisory group meeting held in London was the first time they had been to London on a train since then. We were interested in Sue's experiences as a carer, and they agreed to being interviewed and photographed for this newsletter.

Sue described being in 'headless chicken mode' when she discovered Graham collapsed at the bottom of the stairs, she knew it was a stroke as her father had had one. It was nearly 24 hours before she was informed that he had experienced a stroke, she remembers feeling despair that not enough was being done for him, and asked the doctors why they couldn't just 'zap the clot and get rid of it', but clearly it was too late for any intervention.

"I was given pamphlets but I didn't read them, I had hope for Graham but I wasn't confident. I just didn't want to think about

him not getting better... They would ask is there anything you want to know, and I didn't know what to ask then. I didn't want to delve too deeply because I was worried what I might find out."

One side of caring for someone is the change in roles that it may bring, Sue was working as a medical secretary when Graham had his stroke: 'I enjoyed the job but I could tell I couldn't carry on with it, I was so stressed out, and I didn't want any more on my plate'. Getting the balance of support right for Graham was also a learning curve. There is no prescription for carers about how to do it,

and support is very individual. Sue gives Graham regular feedback about how he is doing, and encouragement, but does worry about him taking risks. "I am not sure if it works but I constantly remind him, I know sometimes it's not the right time to, but I just can't leave it, I have to correct him. He goes on the treadmill and I can hear it in the rhythm of the walking, and I say 'listen to the sound of your walking and linger a bit longer on the left' and he corrects it".

We are very grateful to Graham and Sue and all the members of the Bridges advisory group for their support and ideas for our development.



Further Findings from the Belfast Bridges RCT funded by NICHHS

Twenty-five participants received either standard care or used the Bridges self management programme alongside community rehabilitation. Changes were measured in terms of quality of life, self efficacy, activity, mood and social integration.

Both groups improved in all measures post intervention. There were positive trends in favour of Bridges for self-efficacy, activity and social integration. At 3 month follow up, the Bridges group showed more positive change scores in quality of life and mood. This feasibility study was not designed to detect statistically significant differences. The research demonstrated that Bridges was feasible to implement and acceptable to all stakeholders. The community stroke team

reported that Bridges encouraged a greater consistency in patient-focused goal setting and using a self-management approach between professionals within their team.

This is the only research to date that has confirmed that an individually tailored stroke specific self-management intervention can be successfully implemented in post hospital stroke rehabilitation. These findings confirm that the Bridges programme for stroke warrants further investigation.

Finally in the words of a *Belfast Stroke Survivor*:

"... it's a tool to help you see your progress because I think if left on your own without the stroke team and Bridges that you wouldn't be able to see the changes that you do make over that period of weeks and by seeing the changes, the motivation then gets better so that you can get on with life quicker and see that things can change and improve."



Sue and Graham Davidson attended our Bridges advisory group for their first meeting earlier this year. Graham had a stroke four years ago and Sue is his principal carer.

Musical chairs and self-management theory: mixing health and social care practitioners in Bridges workshops

Multi-disciplinary workshops have been carried out with teams across the Kingston stroke pathway, in a project aiming to improve continuity of care for stroke survivors.



The first Bridges project involving significant numbers of social care practitioners is now firmly underway in Kingston. Sixty-five participants from health and social care teams across the stroke pathway received Bridges training in February. An eclectic mix of professionals attended the workshops, including therapists, nurses, rehabilitation assistants, enablers, social workers and support workers. All teams working on stroke in Kingston were represented: the acute stroke unit at Kingston Hospital, inpatient rehabilitation, the intermediate care team, social care and local voluntary organisations.

Unfortunately, due to restructuring within Kingston's social care department, fewer social workers could attend the workshops than expected. Thanks to the South-West London Academic Health and Social Care Network, funding was increased to allow for an extra workshop in May, when another 24 health and social care practitioners will be trained to use the Bridges programme, thereby ensuring coverage of staff across the whole pathway.

Feedback from workshops has been positive so far. Participants welcomed the opportunity to meet colleagues from different teams, and 97% thought the training would change their practice. As the participants concentrate on using the workbook in their practice before the follow-up workshops in May, a short 'executive session' is being organised for GPs and managers working in stroke in Kingston, to build understanding and enthusiasm about Bridges at management level.

Research and policy update

The Care Quality Commission (CQC) recently published their review "Supporting Life After Stroke" in England. It identifies that most attention focuses on the acute end of the stroke pathway, with services further down the pathway highly variable. The review identifies the importance of supporting carers to help them cope, and to maintain independence of the stroke survivors. Social care services should be involved more, but there may be organisational and cultural barriers. While local assessments are needed to determine areas for action, some common themes in need of improvement are commissioning and involving the correct people in reviews. The CQC aims to offer support with data collection tools and sharing good practice.

The Quality, Innovation, Productivity and Prevention have produced a poster to support professional engagement in self-management of long term conditions in England. It covers the five E's of self-management:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123012.pdf

One theme to emerge from 2010's white paper *Liberating the NHS* was "choice and control". This aims to allow the patient to play a major role in choice of GP, consultant and rehabilitation programme, with statistics available on the quality of care. The paper develops the personal health budget idea, and maintains the emphasis on prevention. A white paper on social care is expected in 2011, with the aim to integrate it better with healthcare. An example of putting this into action is shown here:

<http://www.worcestershire.gov.uk/cms/health-and-social-care/choice-and-control.aspx>

Greenwood and Mackenzie's (2010) review concludes that caring for stroke survivors centres around change such as roles and relationships, losses such as autonomy, and uncertainty about the future. These challenge carers' perception of their identity, but may be followed by adjustment and acceptance. By acknowledging these issues, clinicians can respond to carers' practical and emotional needs:

Greenwood, N. and Mackenzie, A. (2010) 'Informal caring for stroke survivors: Meta-ethnographic review of qualitative literature', *Maturitas*, vol 66, issue 3, pp268-276

The use of Bridges with stroke survivors from ethnic minority groups

Research has begun exploring the use of Bridges with stroke survivors from ethnic minority groups. This research is critical as adults from ethnic minorities are at a higher risk of stroke and there is some evidence to suggest that they have poorer functional outcomes. Language barriers, family involvement and cultural differences between therapist and client have been suggested as influencing factors, but research is lacking. Understanding how Bridges is currently used, its success and challenges with this group will inform the development and utility of this approach.

For further information, or if you have used Bridges with stroke survivors from ethnic minority groups please contact Meriel at Meriel.norris@brunel.ac.uk

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Dr Ajay Bhalla Consultant Stroke Physician
David Borer Stroke survivor
Eileen Collins Stroke survivor
Graham and Sue Davidson
Stroke survivor and carer
Thérèse Jackson Consultant Occupational
Therapist in Stroke, NHS Grampian
Dr Cecily Partridge Reader in Physiotherapy
Carole Pound Former Director of Innovation,
UK Connect
Dr Jane Williams Stroke Nurse Consultant

Register your interest:

For further information, including a copy of our 'frequently asked questions' and a booking form, or to join our mailing list and receive regular updates on the progress of Bridges and a copy of future editions of Bridges News, please contact:

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This programme encourages self-management, focuses on the successes, and decreases dependence on therapists.