

For everyone concerned with stroke rehabilitation

Spotlight on stroke research – Home visits after a stroke

Avril Drummond, University of Nottingham

People who have had a stroke and who are admitted to hospital may be offered a home visit with an occupational therapist before they are discharged from hospital.



Such a visit provides the patient and carer with the opportunity to practise the techniques they have learnt in hospital in their own home, with a therapist present to offer advice. Professor Avril Drummond is a research occupational therapist with an interest in these pre discharge home visits and leads the **HOVIS (Home Visits after Stroke)** research team.

The HOVIS team have highlighted the variation around the country about the number of visits being undertaken and have shown that some units do more of these visits than others. A lot of time is spent on conducting visits; the average length of a visit is 4 hours and up to an hour of the therapist's time can be spent writing the report. Interestingly the person who is least likely to see this report is the patient!

The HOVIS team have just completed a trial and are currently analysing the results in order to calculate the costs of these visits. This is important information as presently we do not know how much one visit costs or indeed whether these visits are beneficial to patients or their carers. We still do not know if these visits actually improve people's confidence or ability to cope at home or whether they actually make people very nervous and stressful. The research has promoted a great deal of discussion about the topic and about how therapists identify which patients should receive a visit. The team hope to start planning for a large trial which will involve a number of hospitals nationally.

Dr Avril Drummond is also part of the research team carrying out a feasibility trial on a modified version of Bridges led by Dr Fiona Jones

Bridges one year on... a sustainability study in South West London

During the evaluation of the Bridges Kingston project , practitioners raised concerns about the sustainability of the Bridges training intervention in their services.



Health and social care practitioners from all over South West London participating in the Bridges 'Catch Up' training workshop

Barriers identified included things like high staff turnover, meaning not everyone was trained in Bridges, and communication problems between teams on the stroke pathway. In light of these concerns, Bridges was funded by South London HIEC to undertake a scoping study, to explore ways of making the programme more sustainable – to make sure Bridges continues to be used in teams and pathways long after the training has been completed.

The project

The first phase of the scoping study was to revisit evaluation data from the Bridges Kingston project, and record all results which were related to sustainability. Using this information, semi-structured interviews were conducted with practitioners from different teams on the Kingston stroke pathway, to explore their views and ideas about sustainability of Bridges within their services. A short online questionnaire was circulated to all participants of the Bridges Kingston workshops, to gauge their views on the Bridges programme one year post-training.

Following preliminary analysis of the results from this study, two workshops were held for any interested stroke practitioners

working in South West London. As almost all Boroughs in SW London have received Bridges training, it was felt the workshops could be opened up to teams outside of Kingston in order to build better links between teams who use Bridges. The workshops included;

Bridges 'catch up' training workshops for new staff, or for those who missed the first set of workshops, to ensure as many staff working on stroke in South West London are trained as possible.

A new 'master class' workshop for interested staff to revisit key principles of Bridges and address ways of integrating the programme into their teams and pathway. The training targeted potential organisational, professional and personal barriers, using feedback from the Kingston evaluation. We also aimed to set up a network of 'Bridges Champions' in South West London to help keep momentum going for using Bridges in the area.

Both workshops were evaluated by participants, and findings will shortly be posted on our website, alongside findings from the online questionnaire and the semi-structured interviews.

Have you ever wondered what people who have had a stroke really think of goal setting?

Karen Coster, Senior Occupational Therapist, Barts and the London NHS Trust, reflects on some important feedback from stroke survivors about using the Bridges workbook to help goal setting.

Members of the Barts and the London Community Stroke Team



Two members from our service user group attended our team Bridges Training workshops in November 2011 and February 2012 – so we decided to take the plunge and find out what their perceptions of setting goals were, and who they actually prefer to set goals with.

Local service users attending the Bridges Training and follow up workshops was a great way for us as a team to understand more about what our patients want from goal setting as well as a great way of helping us practice our skills such as introducing the Bridges workbook and goal setting.

Following this, our team Service Manager (Tess Baird) and one of our Rehab Support Workers (Nathalie Harvier) met with the service users over coffee to explore further about how we can

best use Bridges in our Community Stroke Team. One of the interesting findings from this discussion was that they both preferred for a Rehab Support Worker (RSW) to lead their goal setting sessions and set the “future goals” due to the RSW’s non-judgemental approach, more frequent contact, as well as more time to talk.

With more emerging research papers supporting the argument that therapists can have ethical conflicts in patient centered goal setting (Levack 2011), as well as changing service structures and demands on therapy time, it seems timely to consider ways we can develop and sustain quality goal setting in our team. So our next challenge is to look at how we can put this into action – ensuring patient preference becomes part of our team protocol for using Bridges goal setting and optimising RSW relationship and skills in the promotion of self management, and of course ensuring more service user feedback as we go!

Karen Coster

News about the Bridges workbook

We always listen to feedback, and the next version of the Bridges workbook will have some small but important changes.

1. We have changed the some of the wording in section 1 to encourage people to reflect on their progress
2. We will have an example of how the Bridges steps have been used to break down a goal into small tasks by someone with stroke
3. We will be changing a couple of the images to ones we hope everyone will like!

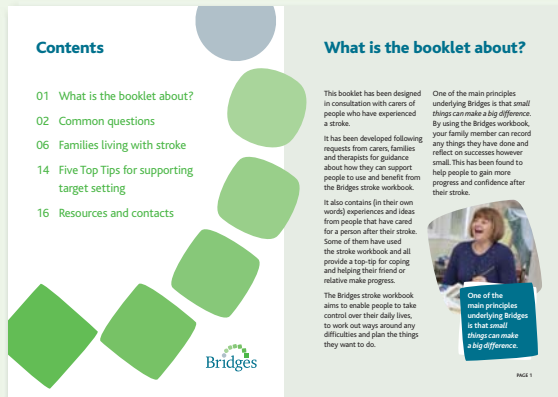
Please contact us if you would like to order copies of the new improved Bridges stroke workbook.



New booklet launch

Bridges booklet for carers and families is now complete

After an extensive period of development and consultation we have now completed our first booklet for carers and family members of people with stroke.



The carers booklet has been developed following requests from carers, families and therapists for guidance about how they can support people to use and benefit from the Bridges stroke workbook.

The booklet was designed in consultation with carers of people who have experienced a stroke. It was developed after many requests from carers, families and therapists for guidance about how they can support people to use and benefit from the Bridges stroke workbook. It contains (in their own words) experiences and ideas from people that have cared for someone after their stroke, all of whom have used the Bridges workbook. They all provided a top tip for coping and helping their friend or relative make progress.

We recently showed the Bridges booklet for carers and families to a local stroke carers group, they gave us some really useful feedback but overall responded very positively:

- "It's interesting and gives people good insight into how people cope. It tells both stroke sufferers as well as carers that they are not alone in their concerns or suffering; it's a real back up".
- "From the book you can find out information about what's normal, what is happening and what can be done. It has a lot of contact numbers of helpful organisations to get in touch with; it's a very handy book".
- "When I first took the stroke workbook home to my mum she was really pleased. The range of pictures/ photos, racial backgrounds and different people who had all had strokes allowed my mother to be able to make a connection. This was very encouraging for her. What was even more interesting was the stories in the workbook stimulated my mum to want to try and write so we had sessions of trying to get her to try and write with her left hand. This book will be very helpful in trying to achieve her goals.

Jan has been fortunate enough to have some supportive friends who she goes out with on Saturday evenings, and her willingness to leave her husband Brian on his own for a few hours at a time has helped her own state of mind.

We would like to thank the following people for their help with the design and development of the carers booklet.

- Doreen, Bob, Jan, Brian, Donna, Pete, Kim, Luca, Carly for sharing their experiences
- Tess Baird, Adine Adonis and Lucinda Brimacombe
- Crystal Waters, Jackie Ishiekwe and Iain McNaughton
- And Wandsworth Stroke Carers Group for their ideas and support.

This booklet was made possible because of donations from Wallington and Carshalton Roundtable, and a sponsored bike ride from Dockenfield to Paris by Sally De La Fontaine and her friends.

Please contact us for free copies of our booklet if you or your team has received Bridges training in the past. Or for any further information contact the Bridges team on 020 8725 2445 or at: bridges-stroke@sgul.kingston.ac.uk

Jan's Top Tip: "I didn't always offer to help if I thought he could do it. I thought no he needs to do that himself, and the sooner he learnt to do it the better really."

New models of training – important news



Bridges has delivered a total of 55 team workshops across the UK

The structure and content of Bridges training was initially developed after a pilot project carried out in 2008 across three different regions of the UK (Inverness, Dorset and London).

Since then we have delivered 55 team workshops across the UK, some have been to 3-4 teams from the same stroke pathway, and our participants have come from every different professional group, and from teams in health, social care and the voluntary sector.

Participants of our workshops always complete evaluation forms about their experience on the training and using Bridges in practice, and most do an in-depth case reflection on using the Bridges programme with a stroke survivor. We now know so much more about how to deliver training on self-management and the workshops are constantly evolving to take into account all the feedback we have received. This has led to changes to Bridges, some subtle some quite large;

- We now include more focus on self-management *principles* which can be applied when the workbook is not appropriate to use.
- We have devised a popular '*top tips*' document, which is based on feedback on getting Bridges to work effectively throughout the stroke pathway
- Our follow-up workshop has now been extended to enable exploration of barriers and organisational challenges of using Bridges
- We include more about the role of family and carers, using our new carer booklet
- Our training is always updated to include current best evidence in relation to stroke and self-management and incorporate some of the key principles needed for practitioners to support self-management after stroke



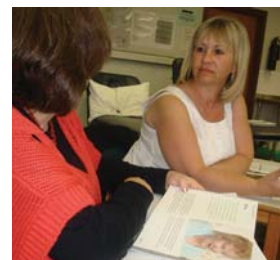
Feedback has also told us that Bridges can be hard to use when not everyone in the team has been trained, we are currently working on different types of training including a refresher workshop, for teams who need an update, running more open workshops for individuals that have missed their team training and a new workshop – our 'Bridges master class' – for team leads or Bridges champions who are interested in developing their individual practice or team delivery of self-management programmes.

Finally, we have been asked to deliver training to teams that are not solely working with people after stroke. This has led to the development of our 'Based on Bridges' workshops, a two day training programme which applies the core Bridges principles to support people with other long term and neurological conditions.

Thank you to all the participants of past Bridges workshops for your help and opinions about our programme. We have listened closely to your feedback and always welcome more!

Please contact us if you require any further information about these new development and workshops

If you would like to host a Bridges workshop please call us on +44(0)20 8725 2445. In our experience, the programme can be implemented more effectively if it includes clinicians from the same team, and ideally representatives from stroke teams in both acute and community settings.





Te Whare Wānanga o Otāgo

Bridges goes to New Zealand

An exciting project is now underway to develop a New Zealand version of the Bridges workbook and training. Dr Leigh Hale is leading the study together with other colleagues from Otago University and Auckland University of Technology.

In New Zealand, 6000 people have a stroke per year, resulting in about 32,000 people currently living with disability caused by stroke. Fiona Jones visited New Zealand to speak about self-management at the 2011 Neurosymposium in Dunedin. The concept of Bridges was met enthusiastically by the physiotherapists who attended this conference, and resulted in work by Dr Hale to gain funding for Bridges to be introduced in New Zealand. In order to achieve this, it was established that further work needs to be done to ensure the Bridges programme is contextually and culturally relevant for New Zealand.

The project has now commenced and has two phases:

1. To make the Bridges workbook, in consultation with stroke survivors and their families/whānua*, contextually and culturally relevant for New Zealand.
2. To pilot Bridges New Zealand (the amended programme) in one district health board to test whether it is acceptable and feasible to use, and to determine any potential benefits of the programme.

The Bridges New Zealand project is currently in the first phase, which involves forming a research advisory group of people living with stroke and their families/whānua, representatives of support services and health professionals with an interest in stroke rehabilitation. It also involves holding focus group discussions with the above groups, and collecting stories from a cross-section of New Zealand stroke survivors to use in the revised stroke workbook.

Phase two, starting in October 2012 will involve piloting the new Bridges New Zealand workbook. Stroke practitioners will complete their training, and the Bridges NZ programme will be used with as many stroke survivors as possible during a six month period. The pilot will be evaluated by a number of measures before and after the intervention and the conducting of in-depth qualitative interviews with participating patients and stroke practitioners at the end of the study.

The second phase of the study will aim to determine how acceptable the participants found the Bridges NZ programme; whether it was feasible to use in practice; how relevant stroke survivors and practitioners found it to be; any potential benefits to stroke survivors of using the programme; and any improvements which could be made. The results will inform a larger trial.

Fiona Jones visited New Zealand in August to carry out the Bridges training workshop with participating practitioners, and stroke support workers.

Contact us for more information on Bridges NZ



Dr Fiona Jones (middle) with Dr Leigh Hale (lead investigator, left) and Dr Cath Smith (right) from Otago University, Dunedin



Participants of the first Bridges New Zealand workshop

Changes to our website

With all the exciting new projects going on at Bridges, we decided it was time to update our website, and make it easier for people to find out what we've been up to.

It's still a work in progress, but if you check our website now, you will find information about the history of Bridges, the evidence behind the Bridges stroke-self management programme, all our current research and development projects, and presentations from our annual Bridges symposiums.

New features will include a Bridges 'to do list', to which we hope everyone will contribute ideas, as well as a section on the many ways you can support Bridges, including community volunteering, carrying out a research project or making a donation. We are also developing sections called 'Resources for stroke survivors' and 'Resources for practitioners', so if you have any ideas of things you'd like to see included, please do let us know.

Finally, we're planning to re-launch the Bridges discussion forum, to give people who are interested in stroke self-management a space to share ideas and ask questions. If you would like to register to use the forum, please visit: <http://www.bridges-stroke.org.uk/user.register.php>

Visit the Bridges website at: www.bridges-stroke.org.uk



'I achieved something that looked impossible from the beginning'

Diana Marsh, speaking at the 2012 Bridges life after stroke symposium

Diana had a stroke two years ago and is 33 years old. She recently agreed to be involved in research exploring participation after stroke because she wanted to share her story with other people.

Diana was also asked to speak at the recent Bridges symposium in May 2012 and highlighted the main things she wanted to do after her stroke, which were returning to her job as a manager of a betting shop, going to the theatre, baking and going on holidays. She explained that going back to work was her main goal.



Diana and Portia talking to participants of the 3rd annual Bridges Symposium, May 2012

Here she lists the personal meaning of work, the things that stopped her and the things that helped her return to work.

What does work mean to me?

- A sense of belonging
- Made me feel normal
- Getting back into my routine
- Independence and stability
- Leaving the house to do something
- Something I enjoyed
- It was a challenge

The other things that helped me:

- Coming to terms with it
- Bridges workbook, breaking things down
- Appreciating the little things I could do
- Practice and determination
- Finding my own little way around things
- Support of family, therapists and work colleagues

Diana described her progress in reaching her goal through achieving the following steps:

- I worked in the office doing paperwork
- I helped out in the shop once a week
- I gradually built it up to 4 days a week

Diana remains motivated to achieve her goal of managing the betting shop full time and would like to resume her evening shifts as well. She says 'I want to work like everyone else does'.



Diana, left, pictured with Portia Woodman. Portia is currently doing a PhD exploring barriers to participation after stroke

Things that made work difficult and things that helped

1. Tiredness:

Things that made work difficult

- Going to bed at 9.30 pm
- Needing a nap in the afternoon
- Activities with friends fell away
- Doing something new makes me tired

Things that helped

- Changing my routine
- Building up hours
- Building up days
- Structured routine
- Planning and organising
- Support from work colleagues and managers

2. Doing things with one hand:

Things that made work difficult

- Putting my uniform on
- Counting the money in the betting shop
- Putting up large newspapers on the wall
- Sorting paperwork
- Stapling and hole punching paper
- Using the computer

Things that helped

- I practiced counting monopoly money
- I worked with the occupational therapist practicing tasks

3. Difficulty concentrating:

Things that made work difficult

- Computer work
- Concentration makes me tired
- Learning new information
- Thinking about something I have not done for a while
- Reading
- Meetings

Things that helped

- I built up my concentration gradually
- I played solitaire on the computer
- Support from work colleagues to change meetings to the morning when I was less tired

4. Transport difficulties:

Things that made work difficult

- Bad experience with people on the bus
- It doesn't look like I need to sit down so people don't offer me a seat
- I don't like all the questions from people
- Pity off people
- Doing it by myself
- Walking makes me tired
- Busy trains

Things that helped

- I learnt to deal with people on the bus and the train
- I started work later to avoid the busy busses and trains
- I took the slow and quiet trains because I can get a seat

Research and publications update

There have been a number of new and useful publications in the area of stroke self-management and issues to do with life after stroke.

Harwood M, Weatherall M, Talemaitoga A, Barber A, Gommans J, Taylor W, McPherson K, McNaughton H. (2012) Taking Charge after stroke: promoting self-directed rehabilitation to improve quality of life- a randomised controlled trial. *Clinical Rehabilitation*. 26:493-501.

This article reports the finding from a trial based in New Zealand which compared the impact of two interventions designed to encourage self-directed rehabilitation on 172 Maori and Pacific Islanders within three months of a first stroke. The study was designed to focus on these two groups within New Zealand as research had shown they had significantly worse outcomes than other New Zealanders at 12 months post stroke. The research team anticipated that this may be due to a complex interaction of cultural beliefs and attitudes towards stroke. The interventions were 1) an 80 minute inspirational DVD which included stories from four Maori and Pacific Islanders and their families 2) an 80 Minute 'taking charge' session which consisted of an individualised risk assessment and goal setting. Both interventions were delivered by an assistant from the same ethnic group.

Results showed that the participants randomised to the 'Taking Charge' session showed clinically significant changes in quality of life, and an improvement in the strain experienced by caregivers.

This study highlights the potential of a simple, low cost intervention to improve the outcomes of community dwelling Maori and Pacific Islanders with stroke, and their carers. More work is required to see whether it is possible to replicate these findings in other groups.

Northcott S and Hilari K. (2011) Why do people lose friends after a stroke? *Int Lang. Comm. Disord*. September- October: 46: 5: 524-534.

Research has shown that people are at risk of losing friends after stroke, and this is most common in people with aphasia. People who become more social isolated and lonely are also more likely to become depressed. Friendships are thought to be important as they provide a sense of continuity and can influence self-esteem and wellbeing. This qualitative study explored why people lose friends. 29 participants were interviewed including 10 people with aphasia; all were between 8-15 months post stroke. Data was analysed using a framework model and revealed themes relating to loss of shared activities, influence of reduced energy, physical disability, aphasia, and unhelpful responses from others, as well as environmental barriers. Those that experienced the greatest loss of friends described it as feeling as if 'they were closing in on themselves', and those with aphasia experienced some hurtful responses from friends, and found it difficult unless they had stable friendship groups prior to their stroke. This paper has relevance to programmes supporting people in the longer term post stroke. Social contacts are beneficial but they need to reflect changing social desires of people after stroke.

Two new articles related to Bridges stroke self-management programmes have recently been published, and one is coming soon:

Jones, F., Livingstone, E. and Hawkes, L. (2012) 'Getting the Balance between Encouragement and Taking Over' — Reflections on Using a New Stroke Self-Management Programme. *Physiotherapy Research International*. doi: 10.1002/pri.1531

Jones, F., Riazi, A., Norris, M. (2012) Self-management after stroke: Time for some more questions? *Disability and Rehabilitation*. Posted early online on June 12, 2012. doi:10.3109/09638288.2012.691938

And coming soon:

Jones, F., Benson, L., Jones, C., Waters, C., Hammond, J., Bailey, N. (Forthcoming), Evaluation of a shared approach to interprofessional learning about stroke self-management. *Journal of Interprofessional Care*.

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