June 2013

Bridges news 6

For everyone concerned with stroke rehabilitation

Update on Bridges New Zealand

The Bridges New Zealand workbooks were completed and delivered in February 2013. They have been modified to include the experiences of four people from New Zealand who have experienced a stroke, and content which is more culturally relevant to New Zealand. Sara Edwards is a physiotherapist working with Dr Leigh Hale (University of Otago) and involved in delivering the programme to people with stroke living in Dunedin, New Zealand.

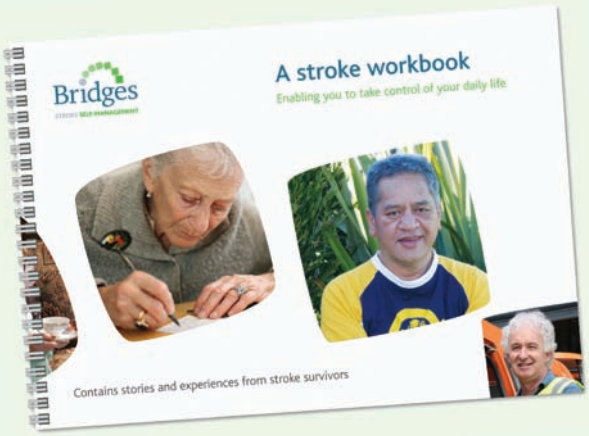
Sara has reflected on her first experiences of Bridges in action in New Zealand.

Sara Edwards is a physiotherapist working with Dr Leigh Hale (University of Otago) and involved in delivering the programme to people with stroke living in Dunedin, New Zealand.

I had been looking forward to delivering the Bridges New Zealand Programme since our training back in August 2012. The workbooks arrived into the country recently and I was able to start familiarising myself with the stories. The New Zealand books were modified to include stories of four New Zealanders who have had a stroke and this has proven to be popular with my first few participants. I think myself lucky to be the first person in New Zealand to deliver the Bridges New Zealand Programme and we have been fortunate here to have support from Fiona in the UK over Skype and email. Due to the structure of the research we are delivering the programme to people with stroke who have been discharged from hospital or rehabilitation back to home.

Initially I was quite anxious about going to see my first participant as it had been some time since training and Dr Leigh Hale (Researcher, also delivering the Bridges New Zealand Programme and my primary support person) was out of the country. I spent some time preparing and trying to pre-empt how the session might go. I had not met the participant before and I was worried that this might be challenging. However, the session had a natural feel to it, it was easy to talk to the participant and it was also very exciting being able to tell him that he was the first person in New Zealand to be a part of the Bridges New Zealand programme. Most importantly he was keen to see the book!

I found that it was really beneficial to be able to talk to him without the restrictions that we face in the acute or rehabilitation setting, for example, time, therapy priorities,



therapy goals. However at the same time I can really see how embedding Bridges into the acute and rehabilitation setting could be incredibly beneficial.

Since meeting the first participant I have started seeing two more. All three participants have enjoyed looking through their workbook, their comments about the books are very positive and they are all thinking and writing about reflection, targets and big goals. I get the feeling that the participants appreciate the fact that Bridges is about them.

I am looking forward to continuing the journey with the participants and being able to facilitate this stage of their recovery.

Published by the Bridges Advisory Group

Reflections on using a diary based on the Bridges Stroke Self-management in Austria

20,000 people in Austria have a stroke every year. Stroke represents the third most frequent cause of death next to cardiovascular diseases and cancer. Stroke also represents the most common disability in adulthood in Austria. After attending a Bridges Workshop in 2012 Christine Gartner decided to focus on self-management in physical therapy in her master's thesis at the Applied University of Science Vienna, Austria. She has started a pilot study using the Bridges programme at the rehabilitation centre "Klinik Maria Theresia" in Styria. Christine describes her experiences and plans.

Part of the Bridges programme was to do a case reflection in the intervening time between part 1 and part 2 of the training. That is when I initially translated the Bridges workbook into German and also asked my mother "to give it a try". My mother had already suffered from several transient ischaemic attacks and one moderate stroke at that moment. Her main problems were anomia and tiredness. She appreciated the section of the workbook where stroke survivors are giving advice by other stroke survivors about how they have managed their problems caused by stroke. Thinking about a goal and how to get there (a technique of this self-management programme) was quite a new approach for my mother and focusing on it was even harder. But writing about her daily challenges and progress has helped her since then and it still does. Her enthusiasm was the beginning of the idea of using the Bridges programme for my master's thesis.

English is not the first language in Austria. Further research will be needed to make a Bridges workbook (in consultation with stroke survivors and their families), contextually and culturally relevant for Austria. But I have decided to do it in a sound but pragmatic way – using a structured diary, which is based on the principles of self-efficacy (Bandura) and on the Bridges Stroke Self-management programme.

The aim of this pilot study is to explore the effect(s) of using a self-management tool (diary) in physical therapy with chronic stroke survivors on walking ability. It is planned to recruit a minimum of 20 chronic stroke survivors within 3-5 months. The intervention group will keep a structured diary (template supplied by the researchers based on the Bridges Programme) throughout their stay at the rehabilitation centre (four weeks) in addition to routine multidisciplinary team care and usual activities. The diary includes a section for reflection on the progress they have made since the stroke ("transition phase") and a goal setting section, where they shall name their primary goal ("improvement of walking") and justify it with personal reasons. The participants have to answer three distinct questions formulated to help them keep this diary and to focus on developing self-efficacy. The control group participants receive routine multidisciplinary team care and usual activities for their four- weeks-stay.

Primary outcome measurements will include self-efficacy (measured by the "General Self-efficacy Scale") and gait / walking ability (measured by the "Ten metres walking Test" and the "Two minutes walking Test"). All three measures are taken at the first and at the last session of physical therapy. A follow-up assessment has not been planned within the master's thesis, but would be of great interest.

Christine Gartner, Physiotherapist

We look forward to hearing about the results of Christine's pilot work later in 2013.

Bridges collaborates with a team of researchers working with people with Huntington's Disease

Dr Monica Busse and Dr Lori Quinn of Cardiff University recently spent a day meeting with Dr Fiona Jones where they discussed the "Bridges" programme and how some of the principles might relate to their research.

Monica and Lari

Lori and Monica are working on a new physical activity project called *Move to Exercise* that aims to improve participation in physical activity in people with Huntington's disease (HD).

Participants enrolled in the *Move to Exercise* Intervention will receive 6 home visits over a course of 16 weeks (weeks 1, 2, 3,6,10 and 14) where they will be supported in developing an individualized life-style approach to enhancing physical activity through interactions with trained physical activity coaches. Coach/Participant Interactions will include discussions on the role of physical activity, strategies to incorporate physical activity of personal preferences, the potential use of a purpose-developed exercise DVD and other options for physical activity. One of the intervention components is the *Move to Exercise* workbook which will be used as a guide to frame the interactions. The workbook has been developed following consultation with people with Huntington's Disease and their family members and incorporates some aspects of the "Bridges" approach in aiming to achieve self-directed changes in physical activity.

This is one of the first times that some of the principles of Bridges have been used to inform a programme for people with a different neurological disease such as HD. This may be one small part of the overall research but we are delighted to have been asked to be involved with this exciting project. We look forward to hearing more about Monica and Lori's research over the next year.

More information about Monica and Lori's work can be found through the website below:

www.activehd.co.uk

Application of self-management principles from day one post stroke. Can it be done?

The hyper-acute stroke unit (HASU) at Bart's Healthcare NHS Trust, UK – assesses and treats patients in the first 72 hours post-stroke.

Therapies play a key role here through assessing new admissions within the first 24 hours. The therapy team have incorporated the Bridges self-management approach throughout the borough's stroke pathway. The main aim is to ensure consistency of messaging and treatment for all patients, in line with the Bridges approach.

This doesn't mean that the 38 staff members across the MDT trained in Bridges haven't faced challenges when applying self-management in practice. They realised it was important to consider a 'whole systems approach' to self-management which takes into account the individual patient needs, professional beliefs and attitudes as well as the organisational context of the pathway.

To gain a better understanding of what and where the barriers to implementation might be, a number of focus groups were run with the staff members trained in Bridges. The groups explored staff views on integrating self-management techniques on a HASU. Initial findings did suggest a change in staff attitudes, and identified a number of Bridges techniques which could be incorporated into the HASU therapy approach. Specific areas highlighted include peer learning, supporting problem solving, and encouraging self-practice and promoting awareness of physiological changes. The introduction of the audit cycle, together with completion of the final focus groups, will support development of a greater understanding of staff behaviour and opinions, and determine where self management fits in on a HASU.

The team had an abstract relating to this project accepted as a poster at the last UK Stroke forum, which can be accessed through this link:
http://onlinelibrary.wiley.com/doi/10.1111/j.1747-4930.2012.00961.x/abstract

Inspired by Bridges: clinical application of self management on a HASU

Coyle M(1), Baird T1, Jones F(2)

Further details about a 'whole systems approach' to self-management can be found in the following article:
Kennedy A, Rogers A, Bower P. Support for self-care for patients with chronic disease. British Medical Journal. 2007;335:968-70.

Helping to shape Bridges

***Dr. Ajay Bhalla* works in stroke and has been a member of the Bridges Advisory Group for 7 years. We asked Ajay how and why he got to where he is today.**

The workbook advocates joint application between physician and patient, which is something I believe in.

What is your current job role?
I am a Stroke Consultant and have worked with Kings Health Partners since 2009. I'm based at Guys & St. Thomas' Hospital, but I also work in the Hyper Acute unit at St George's Hospital. I have been a stroke physician for 10 years and I am also the Deputy Clinical Director for the South East Stroke Research Network.

Why did you choose stroke as your field of expertise?
As a doctor, I was always interested in the application of science to everyday clinical practice and this is an outlook I have always followed through my medical school training. I was hooked on understanding and deciphering the neuroscience aspects and the complexities around managing the stroke patient in rehabilitation. There was a promise of new treatments and therapies being evolved in stroke care and I wanted to be a part of this.

What is your interest in Stroke Rehabilitation?
In the UK one size doesn't fit all; there are various different therapy models that work for certain areas and certain patients and not for others. My interest is seeing how the research evidence is being deployed in day-to-day stroke service delivery. One particular interest I have is looking at how patients can be managed a lot earlier in their home environments through early supported discharge, rather than keeping them in the hospital. There is very strong evidence for a certain group of patients that it is better for them to be managed at home. I'm also really interested in the patient perspective and self-management techniques to enable them to take the lead in their own care, rather than it being completely directed by health professionals.

Recovery is complex and still misunderstood. But I have seen a sea-change within the medical profession, whereby patients are seen as more of partners rather than subjects in the rehabilitation process and goals are more led by patients than therapist. This can be seen with the Bridges programme which is now being applied and tested in various ways within the stroke community.

How did you get involved with Bridges?
Fiona [Jones, Bridges Director] knew me from my work at St Helier's hospital and invited me to join the Bridges Advisory Group following some workshops we were both involved in; I have now been a member of this group since 2006. I have seen Bridges stroke self-management really explode and it is a very successful venture now being tested in a clinical trial setting. The good thing about being involved in Bridges, is working with other key stakeholders in stroke research and rehabilitation.

Have you had the chance to use the Bridges workbook with patients; can you tell us about your experiences of doing so?
I do subconsciously use the strategies involved in the workbook in terms of encouraging patient to direct themselves rather than me putting my goals onto patients' beliefs. The workbook advocates joint application between physician and patient, which is something I believe in.

Is there any current research you think highlights particularly interesting points regarding stroke?
Self-management and rehabilitation are now at the forefront of stroke treatment and research. This was mentioned in the National Stroke Strategy in 2007, where more emphasis and drive was placed on stroke as a long term condition rather than only focusing on hyper-acute and acute care. More community involvement is occurring within stroke treatment and research, with support for longer-term conditions being required. The patient is now viewed at the centre of the circle with stakeholders around the circle dipping in and out as necessary.

Could you tell us two things you like to do when you have time off?
I'm an Arsenal fan! I have 2 young boys and we all support Arsenal, with their twice weekly games being in pole-position on our social calendar. I used to run marathons, but now I have moved onto cycling. I am doing a 100km cycle ride at midnight in June, to raise money for the Stroke Association. I'm currently spending a lot of time cycling around Richmond Park to get ready for this event – 8 laps of the park is 100km (but I usually get bored after 3 or 4)!

Bridges Advisory Group (BAG) has recently gained some new members. Bridges Administrators take time to get to know *Robin Cant*, one of the new contributors to Bridges Stroke Self-Management:

Can you tell us a bit about yourself and what you have done?

Well, I am nearly 68 years. I completed my first degree in Sociology and a subsequent Masters degree in Educational Research at Lancaster University and I have taught social sciences to a wealth of people, including Nurses, Occupational Therapists and Radiographers.

In January 1996 I had a stroke. I was 50 years old at the time. People generally expect cancer, but no one expects a stroke. Following my stroke I was hemiplegic on my right side; I could walk, but didn't have much use of right arm or hand. Luckily, I escaped any cognitive damage – no one has told me any different!

The local Stroke Association asked me to talk about stroke when I had mine, I offered to set up a group for young stroke survivors in the Kent area. The group grew to over 260 people and we all met 4 times per month in 4 different pubs in Kent. We also went for sailing trips on boats adapted for people with disabilities.

Over the years I have become more and more involved in stroke research and planning. I joined the national section of Stroke Research Network, I am also the lay-member, as a stroke-survivor, of the Guidelines Development Group at NICE, and am assisting with the development of new NICE guidelines regarding stroke rehabilitation.

What do you think professionals should consider when supporting someone after stroke?

It is difficult to say because different people want different things. Some people are very grateful for any help, but others find it hard as they cannot come to terms with what has happened to them and resist help. I would suggest that an openness and willingness to take on board where the person is coming from are qualities needed by health professionals.

What has been important to you in relation to your progress and self-management?

I feel that loss of self-confidence and self-esteem following stroke is not considered enough. Originally you are a fully functioning adult, and then you're a patient in a hospital bed and not much else. I'm trying to place more emphasis on rebuilding confidence through group support.

It is also important to continue building a public awareness of what stroke is and how it affects individuals; not only the person who suffers the stroke, but their family and friends too. People need to be made more aware that the carers also suffer problems associated with stroke. For example, what then becomes of their role, as well as living their usual lives?

Stroke has actually opened up a new life and a new career for me

How did you get involved with Bridges?

Following a presentation I gave at the UK Stroke forum in 2012 at Haringey, I was asked if I wanted to be involved on the Bridges advisory group. Stroke has actually opened up a new life and a new career for me.

Have you had the chance to use the Bridges workbook yourself; can you tell us about your experiences of doing so?

I have looked through it and think it provides a possible avenue for an individual's personal rehabilitation. I feel very positive about the Bridges workbook and programme.

Could you tell us two things you like to do when you have time off?

I love gadgets; especially computer programmes! Prior to my stroke I did a lot of DIY; playing with gadgets has replaced that as it requires less physical dexterity but still gives me a great sense of achievement.

I also like travelling and meeting new people. I spent my recent birthday in the mountains of Tunisia and completed a 6 day archaeological tour whilst I was there, which was fascinating. I've also been to Berlin recently and plan to go travelling again as soon as I can!

Whilst a patient in hospital following his stroke, Robin kept notes using a Dictaphone which he transcribed into an article. You can read more about Robin's perspective's of being a patient here:

Cant, R. (1997) Rehabilitation following a stroke: a participant perspective. *Disability & Rehabilitation*, 19 (7). Pp: 297-304.

Update on policy relevant to self-management

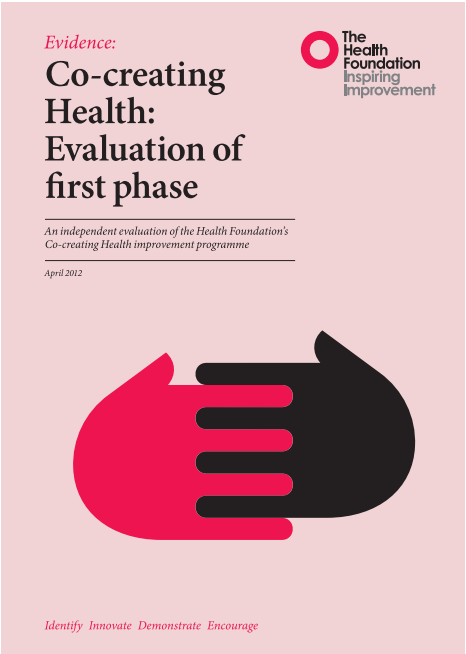
We have summarised 2 recent reports below published by the Health Foundation, which provides a number of really valuable resources and publications relating to self-management.

Wallace, L.M., Turner, A., Kosmala-Anderson, J., Sharma, S., Jesuthasan, J., Bourne, C. & Realpe, A. (2012) 'Co-creating Health: Evaluation of first phase'. An independent evaluation of the Health Foundation's Co-creating Health improvement programme. *The Health Foundation: London*. Available [online] at: www.health.org.uk/publications/co-creating-health-evaluation-phase-1/

This report highlights the findings from phase 1 of Co-Creating Health; a 3 year initiative that began in 2007. It ran across 8 UK sites and aimed to uncover the impact on both health professionals and patients, of integrating self-management support into routine care for individuals with long-term conditions.

The report highlights the key findings as:

- *"The self-management support programme for patients improved the activation and quality of life of people with long-term conditions.*
- *Adopting self-management approaches requires long-term behaviour change, and the interventions to achieve these also need to be long-term.*
- *Self-management support must be normalised into existing ways of working within health economies.*
- *Techniques to support self-management, including agenda-setting and goal-setting, were well received and implemented following training.*
- *Co-delivery is an important way of changing patients' and clinicians' perceptions of their roles."*



King, E., Taylor, J., Williams, R. & Vanson, T. (2013) 'The MAGIC programme: Evaluation'. *The Health Foundation: London*. Available [online] at: www.health.org.uk/publications/the-magic-programme-evaluation/

The Health Foundation's MAGIC (Making good decisions in collaboration) programme aims to support clinical teams in primary and secondary care to cement shared decision making into daily practice. Decisions should be jointly based on clinical evidence and patient's informed choices; it is essential that all parties are provided with evidence regarding options, outcomes and possible uncertainties for an effective outcome. Accurate records of patient preferences and counselling when decision making also contributes to more positive outcomes.

Results show that shared-decision making can create positive change for both health care protocols and patients themselves. However, it is a lengthy process requiring a change to the core infrastructure of health care systems, and also to the attitudes and the skills pertaining to those working within, and being treated by, them. It is more than simply 'good communication skills'.

The Evaluation of the MAGIC programme saw the following consistent improvements:

- Change in dynamic between clinicians and patients; patients more empowered and doctors were much more open to discussion.
- Structured consultations enabling patients to now consider lifestyle changes that may be more likely to lead to longer-term health benefits.
- Increase in staff reflection; enabled staff to consider how they use consultation and communication skills in practice.

There were also the following challenges reported:

- Patients are not always ready for shared decision making, due to lack of confidence in medical self-responsibility/external locus of control.
- Many primary care settings found during their busiest periods, it was tempting to revert to old ways where patients were not so involved, simply to keep care moving.

Full details of the improvement stories across 7 UK sites can be accessed in the Health Foundation's Learning Report 'Implementing Shared Decision Making', available [online] at: www.health.org.uk/publications/implementing-shared-decision-making/

Workshop

Experiencing a Bridges workshop, from participant to potential trainer

"De-therapising yourself is hard to do and I still find myself slipping back into 'physio-fix-it mode." Katie Campion pictured here with Gladys

Katie Campion talks about her recent participation in a Bridges workshop in Bury, Greater Manchester.

After doing the Life After Stroke masters module at St George's University of London I became interested in the Bridges workshops. What? Give people some ownership over their rehab? Amazing! Sign me up! I'm a physiotherapist by trade but my eclectic interests and love of teaching mean I've run a number of workshops. I've taught Sushi-making in Edinburgh, knitting in New Zealand and whisky tasting in London. After presenting to my trust about the Life After Stroke course my supervisor suggested I contact Bridges to see if I could get involved in running the workshops.

Shortly after this I got the opportunity to tag along to a workshop in Bury to find out what it was all about. I was really excited getting on the packed train with all the other commuters. This was the closest I'd ever been to a 'business trip'! The team from Bury were fantastic, you couldn't have a better introduction. They are an early supported stroke discharge team and were very welcoming, positive and insightful. The team dynamic was so inclusive that any hierarchy that may exist was impossible to see. I have to admit the amount of biscuits and cakes we consumed during the day were also a winner!

I came away from the trip full of 'self-efficacy' and went into work the next day enthused and ready for action! I had the chance to use the Bridges Workbook with one of my clients, Gladys. Gladys is doing well since her stroke earlier this year and has gone from shopping for essentials to shopping for fun stuff like clothes. I have to tell you what she told me yesterday. Gladys was out shopping when she saw a man across the street. He had his arm tucked up close to his chest. She crossed the street.

'You got stroke?' 'Yes Mam' the man replied. 'Well I got stroke too, you can't be keeping your hand up like that, it'll get stiff man! You put it in your pocket or you let it hang. You gotta keep working on that hand man. I gotta bad hand but you gotta keep working on it.' I should imagine the man was a little taken a back, but he thanked Gladys 'Thank you mam, thank you, I'll do that.'

Gladys had been reading Chandrakant's story in the workbook and this had inspired her to cross the street and spread the word.

It's not easy using the Bridges Workbook. De-therapising yourself is hard to do and I still find myself slipping back into 'physio-fix-it mode'. But it's worth the effort. The thing I like about it is that it keeps working its magic and seeping into your clients thoughts even when you've clocked off and you're back home on the sofa watching the telly with a glass of wine. Oh and you find out really cool things. Deep down Gladys's big dream is to go to Fort Lauderdale on holiday to visit family. Watch out America!

Katie Campion – Physiotherapist

What do clinicians think about Bridges workshops?

We have now delivered Bridges workshops to over 1000 practitioners. After each workshop participants are asked to provide feedback by completing our workshop evaluation forms.

Analysis of these evaluations has found that, after attending both Bridges workshops, 99% of people completing our course evaluation forms felt that the workshops would enhance their practice and 99% would recommend a similar workshop to their colleagues.

The following quotations have been taken from the workshop evaluation forms:

"This will greatly influence my practice as it has given me the knowledge and confidence to be able to interact with with my patients more."

"I feel it will enhance my practice by encouraging patients to make their own personal goals."

"I have another tool that I can use with my clients, to promote independence and encourage service users to have some control over their progress."

"I feel I now know and can understand how I can facilitate self-management interventions with a stroke survivor."

"The knowledge, workshop and stroke workbook will be a great help to my practice... enabling me a greater perspective."

"It has given language and evidence for what I do."

What's new?

Update on research relevant to Life after Stroke

The summaries below describe important research in the area of post-stroke aphasia and approaches to goal setting as well as the role of the family members in rehabilitation.

Hersh, D., Worrall, L., Howe, T., Sherratt, S. & Davidson, B. (2012b). *SMARTER* goal setting in aphasia rehabilitation. *Aphasiology*, 26/2, 220-233.

This paper presents a new 'SMARTER' framework for collaborative goal setting that emphasises the importance of involving people with aphasia and their family along with the multi-disciplinary team in the establishment, continual review and revision of goals. It was developed based on the outcomes of a multi-site qualitative study, 'the Goals in Aphasia Project', conducted in Australia involving interviews with 50 patients with post-stroke aphasia, 48 family members and 34 speech therapists.

The publication challenges the use of SMART goals, arguing that used in isolation they can potentially mean a loss of the collaborative process – rehabilitation therapists can dominate the goal setting process, being more focused on establishing objectives that are realistic and achievable within a specific time-period. This is often at the expense of patient involvement in goal setting, resulting in lack of motivation and goal ownership. The SMARTER framework – Shared, Monitored, Accessible, Relevant, Transparent, Evolving and Relationship-Centred – is a goal setting process that both supports and challenges the development of SMART goals.

Establishing person-centred goals is important across stroke rehabilitation settings, however the publication authors argue it is not always evident in practice. The SMARTER framework is not specific to people with Aphasia, and can be adopted to establish a more consistent and effective approach to collaborative goal setting in broader environments.

''You needed to rehab families as well': family members' own goals for aphasia rehabilitation', in International Journal of Language & Communication disorder. Howe, T., Davidson, B., Hersh, D., Ferguson, A., Sherratt, S., Gilbert, J. (2012), 47(5), pp. 511-521.

This research highlights the importance of recognizing the goals of family in aphasia rehabilitation to allow development of effective services for the disorder. The study aimed to explore the role of family in therapy for stroke survivors, in order to identify the personal goals of family members.

This was a qualitative study conducted in Australia across three sites, as part of a wider research project exploring the goals of individuals with aphasia. It involved individual in-depth interviews with 48 family members, (36 female and 12 male, aged 24-83) including the husband/wife, children and siblings of those with aphasia following stroke. Analysis of the interviews showed participants' goals could be allocated to one of seven categories: to be included in rehabilitation; to be provided with hope and positivity; to be able to communicate and maintain their relationship with the person with aphasia; to be given information; to be given support; to look after their own well-being; and to be able to cope with new responsibilities.

The results highlighted the variety of goals associated with therapy, and the study researchers stress the importance of identifying individual goals for individual family members. Recognising the vital role that family can play in therapy progression, and adopting a more family centred approach to rehabilitation of aphasia, will potentially lead to enhanced effectiveness of treatment.

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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.

Kingston University London | St George's University of London