Shine 2014 final report

Early integration of the Bridges self-management support package into usual care following traumatic brain injury: a feasibility study

King’s College Hospital NHS Foundation Trust
Bridges Self-Management Limited

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Part 1: Abstract

Project title: Early integration of the Bridges self-management support package into usual care following traumatic brain injury: a feasibility study

Lead organisation: King’s College Hospital NHS Foundation Trust

Partner organisation: Bridges Self-Management Limited

Lead Clinician: Petra Mäkelä, Consultant in Rehabilitation Medicine

Introduction:
Persistent cognitive, psychological and emotional symptoms following traumatic brain injury (TBI) represent hidden disability, for which limited support exists (Andelic et al, 2014). Supported self-management is underpinned by variable assumptions, which may determine and preference which groups are considered likely to benefit by healthcare professionals (Kendall et al, 2011). The extent to which people after TBI have been involved in improving experiences of healthcare is limited, though this approach has been used in the development of supported self-management resources with people following stroke (McKenna et al, 2015).

Aims:
The aims of this project were to develop self-management support through engaging people who had experienced traumatic brain injury in the co-design of resources, to enhance the skills of healthcare professionals in supporting self-management, and to implement the newly developed self-management support package across a traumatic brain injury pathway, commencing in the acute setting.

Method:
(1) Development phase: A diverse range of individuals who had sustained traumatic brain injury, and their family members, contributed to co-design of supported self-management resources through focus groups and interviews.

(2) Training and implementation phase: A series of ‘Plan-Do-Study-Act’ cycles, informed by Normalisation Process theory (May and Finch, 2009), sought to generate interest in supporting self-management among multidisciplinary healthcare professionals, facilitate sense-making through tailoring training to work contexts, engage staff in collective action to discover their own ways to implement the principles, and to reflect upon the new ways of interacting with patients and families.

(3) Evaluation: Change in beliefs, attitudes and skills of staff supporting self-management were assessed through pre- and post-training questionnaires, and through semi-structured interviews following a 3-month implementation period. Standardised patient outcome measures, health and social care utilisation data, and qualitative feedback from patients and families were collected.

Results:
Through this project, self-management support tools specific for the traumatic brain injury context have been co-designed and implemented within the acute Neurosciences and Trauma wards of a Major Trauma Centre, a Rehabilitation Unit, and in Headway, the brain injury charity, settings. The resources comprise a patient-held interactive book, a family and friends’ book, and a multi-disciplinary bespoke training package for supporting self-management.
Seventy multidisciplinary healthcare professionals and voluntary sector workers participated in joint 3-stage training, and an additional 40 staff and managers participated in abbreviated training. Questionnaire responses demonstrated a significant difference in the levels of confidence expressed by staff regarding their knowledge and skills to support people with traumatic brain injury and their families to self-manage, following training.

Implementation of the intervention has been undertaken with over 70 patients and their families within the initial 3-month implementation period. Standardised measures for anxiety, depression and quality of life demonstrated representativeness of the group for whom Bridges was implemented, compared to a historical sample from 2014, prior to project initiation. Qualitative evaluation revealed the ways in which staff had used the Bridges package to motivate patients to plan and to gain ideas from others who had experienced TBI, while patients reported the value of writing down thoughts and goals as record of what had been going on at a time of great disruption, during which their memory had often been impaired.

Discussion:
This is the first project to co-design self-management support with people after traumatic brain injury and achieve implementation across acute, rehabilitation and community services. Challenges were encountered due to lack of a cohesive team structure within acute services for people after traumatic brain injury. Individual, team and organisational responses demonstrated a range of engagement and adaptation according to their contexts. Future work will focus on sustaining and evaluating the intervention within project settings, and spreading the approach within the pan-London major trauma system.
Key project stages are illustrated below:

**Stage 1: Development phase**
Co-design of ‘Bridges Brain Injury’ supported self-management package with patients after traumatic brain injury and family members
Stage 2:

Training

- 70 multidisciplinary staff attended 3-stage training workshops

Staff from acute, rehabilitation, clinic and community third sector settings

Mix of backgrounds and settings facilitated interdisciplinary and cross-organisational awareness

Implementation settings

- Acute wards in King's Major Trauma Centre
- Inpatient rehabilitation unit
- Headway (brain injury charity) centres
- Brain Injury outpatient clinic
Stage 3: Evaluation phase

Assessing staff confidence and attitudes to supporting patients and families in self-managing after brain injury

Capturing implementation data: patient numbers, settings, standardised and qualitative outcomes

Learning from new ways of integrating, adapting and sustaining. Evaluation of patients' and families' experiences, feedback to staff

“Bridges has eased me in - reminding me what can be done and that there are things as parents that we can do ourselves”

Father of 21yr old male with TBI in Trauma ward

“[Bridges] has assisted us in increasing our multidisciplinary team working when discussing implementation of the book, and it also means the language and approach used is the same.”

Occupational Therapist
Major Trauma Centre
### Key learning points

| **Coproduction with people after brain injury** | • Willingness of people after TBI and families  
• Feasibility of service improvement collaboration  
• Impact of patient stories in iterative PDSA cycles |
| --- | --- |
| **Supporting self-management in acute setting** | • Challenging but achievable in Major Trauma Centre  
• Lack of cohesive acute team impacts embedding  
• Need for authentic organisational support |
| **Perservering to enable organic integration and growth** | • Regular, planned communication  
• Adoption and adaptation take time to emerge  
• Early findings guide ongoing sustainability activities |
Part 2: Quality impact: outcomes

Course of the intervention and changes to original plan

During project set-up stages, the need for modifications to the initial plan became apparent through discussions with stakeholders, requiring change in two key areas:

1) An extension of the multidisciplinary training to include staff working in the later-stage pathway settings of the inpatient specialist neurorehabilitation unit and at the local branch of Headway, the brain injury charity, providing community- and day centre-based support for people after brain injury. This extension was required to facilitate continued implementation of the approach and assess relevance and feasibility, at these later stages.

2) In addition to original plan for the Bridges Brain Injury patient-held book, the need for a complementary book specifically for families, friends and other supporters of people after brain injury became apparent, to be implemented during acute stages but also applicable over a longer period of time for adapting post-injury.

Measures

The intervention requires implementation of a supported self-management package into a range of contexts across the brain injury pathway, for which a period of time is required for integration into ways of working and for new practices to emerge. We have taken a predominantly developmental approach to evaluation (The Health Foundation, 2015) with focus on factors in context, mechanisms and outcomes that have affected success or failure (Pawson and Tilley, 1997). This has facilitated real-time feedback to the intervention team through identification and exploration of emerging changes, allowing ongoing development and review of our theory of change (see appendix 2 for project logical framework).

Standardised measures were collected for a subgroup of patients with whom the intervention has been implemented, in order to contextualise the project group against a historical comparator group who were under review through the Brain Injury clinic prior to this intervention (in 2014): the quality of life measure SF36, from which the SF6D (Brazier et al, 2002) can be used to estimate quality-adjusted-life-years gained for further economic evaluation; the Hospital Anxiety and Depression Scale (Zigmund and Snaith, 1983); and the Rivermead Post Concussion Symptom Inventory (King et al, 1995). We considered qualitative evaluation from a subgroup of participants across project settings to be an essential part of our developmental evaluation, as the standardised clinical outcomes measures do not reflect individuals’ need to “be me” in the contexts of their daily lives (Boger et al, 2015).

In addition, a bespoke Health and Social care utilisation questionnaire was developed (see appendix 1) and feasibility of its use was assessed. Piloting involved ‘probing’ to ask people for their interpretation of terms, allowing for identification of issues with understanding, remembering and responding.

Data regarding professionals’ changes in attitudes and beliefs to supporting self-management were collected through pre- and post- training questionnaires. An online survey and qualitative data from staff interviews contributed to evaluation after a three-month implementation phase.

Variation from initial evaluation plan

1) We had initially intended to assess staff attitudes through the Clinical Activation Measure®. However, we did not ultimately use this tool, as it is significantly orientated to health-related rather than broader self-management support items. Two MSc students,
supervised by Professor Fiona Jones at St George’s University of London, developed bespoke questionnaires for staff working in TBI contexts.

2) We added a standardised measure of self-reported self-efficacy, the Generalized Self-Efficacy Scale (Schwarzer and Jerusalem, 1995) to assess feasibility of its use within this patient population, as the Bridges intervention package is underpinned by social cognitive theory and the concept of self-efficacy, i.e. an individual’s beliefs in their capabilities to produce given attainments (Bandura, 1997).

Overview of outcomes

Changes in staff attitudes, beliefs and skills in supporting self-management:
Approximately 70 multidisciplinary staff from acute, rehabilitation and third sector settings attended three-part training workshops. A summary of professional backgrounds, and findings from pre-and post-training questionnaires, is included in appendix 3. A significant change was found in self-reported knowledge and skills for supporting people with traumatic brain injury and family members to self-manage their condition and everyday life. Changes in staff understanding of the supported self-management approach demonstrated a shift away from more didactic approaches such as provision of information and staff determined goal-setting towards more collaborative methods, which underpin the Bridges package. In addition, following training, significantly fewer felt that specific time would need to be set aside to support self-management.

Patient and family quantitative data:
Data presented below relates to 73 patients (67% male) after traumatic brain injury, for whom introduction to Bridges included use of one or both of the books by staff who had taken part in 3-stage training. Demographic and injury-related data for these patients is included in appendix 3, p.35. Data from across pathway settings (Figure 1) demonstrate that implementation within the acute setting exceeded that in later pathway stages. This is consistent with our initial intention to provide self-management support from the early stages after admission, as it is established that the majority of patients after TBI will not be admitted to a rehabilitation unit or have timely access to community input following discharge home. Within the Major Trauma Centre, the majority of people and families were introduced to Bridges between one and two weeks after injury, as shown in Figure 2.
Standardised outcome measures were collected with 18 people with traumatic brain injury with whom the Bridges package had been implemented (14 introduced on acute wards of a Major Trauma Centre, 3 in a brain Injury clinic and one from the Headway community setting). It was not possible to collect data from 23 patients with whom the Bridges package had been introduced in the acute setting. The reasons are illustrated in Figure 3 below.
Patients who had been introduced to Bridges Brain Injury within the project were matched to a historical sample of patients (measures had been collected in Brain Injury follow up clinics usual processes in 2014, prior to project initiation). Patients were matched according to age, gender, whether they had required initial neurosurgical management, and their length of stay in the acute hospital.

The outcome data and matched historical outcome data for the Hospital Anxiety and Depressionss scale (HADs) are illustrated in Figures 4 and 5, and the Short Form Health Survey (SF-36) in Figures 5 and 6. The intention was to profile patients in each group, allowing assessment of representativeness of the patients with whom the Bridges package had been implemented (rather than to achieve statistical analysis of change). The data revealed higher HADs scores for the matched historical sample than the Bridges group, consistent with greater levels of anxiety and depression. For the SF-36, mean scores for physical health for both groups fell in the ‘well below average range’. The SF-36 mental health mean score for the historical group fell in the ‘well below average’ category but for Bridges patients was higher, falling in the ‘below average category’.
Figure 4
Hospital Anxiety and Depression scale (HADs):
Bridges project group versus historical comparator group

HADs Anxiety Scores

Figure 5
HADs Depression Scores
Short Form Health Survey (SF-36): Bridges project group versus historical comparator group

Figure 5

SF36 Physical Health Scores

Figure 6

SF36 Mental Health Scores
Self-reported measure of ‘symptom burden’
The Rivermead Post-Concussion Symptoms Questionnaire scores for patients introduced to Bridges are shown below (Figure 7; the maximum possible score is 64 and a higher score indicates more symptoms are present.). There were few historical comparator patients for whom scores had been recorded for this measure (n=6); hence scores were not matched for this outcome.

Figure 7

![Rivermead Post-Concussion Symptoms Questionnaire scores for patients introduced to Bridges](image)

**Self-efficacy measure**
The General Self-Efficacy scale data for patients who had been introduced to Bridges is shown below (Figure 8; minimum possible score of 10, maximum possible score of 40 and a higher score indicates higher self-reported self-efficacy). This scale was not in use with the historical group, hence comparator data is not available.

Figure 8

![Bridges Patients' Self-Efficacy Scale Scores](image)
Summary of patients, families and staff qualitative evaluation data

Qualitative data were generated from 17 staff, patients and family members who were interviewed or gave written feedback about their experiences of using Bridges resources or having been trained to support self-management using the Bridges approach. Of interest were the shared views expressed by both groups (staff and patients/families) of the usefulness of the TBI and friends and family book, particularly the value of reading about other peoples’ experiences. Patient and families felt that it helped them to feel they weren’t alone and staff felt it helped to facilitate discussion about how other patients had found ways to self-manage:

“I find some comfort in seeing how they progressed and knowing that hopefully I will progress in the same way or even better. That encourages me”.

Whilst patients were not necessarily aware of any particular approach used by staff to support self-management, staff perceived some subtle but key changes in their practice post-training which included an awareness of being less directive and an ability to step back and encourage patients to find their own solutions.

“I think that there is an element where we want to rescue people. Having been on the Bridges training, that is definitely something that has changed for me. I push things back into people’s own courts a lot more. When they say, “This isn’t going to work, and this isn’t going to work, and this isn’t going to work…” instead of coming up with 50 solutions”.

Analysis of interview data also revealed discrepancy in how some staff and patients perceived the appropriateness of starting self-management support in an acute setting, differences which were also revealed through other data sources. Some staff had used Bridges successfully with patients days post injury, whilst others felt the environment and some patients (mostly young male) were not suitable. The readiness for self-management support was not so much of a concern for patients and family members but there was acknowledgement of the added value of family members using the books in the acute setting:

“I found the ‘Changes in your family member/friend’ [section] most interesting. I can see that now that everything is not 100%; without you reading, it would all come as a shock”.

Finally there were several aspects of self-management support revealed by staff, patients and family, which underpinned the Bridges approach. Staff talked about using the stories and small steps to motivate patients to plan and gain ideas from others, whilst patients reported the value of writing down thoughts and goals as an aide memoir, which could also act as a comfort to have a record of what was going on at a time of great disruption and often in the context of memory impairment.

Further qualitative evaluation from staff, patients’ and families’ interviews and feedback can be found in appendix 3 (page 37)
Sample quotes from implementation of Bridges Brain Injury package
- demonstrating patient feedback to staff implementing the approach

19 year-old male, one month after TBI in Neurosurgical ward

“Sometimes I think, ‘I don’t want to listen to anyone’. This book makes me comfortable because, when I am reading, it is just me and the book. The reading makes me more comfortable. The stories are good; they make me feel I don’t have to hide anything. The more I read how they had head injury, the more I can open up and the more I can compare myself to them...I read it every day; I use the goals as well. I might forget them, but if I write them down, I know”

“I think it is really nice to hear that kind of feedback, as maybe the therapist in the acute setting thought they weren’t engaging with it, when they introduced [Bridges].”

Occupational Therapist in post-acute rehabilitation setting
Part 3: Cost impact

Factors contributing to financial impact
This project was developed with the intention to “support people to take a more active role in their own health and care”, rather than to “improve quality while reducing costs”. The aim was to evaluate the feasibility of delivering integrated self-management support for people with traumatic brain injury across a neurotrauma pathway. We anticipated that the financial impact of the project would not show an immediate cost benefit, as staff will take time to integrate this way of working into their practice. However, we hypothesise that if self-management support becomes an integrated part of care and rehabilitation it will deliver costs savings in two main ways:

1. Patients and families become more confident to self-manage and require less follow-up support.
   There was no historical data to compare health and social care utilisation and because of this a bespoke tool was developed together with our health economist and piloted in order to capture direct and indirect care costs. This has been used during routine post-discharge follow-up appointments and will now allow a more accurate way of tracking the true costs of living with unmet needs and an unseen disability such as TBI (the data collection tool and a summary of findings are included in appendix 1).

2. Staff will use their time more efficiently by focusing on a collaborative model of care
   Traditional care approaches can foster dependency on professional expertise. Teams who have reached a shared understanding and achieve a culture of self-management support will discharge patients earlier and deliver fewer unnecessary treatment sessions. This has been shown to be the case in previous work in stroke, and we anticipate that there are similar gains to be made in TBI.

Costs of existing services
The current follow-up service comprises the following key costs:
- A follow-up appointment in the Brain Injury clinic ~£160
- An appointment for a new referral (e.g from a peripheral hospital) ~£392
- For persistent problems: outpatient assessment in the Brain Injury Neuropsychiatry Clinic ~ £900 for initial appointment
- Assessment for suitability for Cognitive Behavioural Therapy (CBT) ~ £480
- Single session of CBT ~ £200 (a course of 8-12 sessions is usually required)

(NB: Costs based on data obtained in late 2013).

Cost of the Shine intervention
The main input costs for our Shine intervention include the costs associated with developing and designing our resources (patient book, friends and family book, and bespoke training package). The costs were higher than anticipated and the shortfall was supported by Bridges Self-management and top-up funding from The Health Foundation. The attention and care given to developing high quality resources has been supported by staff, patients and families who have given positive feedback. This suggests to us that work to provide good quality materials will increase the likelihood of sustained use which will in turn lead to a longer term benefit for patients and families. There are substantially lower costs required post-project and ongoing costs will be limited to supplying of books, and for training updates.

Implementation costs
Our overriding message to staff has been that the Shine intervention should not be perceived as an add-on to practice, rather it is integrated. Our implementation costs have
been associated with awareness raising through briefing sessions and support for staff from King’s staff champions and the project team.

Service leads have lent their time and support for the project, and despite initial concerns they released staff to attend 9 hours of training (the only time commitment required). High staff turnover has been a challenge, but we now have evidence of new staff being inducted to use Bridges by trained staff, reducing reliance on every staff member requiring full training. We have also facilitated a model in which teams identify champions who can help the spread and adoption, and provided an additional briefing session for staff who missed training. Managers who wished to understand more about the Shine intervention also attended this.
Part 4: Learning from your project

Enabling factors in achieving project intentions

Whole systems approach
We have taken a ‘whole systems’ approach, in which we have considered a range of staff workplace contexts and the needs of patients and families across a range of stages. This has been facilitated by early establishment of a broad strategic group for the project, including members from beyond the project implementation settings and has included collaborators from two of the other three Major Trauma Centres in London. In addition, the strategic group has included the Social Rehabilitation Manager from the local branch of Headway, who has contributed specialist knowledge of ways of working within the brain injury charity context.

Coproduction with people after traumatic brain injury
Our most significant learning has come directly from the participants who have been willing to share their experiences and to work with us in the development of the Bridges Brain Injury resources. This has been facilitated through four focus groups in the developmental stages of the project, acting as ‘working parties’ to guide content and direction, as well as one-to-one discussions, interviews, and through regular, informal contact with project participants to enable ongoing communication and iterative co-development processes within the project. Participants have also been very willing to contribute to workshops external to the project, and to co-present with project team members at dissemination events.

Organic integration processes
The Bridges books embody a person-centred approach which has a ‘natural fit’ with patients and families, and which provide staff with a tangible mechanism through which to implement the supportive strategies within their everyday work. Additional cultural artefacts have also been implemented as structures and materials through which the initiative can become embedded and ultimately sustained as “the way we do things here” - such as language used during care and rehabilitation interactions to facilitate self management, goal-setting practices, multidisciplinary documentation, and format of multidisciplinary or family meetings. These aspects are important in order to fully integrate self-management into everyday work practices and are related specifically to the collective action required for the normalisation of any new way of working, as described by Murray et al (2010).

Culture and context
We have learned about the impact of organisational subcultures on planning and implementation of this initiative. Understanding of the demands of the context, such as shift-work arrangements, has also been required in order to offer workshop sessions in as flexible and accessible a way as possible. We were unable to cover backfill costs within our budget and so achieving sufficient buy-in for senior staff to approve the release of their staff to attend training was challenging within busy, acute settings. Through perseverance and a range of approaches we have secured high-level support, as well as developing an ally base and network ‘on the ground’.
Challenges and to achieving project intentions and associated team strategies

Staffing changes affecting core team
Following the initial set-up phase, our project Clinical Coordinator was successful in progressing her career and, unfortunately, was lost to the team. This was followed by a period where the post was unfilled, and subsequently the replacement post-holders required induction and orientation time. There was risk to the project of losing momentum, addressed through other team members sharing tasks and maintaining effective communication. The replacement arrangement involved two clinical coordinators working on a job-share basis, each with additional responsibilities in other locations during the other 0.5 of the post (funded by Headway). These arrangements had impact on project continuity and the building of rapport with healthcare professionals, particularly in the acute settings where the lack of cohesive clinical teams presents an added challenge. In addition, our project manager (a member of the core project team at set-up) secured employment elsewhere, resulting in alteration to our project management processes and responsibilities.

Costs exceeding predicted budget
The first half of the project was resource-intensive to ensure high-quality development, design and publishing of the Bridges Brain Injury books\(^1\). The extent of interviews with participants to develop this content resulted in a large amount of transcription requirements. The additional allocation of funds in our initial costing, to enable professional transcribing, would have enabled us to proceed more rapidly through this stage. Fortunately, a committed team of transcribers was formed through students who were willing to get involved, at affordable costs. Financial impact also affected our evaluation process, as the intention had been that research assistants would be paid to carry out follow-up interviews but project team members ultimately undertook these tasks alongside existing workloads, in order to obtain rounded evaluation within the project deadline.

Acute setting for project implementation
King’s Major Trauma Centre is a relentlessly busy and highly demanding setting in which to attempt a complex intervention aimed at behaviour and organisational change. The challenges related to gaining buy-in from staff, in the face of multiple competing priorities. In addition, the lack of a cohesive multidisciplinary team approach, or co-located beds for patients after brain injury, creates a fragmented care pathway that presented logistical challenges in embedding a team approach to supporting self-management. Identification of the need for self-management support for people early following traumatic brain injury had been considered a possible challenge in the early planning stages of the project, however, the degree of implementation (as described in Part 2) has now demonstrated feasibility within this context.

Reflection on aspects of project that could have been approached differently
Our co-production phase was more labour intensive and time consuming than initially anticipated, as we were keen to include enough iterative stages to deliver a high quality self-management tool. In hindsight, this phase and our staff training should have started earlier, giving longer for staff to implement and evaluate the impact on their practice and the experiences of patients and families. We would have benefitted from pre-empting some of the developmental stages, such as approaching people and their families before project launch, in order to start focus groups and interviews much earlier.

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\(^1\) Copies of the Bridges patient-held and ‘family and friends’ books have been posted to the Health Foundation for review alongside this report.
Part 5: Plans for sustainability and spread

Sustainability in host organisation
The Bridges Brain Injury training emphasised the need for key modifications in practice and organisational change to sustain this way of working. 'Bridges champions' have been identified and will be supported in maintaining momentum after the Shine project phase is complete. In addition, examples of sustainability are emerging through processes of induction by trained staff to new, incoming staff, demonstrating the transition from 'project' to a standard way that care is delivered. We are gathering information on how this has been achieved by early adopter staff and will share learning with other teams. Rehabilitation clinical leads and managers in the Trust are considering options for extending Bridges across a range of services within and beyond the traumatic brain injury context.

Regional spread to pan-London Major Trauma Centres
Major Trauma Centres are established across England, each linked with a number of supporting Trauma Units within regional networks (NHS CAG for Major Trauma, 2010). The first London Major Trauma network was launched in 2010, and four are now established (see figure below). During the Shine project we have maintained communication through professional networks incorporating each of the other three Major Trauma Centres in London, where enthusiasm for involvement has been expressed.

Major Trauma Centres: plan for Bridges Brain Injury pan-London spread
Strategy for regional spread

1. Production of a brief video featuring adopters and adapters talking about what has worked well, including patient, family and Headway’s views.

2. **Masterclasses for Bridges champions** – combining staff already implementing the intervention at King’s with multidisciplinary staff from each of the other three London Major Trauma Centres who have already expressed enthusiasm.

3. **Taster training sessions** to be open to range of staff from each of the other three London Major Trauma Centres.

4. **Briefings** for managers and senior staff at the Major Trauma Centres and their associated Trauma networks.

5. A **stakeholder event** to bring together existing supporters with representatives from King’s and the other Major Trauma Centres, to share information and launch sustainability plan in the additional London locations, also to consider later-stage spread to Major Trauma Centres nationally.

6. **Dissemination activities** including further conference presentations, communication bulletins, press releases and open access publications.

7. Support to build on **methods to capture impact** within the dissemination locations, capturing staff/team efficiency and monitoring patient experience.

We are developing this strategy within an application to submit for the Health Foundation’s ‘Spreading Improvement’ programme.

Presentations and other communications

- Fiona Jones delivered keynote lecture on ‘Self-management’ at North West London Trauma Network conference 25th June 2015

- Bridges Annual Symposium, 10th June 2015 at St George’s University of London: Petra Makela co-presented with Bridges Brain Injury project participants.

- UCL Partners’ Centre for Neurorehabilitation symposium, 28th April 2015: Petra Makela delivered presentation incorporating video contribution from our project participants.

- British Sociological Association Medical Sociology event, 22nd June 2015, University of Cambridge: Petra Makela delivered presentation on ‘Coproducing services with people after brain injury’ incorporating Bridges Brain Injury project work.

- Publicity through the Bridges Self-Management Limited website and newsletters (http://www.bridges-stroke.org.uk/bridges_tbi_project.php) and twitter (@bridgesselfmgmt)

- News story featured in King’s Health Partners’ bulletin (see appendix 1, page 30)

- Feature on the project will be included in the Autumn 2015 edition of the “@Kings” quarterly Trust publication.

- Liaising with Headway UK regarding a story to be featured in their national publication ‘Headway News’; also discussing their potential involvement in video creation.

- Submissions for presentations at:
  - The 17th International Trauma Care Conference: 17-21st April 2016, Staffordshire.
References


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Appendix 1: Resources from the project

Bridges Brain Injury Project
Health and Social Care utilisation questions

NB: This questionnaire is intended to be administered by a project team member, rather than for self-completion
“Please tell us about your use of health and social services since your discharge from hospital”

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<td></td>
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<tr>
<td>• psychologist</td>
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</tr>
<tr>
<td>Please specify professionals</td>
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</tr>
<tr>
<td>Other health professionals eg dietician, audiologist</td>
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<tr>
<td>Please specify professionals</td>
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</tr>
<tr>
<td>Other hospital outpatient Please specify which</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital inpatient stays</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How many hospital stays?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total number of days in hospital</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Please tell us about any other health care you have received, For example
• A&E
• private doctor or therapist
• complementary and alternative therapies
• Other *(please specify)*

<table>
<thead>
<tr>
<th>Tick if used</th>
<th>If yes, what services?</th>
<th>How many times?</th>
<th>Reason</th>
</tr>
</thead>
</table>

Reasons:

1: Health issue – New problem
2: Health issue – Old problem
3: Other reason – please state

Because of your brain injury, have you had help from **social care services that you have paid for?**

<table>
<thead>
<tr>
<th>If yes, what help?</th>
<th>From whom?</th>
<th>How often (on average)?</th>
<th>How long does the contact normally last for?</th>
</tr>
</thead>
</table>

Because of your brain injury, have you had help from **social care services that you did not have to pay for?**
(NB Include reablement team here)

<table>
<thead>
<tr>
<th>If yes, what help?</th>
<th>From whom?</th>
<th>How often (on average)?</th>
<th>How long does the contact normally last for?</th>
</tr>
</thead>
</table>

Because of your brain injury, have you had help from **voluntary agencies that you have to pay for?**

<table>
<thead>
<tr>
<th>If yes, what help?</th>
<th>From whom?</th>
<th>How often (on average)?</th>
<th>How long does the contact normally last for?</th>
</tr>
</thead>
</table>

Because of your brain injury, have you had help from **voluntary agencies that you did not have to pay for?**

<table>
<thead>
<tr>
<th>If yes, what help?</th>
<th>From whom?</th>
<th>How often (on average)?</th>
<th>How long does the contact normally last for?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question</td>
<td></td>
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<td></td>
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<tr>
<td>------------------------------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Because of your brain injury, have you had help from <strong>friends and family that you did not have to pay for?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If yes, what help?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>From whom?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often (on average)?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Estimate of amount of time that has been required:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Questions for relative/significant other (if applicable):**

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you <strong>stopped doing</strong>, or are you spending less time doing, something that was part of your previous routine, as a direct consequence of providing support or to carry out care activities since your relative’s discharge from hospital?</td>
</tr>
<tr>
<td>If yes, in what way?</td>
</tr>
<tr>
<td>How much time would you have been spending on these activities, (which you are no longer doing in order to support your relative)?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you <strong>taken time off work</strong> as a direct consequence of providing support or to carry out care activities since your relative’s discharge from hospital?</td>
</tr>
<tr>
<td>Yes/No</td>
</tr>
<tr>
<td>How much time off?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have support or ideas from Bridges Brain Injury resources <strong>affected the ways in which you manage</strong> your time or approach activities with your relative, since their discharge from hospital?</td>
</tr>
<tr>
<td>In what way?</td>
</tr>
<tr>
<td>Description:</td>
</tr>
</tbody>
</table>
Summary of findings from ‘Health and Social Care Utilisation’ questions

Of the 13 people for whom complete health utilisation data were available, 12 had used their GP service since their discharge from hospital either by visiting their GP, phoning their GP or having a home visit from their GP, and 9 had had contact with a Community Rehabilitation Team (9 had seen a community physiotherapist, 5 had seen a community occupational therapist, 3 had seen a community speech and language therapist; none had seen a clinical psychologist). Nine of the 13 patients reported attendance at outpatient clinics (in addition to the Brain Injury clinic where these data were collected), and 3 patients reported that they had visited A&E since discharge.

Few people reported using social care or voluntary services: one person had one week of enablement for one hour per day; two people had support from the voluntary agency Headway. However, 10 of the 13 responders reported they had received help from family and friends for a range of reasons including personal care, emotional support, supervision, childcare, shopping and housework. Six family members reported they had taken time off work to support their family member since they were discharged from hospital (average of 4 weeks; range 1 - 8 weeks).
Staff e-bulletin

A news update for staff across King's Health Partners

20 August

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In This Issue

- Get a healthy heart on the London Heart Trail
- GP records to be added to KHP Online
- Trusts highly rated in PLACE
- UK first heart operation saves London’s Strongest Man
- King’s College Hospital welcomes new Non-Executive Director
- Excellent dementia care ratings for trusts
- Brain activity sheds light on ADHD persistence and recovery
- Unique child stroke service celebrates second birthday
- New Fertility Centre opens at King’s College Hospital
- Biomedical Research Summer School
- New 3D printer sparks ideas for patient care
- King’s College Hospital supports self-management for traumatic brain injury patients
- Elevier Outstanding PhD Thesis Prize winner
- Media Highlights
- Events

King’s College Hospital supports self-management for traumatic brain injury patients

The King’s College Hospital Major Trauma Centre is now the clinical partner in an important initiative which supports the self-management of patients with traumatic brain injury, starting in the inpatient setting and continuing when they have been discharged from hospital and are re-adjusting to life back at home.

Bridges Self-Management Limited is a social enterprise that has developed self-management support for people following stroke. This approach has now been adapted to help patients, their family and friends cope with the challenges of living with traumatic brain injury, and other long-term neurological conditions.

The project has involved specialist self-management training for around 70 multidisciplinary staff based at King’s College Hospital: in acute Neurosciences and Trauma, at the Frank Cooksey Rehabilitation Unit based at Lewisham Hospital, and at the regional branch of Headway, the brain injury charity.

In addition, two books have been co-produced with patients who have been treated at King’s College Hospital: an interactive book for patients, containing stories, tips and strategies from people who have themselves experienced traumatic brain injury, and a complementary book specifically for their family, friends and other supporters.

Patient and relative who have taken part in the project pictured above.

The intention is to sustain self-management support in acute, rehabilitation and clinic settings beyond the project, and extend to other services in the regional trauma network that works with King’s College Hospital.

The project is funded by a £70,000 Health Foundation Shine 2014 Award.

For more information about the work taking place at King’s College Hospital,
Appendix 2: Bridges Brain Injury project logical framework

**Overall goals:** (1) Patients and families feel more confident in coping with transitions between services and taking control of challenges after traumatic brain injury; (2) Staff use their time more efficiently by focusing on a collaborative model of care.

**Intermediate result:** Staff support self-management as part of usual interactions with patients and families, starting during acute admission after TBI.

**Objective 1**
Increase in multidisciplinary staff's confidence in supporting self-management.

**Objective 2**
Accessible resources & support to sustain the approach.

**Objective 3**
Facilitation for Bridges established across pathway settings.

**Moderating factor:**
- Organisational support
- Team cohesion

**Project intervention**

<table>
<thead>
<tr>
<th>Inputs</th>
<th>Activities</th>
<th>Outputs</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Co-design of self-management support resources with people and families after traumatic brain injury</td>
<td>- Deliver 3-stage 'Bridges' multidisciplinary training workshops: range of date and location options</td>
<td>- Numbers of staff attending 3-stage workshops and 'Brief Bridges' overview sessions</td>
</tr>
<tr>
<td>- Development of bespoke 'Bridges' training for multidisciplinary staff</td>
<td>- Publish and disseminate books to staff workplaces</td>
<td>- Numbers of patients and families Bridges approach implemented with and followed-up</td>
</tr>
<tr>
<td></td>
<td>- Maintain awareness of supported self-management by update communication</td>
<td></td>
</tr>
</tbody>
</table>

(Adapted from Goeschel et al, 2012)
Appendix 3: Outcome data

Staff training evaluation

Evaluation of changes in staff attitudes, knowledge and beliefs about supporting self-management

(Collated by Charlotte Glebocki, and Sophie Hobson, MSc students at St George’s University of London, supervised by Professor Fiona Jones).

Data Summary
Sixty-two participants completed the bespoke pre-training questionnaire at the Bridges Part-1 workshops, and 45 completed the post-training questionnaire (six were excluded from analysis who had not attended all training sessions).

<table>
<thead>
<tr>
<th>Role</th>
<th>Pre-training questionnaires</th>
<th>Post-training questionnaires</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Healthcare Assistant</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Nurse</td>
<td>18</td>
<td>5</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Psychologist</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Rehabilitation Assistant</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Speech and Language Therapist</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Voluntary Sector (Headway)</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>62</td>
<td>39</td>
</tr>
</tbody>
</table>

Reasons given (where available) for participants’ non-attendance at Part-3 training

<table>
<thead>
<tr>
<th>Reason</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bereavement</td>
<td>1</td>
</tr>
<tr>
<td>Sickness</td>
<td>1</td>
</tr>
<tr>
<td>Current workload too high</td>
<td>1</td>
</tr>
<tr>
<td>About to leave current job</td>
<td>1</td>
</tr>
<tr>
<td>No longer working within Headway</td>
<td>1</td>
</tr>
<tr>
<td>Nursing staffing issues</td>
<td>8</td>
</tr>
</tbody>
</table>
Beliefs, attitudes and skills in supporting self-management

The following statements showed significant change (pre- versus post- training; Wilcoxon Signed Rank test) regarding the individuals’ perceptions of whether they are able to support self-management:

- I have the knowledge and skills to support any patient I work with in the self-management of their condition and everyday life ($p = 0.00$)
- I have the knowledge and skills to support most people with TBI to self-manage their condition and everyday life ($p = 0.001$).
- I have the knowledge and skills to support families of people with TBI to facilitate their family member to self-manage their condition and everyday life ($p = 0.001$).

Headway practitioners reported lower post-training confidence in their own skills and knowledge in supporting self-management, compared to acute and rehabilitation practitioners’ post-training confidence. A trend was seen across all confidence statements, whereby therapy staff had the highest levels of confidence, followed by medical then support staff.

From an analysis of 20 statements regarding supporting self-management, six statements showed a significant change (towards concordance with the supported self-management approach, after training):

- Educating people with TBI is the most important part of supporting self-management (fewer participants agreed with this post training; $p=0.004$)
- A specific time needs to be set aside to support SM (fewer participants agreed with this post training; $p=0.045$)
- It is important to guide people with TBI to set ‘SMART’ goals (fewer participants agreed with this post training. NB: ‘SMART’ goals are not considered consistent with the Bridges supported self-management approach; $p=0.006$)
- Practitioners should use their experience and expertise to direct the goal setting process (fewer participants agreed with this post training; $p=0.001$)
- It is important to advise an individual if they have unrealistic hopes about what they can achieve (fewer participants agreed with this post training; $p=0.004$)
- Goals phrased in the person’s own words can be more effective (more participants agreed with this post training; 0.01).

Barriers to supporting self-management

Practitioners agreed with 9 potential barriers to supporting self-management in the TBI population to a lesser extent following the training, compared to before the training. These barriers included: Person with TBI has a history of substance abuse; negative perceptions of supporting self-management within team; lack of support from team/management; person with TBI has severe communication impairments/is medically unstable/has co-morbidities/lacks skills or knowledge about their condition/is not engaged; risk-taking; and lack of time.

The proposed barrier for which a significant change ($p = 0.041$) was demonstrated from pre-to post- training was:

- ‘Self-management support is often not possible when a person with TBI is not engaged in their rehabilitation’.
The following additional themes arose from analysis of qualitative barriers given by practitioners:

- **Resources and sustainability**: Barriers regarding funding, resources and the sustainability of supporting self-management were predominantly mentioned post-training. Within acute setting staff, insufficient time, difficulty with judging timing of supporting self-management, and risk-taking were also raised.

- **Collective involvement**: Barriers were perceived relating to the collective involvement of the team of practitioners: the whole team’s engagement, working together and having a joint focus.

- **Family involvement**: Practitioners felt family members were either too involved but not facilitating self-management, or they were not engaged and not supporting the individual’s rehab.

- **Individual attributes**: The attributes of the individual with TBI (e.g. post-traumatic amnesia, reduced insight, ‘not being engaged’) and of individual practitioners (having a lack of skills or low confidence) were reported as barriers.

**Defining ‘supported self-management’**

Practitioners were asked to provide a definition of their own understanding of supported self-management. The following themes arose from thematic analysis of the responses given:

- **Shifting the nature of goal setting**: Practitioners spoke about goal setting in both pre- and post-training definitions, but a difference was seen in the way in which they did this. Post-training understanding emphasised the importance of meaningful goals, goals being broken down and the inclusion of individuals with TBI in the goal setting process. A shift away from an impairment focus was seen following the training.

- **Principles specific to Bridges**: Principles specific to the intervention: reflection, problem-solving, self-discovery, experimentation and risk-taking, were including in post-training definitions given by practitioners.

- **Self-efficacy**: Self-efficacy was a strong theme in post-training understanding of supported self-management. Prior to training social persuasion was valued as a source of self-efficacy by practitioners. Post-training a shift was seen, with practitioners more likely to focus on the mastery experience of the individual.

- **From giving to taking control**: A theme surrounding the idea of ‘control’ arose from analysis. Pre-training understanding emphasised the need for people to take control, but was sometimes paradoxical in saying that people ‘should adhere to a programme’. The focus of pre-training understanding was on the ways in which practitioners could give control, i.e. education and resource provision. Post-training understanding concentrated on the individual taking control, rather than the practitioners’ perception that they were handing over control.
Patient demographic and injury profile data

- Full implementation of Bridges package from June to August 2015
- Patients with whom Bridges Brain Injury implemented: \( n = 73; \) 67% male
- Consistent with higher incidence of TBI in males (Maas et al, 2008)

### Ages of patients introduced to Bridges Brain Injury - all project settings (n=73)

<table>
<thead>
<tr>
<th>Age Range in Years</th>
<th>Number of People</th>
</tr>
</thead>
<tbody>
<tr>
<td>16-21</td>
<td>5</td>
</tr>
<tr>
<td>22-30</td>
<td>7</td>
</tr>
<tr>
<td>31-39</td>
<td>15</td>
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<tr>
<td>40-49</td>
<td>25</td>
</tr>
<tr>
<td>50-59</td>
<td>10</td>
</tr>
<tr>
<td>60-69</td>
<td>7</td>
</tr>
<tr>
<td>70-80</td>
<td>7</td>
</tr>
</tbody>
</table>

### Ethnicity across all project settings

The majority of people introduced to Bridges identified as White British (48%) but there was a mixture of ethnicities and 32% of people did not have an ethnic origin stated.
Falls were the biggest cause of brain injury for those introduced to Bridges at Kings (58%).

The majority of patients introduced to Bridges on the acute wards had a hospital stay between 1 and 5 weeks with a mean length of stay of 20 days.
Qualitative evaluation: staff

Staff feedback
There was some difficulty in scheduling interviews with staff as planned, and analysis for this summary was mainly derived from a OT trauma lead (Acute); OT rehabilitation lead (step-down unit); Rehabilitation Consultant, trauma nurse and Headway support workers. Whilst the number of interviews was disappointing, it does provide some depth and understanding of feedback generated in our post-implementation survey.

Headway staff also reported using Bridges both as a one to one approach and in a group setting and reflected on the benefit of discussing book content as a group:

“At the [Headway] centre, Bridges reading groups are semi-structured sessions, members take turns to read sections aloud with breaks taken spontaneously allowing people to speak about a related theme, topic or experience”.

“Across all groups it has been noted by staff how individuals have used the space to have ownership of their experience by vocally expressing their stories in a non-judgemental and sympathetic space”.

Staff who took part in the training and facilitated the groups also felt they had gained more insight about the impact of brain injury by reading the stories:

“Reading the two books in my role as keyworker at Headway was valuable; having not worked with people with brain injuries before they were a concise exposure to a wide variety of individual experiences. They represent a very raw human face of acquired brain injury, which for me is directly relevant as I work with individuals and not textbook case studies”.

Further analysis involved interpreting the mains ideas and messages across the data set. The main emerging themes were ‘common language and common understanding’; ‘stories and small steps’; ‘who is ready and when to use’; ‘changes to practice’.

1. ‘Common language and common understanding’

Staff reflections on Bridges training and how they had used some of the principles revealed some subtle changes in language and approaches to supporting people with TBI, in some cases the changes become a natural way of working.

“I think that actually once you start working in this way, it becomes self-sustaining because you get into a pattern of working where I have seen positive changes and positive results so I have carried on doing it. It is not something that I have sat down and thought, “I need to be all Bridges about this”; it is a natural thing to do once you get into the habit”.

“We now have a consistent approach in how we manage and support those patients and families who present with mild/moderate brain injuries. The approach has assisted us in increasing our multidisciplinary team-working when discussion implementation of the book and it also means the language and approach is the same. Our approach is now more patient focused rather than professional driven, with the focus being around individual treatment plans rather than therapy plans with a potential agenda”.
A lead trauma OT also highlighted one of the key principles of Bridges approach to self-management support and how it had stuck with him.

“The term ‘self-discovery’ has really stuck. I think it describes really well the experience a lot of people go through understanding their own injury, how it affects them and how they will cope”.

2. ‘Stories and small steps’

The TBI book and friends and family books were appreciated by staff as a tool to support self-management and they gave various examples of the impact of using different sections:

“It has been noted by staff how individuals have used the space to have ownership of their experience by vocally expressing their stories in a non-judgemental and sympathetic space”.

“It was about the little steps as well. She was working before as a playground supervisor and she couldn’t see how she might be able to get back to that. All she could do was see how far away she was from that, and not how to get there. So it was very much a case of breaking it all down into little goals, she responded well to the idea that these were little steps towards her bigger goals”.

A lead rehabilitation Occupational Therapist also reflected on the impact the stories in the TBI book had on the way in which family members approached rehabilitation:

“There was a young guy here, he was assaulted, and Bridges was really good for him and for his family, because they were a bit like, “Look, poor D, this has happened to him, and how are you going to fix it?” and by the end they were very much, “Come on D, what are you going to do mate, you are the one lying around here in the bed all day, what are you going to do to fix it?” And they really liked it, in fact they asked for several copies of the Bridges family book, because they were separated and so the dad read it and said, can I take one for his mother as well, and they responded really well to that. And D himself did actually sit and read his book”.

The family and friends book was felt to be a useful additional resource particularly in the acute setting:

“With the family book this also gives us another dynamic and we now have a tool to educate family members when their loved one is going through a very distressing phase of their injury”.

3. ‘Who is ready and when to use’

Staff training sessions often generated discussion about the readiness of patients to take on the concept of self-management particularly in the acute setting. Distinctly different views and experiences were expressed by staff:

“I introduced the book and talked through with her the part of the book where she could write down her own thoughts and feelings. The next day when I saw her, she said that she had not been able to sleep overnight, and she had decided to write
down in the space about what she hoped to do next in her life. And she had written down that she would like to do a knitting course, she thought this would be able to create a kind of job where she could make some toys or other things. She had found that very helpful because she couldn’t sleep, and then looked back later on what she had written down during that time and was amazed at what she had managed to write there. This would have been around one week after her brain injury, while she was here in one of the Neurosurgical wards”.

“My primary difficulty with implementing Bridges is that within the acute phase of TBI the majority of patients whether they are mild or moderate are not yet ready to access it. In addition the main population of TBI (young adult males) can be very dismissive of booklets and these individuals require more individually tailored therapy programmes within the hospital phase. I think following discharge home and a period of self-discovery they will be ready to access the booklet so providing it is important but it is the community or clinic teams who will see the most gains and participation from patients”.

The different experiences and concerns represented in the two quotes above reveal how staff perceive the challenges of introducing self-management support. It also illustrates how some staff have introduced Bridges without concerns about whether it is the ‘right time’, with positive results. These examples will be extremely useful as training tips in future work to sustain and integrate this approach in the acute setting.

4. ‘Changes to practice’.
Our pre- and post-training questionnaires showed distinct changes in practice reported by staff. The following two examples from a lead OT and Doctor illustrate how practitioners realised how their own attitudes may not be conducive to self-management. This requires an openness on the part of the practitioner and critical reflection on their interactions with patients:

“I think that there is an element where we to want to rescue people. Having been on the Bridges training, that is definitely something that has changed for me. I push things back into people’s own courts a lot more. When they say, “This isn’t going to work, and this isn’t going to work, and this isn’t going to work...” instead of coming up with 50 solutions”.

A rehabilitation physician from the inpatient rehabilitation unit reflected post-training on some key changes she felt that she needed to make to her own practice to achieve a more person-centred approach and provide more opportunities to support self-management, they included:

“Letting the patient try and taking some risk is necessary for awareness improvement’

“I need to spend more time in asking before prescribing and for having a peer discussion with patient and family, rather than speaking only on clinical matters”.

Finally, two further issues of note were raised in addition to the general themes:
1. The way in which the TBI book embodies an approach to patient engagement in self-management

“Indeed, the patient book is what impressed me the most. I understand that it is just one of the tools however I feel that in some cases it might be the key for patient engagement. It is doubtless successful in getting patient awareness, helping them finding solutions, and supporting them through other people who had same experience - rather than providing formal advice coming from a clinician who has only indirect experience. For a similar reason we decided to leave some copies of the patient book in the ward day room, for free consultation”.

2. The need for more staff to be trained and able to share a similar approach to self-management

“When I’m back on the ward banging on, gently, on my own, it is not quite the same as going on a whole afternoon of everyone talking about this in the training. You have to go back and actually give it a go”.
Qualitative evaluation: patients and families

Patients and Family feedback
Feedback was collated from people with TBI, friends and families experiencing Bridges in either an acute hospital, rehabilitation in-patient ward, or Headway community setting.
Data were retrieved from a number of different sources, including transcribed interviews, feedback sent by email, group discussion. Overall people with TBI and their family members were positive about how all or part of the book could be used. Most felt that the books could be useful at any time, just one family member expressed concern about being given the resources too early. They were worried when they read a story of someone not getting aftercare for their brain injury, and feared this might happen to their relative.

Analysis was carried out using a modified thematic approach, which involved coding and categorising responses and interpreting the main ideas and messages across the data set. Four main themes were evident and illustrated the different ways in which people and their relatives had found the book useful. Very few gave feedback about how the staff had approached their care, other than to comment on the support they had received. One of the contributors to the TBI book also reflected on her thoughts about being involved in the project which provides a useful overview as someone who is both recovering from TBI herself and supporting others through her voluntary role with Headway.

“The thing is these are real people and this is what happened to them. I think it is great that it is offered to people, and you can actually say, 'Here is what people have gone through' and also for friends and family, because maybe the person would not be ready for it straight away. I think that the book itself is good to take to people and just show them. They can skip through different sections, without too much information crammed into one page.”
Summary of themes from patient and family feedback

1. Helping acceptance and understanding ups and downs
There were a number of accounts of how the Bridges TBI book had helped see a path to becoming normal again. One 19-year-old male reported how reading the book had helped him feel comfortable:

“This book makes me comfortable because when I am reading it is just me and the book. The reading makes me more comfortable. The stories are good; they make me feel I don’t have to hide anything. The more I read how they had head injury, the more I can open up. The more I can compare myself to them”.

Another person felt it had helped even if they had sustained brain injury through a non-traumatic cause:

“One of the things I find is…it is not about me…you know…this (pointing to the Bridges Brain Injury book) wasn’t about me…but of course it is about me, it is just in a different connection really”.

Reading the book also raised questions for some, particularly those who hadn’t received their brain injury in the same way as those in the book:
“I have found this book really good in parts, but have found it hard to pick up once I put it down. I cannot remember what I have read before. That’s the down side and it leaves you with a question about yourself: with such a minor injury, should I still be like this?”.

Family members reading through both books had some mixed views but overall felt it had helped then understand some of the changes they were seeing in their relative:

“I found the ‘Changes in your family member/friend’ most interesting. Can see that now, that everything is not 100%; without you reading, it would all come as a shock”.

“I can read out some of the stories in the book to him – there are some aspects of the people in there whose activities fall in line, not totally with [my son’s], but in line with how to think about moving forward on this”.

People also talked about using the book to try and understand their own experiences and find ways around different challenges.

“I tend to look at other peoples’ experiences, see how they resolve their issues and try and transfer it to my situation. Try and…might be bad to say this…but try and see how my life isn’t so bad. They have gone through more than I had”.

2. You are not alone - ‘picking out someone like you’

The way in which people with TBI their families had used the stories of other people in both books was evident throughout the interviews and feedback. They took comfort in reading about others and gained ideas about how to resolve problems:

“I tend to look at other peoples’ experiences, see how they resolve their issues and try and transfer it to my situation”.

“I find some comfort in seeing how they progressed and knowing that hopefully I will progress in the same way or even better. That encourages me”.

“Yeah, like the story of some people in the book…that had brain injury. When I go through it…that helps me. Like the story of somebody…John. He was married with two grown up daughters. He was hit by a car”.

Families also appreciated reading about how other families had coped, finding similarities with their own experiences:

“I liked the way that it stressed that it is not just something affecting the person with the brain injury but also the family, because at first you don’t think anyone has realised that. You think that it is just you, so it is nice to hear about other families’ experiences. Without those stories, I would not have thought about other people and what they went through – you feel at the time that it is just you going through these things. So it puts it into perspective”.

“One lady in the family book talked about the support in the family room in ICU and talking to other people in there – that was very true, I very much related to what she was saying about that. I felt safer in the family room, I felt as if I was understood,
when I chatted with the other people. So the Family book as well would have been very useful [if it had been available] at the beginning, definitely”.

3. Should give the book to everyone - 'a guide to life'
Although there some mixed feelings were expressed about when the book might be useful for people with TBI, overall there was support for the Bridges approach and use of the books. Some families felt that the TBI book was more useful for them in the earlier stages than for their family member:

“This book [patient-held book] is not pointless for us at this stage, this might actually be more helpful for us now, than it would be for him”.

“I think you should have this early on in rehab. Small steps - don't be too hard on yourself. When writing down future hopes and plans, try to take small steps at this, otherwise disappointment will creep in…. We should get this in patients’ thoughts early, I cannot stress this enough. The only way I am going to know if this works is to try it”.

“We didn't have the Bridges book then [not available prior to the discharge home] but it would have been useful especially during those weeks when we just did not know what to expect and I was very worried. It would have been good to know how other people had coped with similar situations”.

“There was the example of the lady in there who broke it down, with her sister, when she started going out on the bus on her own. The stories as well, in both the books, would have been useful at that stage to help me step back a bit more and let P do more himself. As a family member I think you worry all the time. I felt more reassured after I had read other people's stories and their experiences. When I read the second book [the Family and Friends’ book] I also had more of awareness of the fact there was light at the end of the tunnel, as someone put it in there”.

People seemed to find different parts of the book helpful, and had used it various ways:

“I really like the tips and reading through other peoples' stories and you can look and see where they are now. I think it could be used before or after activities we do at the moment. We can sit down and have a look through the book and have a discussion. I like it that they can see my story in there too…to see how far I have come now”.

“I know that J has been writing in the Bridges book, she has been writing day-to-day things that she has been doing, and about how she has been feeling. I haven’t actually looked at her book myself, but she has definitely said she has found that useful, yes”.

4. Helps to remember targets, goals and plans
The way in which people had used specific techniques to remember and plan was evident: making a plan, reflecting on how they had been doing and setting targets are key parts of the Bridges programme. Some spoke about how they had used the book to help them do some of these strategies.
“I write bullet points down now and it opens the door for more conversation with people that way. So that is a great point. From someone that never used to take notes, or was that way inclined…I would have never done that before”.

“This is very true, the achievable small steps, yes I do that. You have got to be realistic about what you can do and what you can’t, and break it down into what you can do. Like the digging a small square and then the next day she [Sarah in book] did more, yes I work up to it like that. I plan more carefully, what I want to do now. It might take me three days to do I job I want to do, but I get there. You have to be realistic that you can’t do it all – you want to, but you can’t do it all at once”.

“I found that book [the ‘Building Bridges after Brain Injury’ book] really interesting because we are now looking after the event, and it was about people’s goals as well, what they are achieving, how they are moving forwards”.
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