



## Coventry & Warwickshire Cardiovascular Network

### SUMMARY REPORT

#### SELF MANAGEMENT FOLLOWING A STROKE USING LIFESTYLE MANAGEMENT

##### AIMS OF PROJECT

The aim of this project was to deliver and evaluate a course of supported self management following a stroke. This generic course was developed by the Thistle Foundation and is 'lifestyle management course' which could be tailored to meet the needs of stroke survivors. Local health care professionals were skilled in the methodology to enable sustainability of the programme.

The project had two objectives:

- To aim to help those affected by a stroke to improve their health and well being by using coping and mindfulness strategies to gain control of their situation to enable recovery. By using tailored strategies, enable stroke survivors to boost their confidence and self esteem and thereby enhance their ability to better manage their condition.
- To skill the workforce in the methodology enabling escalation of the skills and sustainability of the programme.

##### METHODS

The Coventry and Warwickshire Cardiovascular Network took lead responsibility for managing the project and ensuring its delivery.

This included, commissioning the programme, enlisting support from appropriate agencies, liaising with relevant people, organising and facilitating meetings, a communication plan with course publicity material, development of information packs, promotional material, organising courses, sourcing and organising venues, catering, seating arrangements, arranging for hearing loop facilities, recruitment of staff and stroke survivors to the courses, arranging attendee 1:1 consultations, sending out confirmation packs – letters, paperwork, maps, details

of dates, time, venues along with managing, facilitating and overseeing the process throughout the duration of the project.

Coventry University were commissioned to lead on the evaluation this included; development of outcomes questionnaires, data collection, running two focus groups, data analysis and the production of a final report (appendix 1).

There were several stages to the project. First, a 2 day solution focused brief training course was offered to health professionals working with Stroke patients across the Networks geographical area of Coventry and Warwickshire.

### **Solution focused brief therapy training (SFBT)**

The course was aimed at health care professionals working with stroke survivors. Health care professionals from across the disciplines, who attended, were taught to use a range of strategies to facilitate brief therapy with stroke survivors:

- Engagement - by seeing the person not the problem
- Listening - by the use of constructive listening
- Best hopes - what does the stroke survivor hope to achieve in terms of working together with a facilitator
- Focusing on the future/preferred future by stroke survivor
- Introducing conversations around self management with stroke survivors
- Eliciting stroke survivors own views about resources and self management strategies
- Focusing on small improvements, learning and insights
- Relapse management
- Giving information
- Negotiating end of support
- Future contingency planning

To publicise the course; flyers, posters, registration forms were developed and circulated widely across the NHS provider units.

22 staff registered for the course. The full 2 day course was completed by 17 staff from across Coventry, Warwickshire and Solihull from a range of services: occupational therapy, speech and language, clinical psychology, IAPT, physiotherapy. All staff completing the two day course received a certificate of attendance.

All staff completing the SFBT course were asked if they would be interested in being involved in the 10 week lifestyle self management course. Having basic insight into SFBT and 'belief' in the approach were felt to be important factors in facilitating delivery of the self management course.

### **10 x week Supported lifestyle self management course**

Two lifestyle self management course were delivered:

Course 1 dates: 11<sup>th</sup> October 2011 – 13<sup>th</sup> December 2011 (10 weeks duration)

Course 2 dates: 24<sup>th</sup> January 2012 – 13<sup>th</sup> March 2012 (8 weeks duration)

Health care professionals (4 facilitators) trained along side Thistle Foundation staff for the full duration of the course.

The course was essentially a health and lifestyle management course aimed to provide support to Stroke survivors and carers using discreet strategies entailing:

- Enablement and empowerment
- Compassion
- Holistic approach
- Partnership
- Personal outcomes
- Strength/asset based approach
- Facilitation
- Community networks
- Risk enablement
- Feedback

3 staff were enrolled as facilitators onto the first 10 week course

1 staff (+ 3 original staff) were enrolled as facilitators for course 2

1 staff attended a few sessions of course 2

Staff interested in training as facilitators had to obtain permission from their managers to be released from their work environment. This proved to be problematic, mainly due to the length of the course as support was sought not only for the first 10 week course but also with the subsequent course. The course length at the time had not been finalised as much was dependent upon feedback from participants in course 1. However, it was made clear that course 2 may be reduced to 8 weeks if appropriate.

Two facilitators participated 'in their own time' and 2 were able to gain support from their line managers.

### **Recruitment strategy for stroke survivors to participate in course 1**

A range of approaches were used for the identification of participants to the course.

The support of the Coventry and Warwickshire Cardiovascular Network Clinical lead, based at University Hospitals of Coventry and Warwickshire (UHCW), and the Stroke consultant at South Warwickshire NHS Foundation Trust Hospital (SWFT) were enlisted, as the plan was to

focus on patients in Coventry in the first instance. This was later changed and the Stroke consultant at George Eliot NHS Trust (GEH) was involved for the second stage course.

Packs were developed which included:

- Professionally produced leaflet by the Thistle Foundation which outlined the course, what to expect, description of what lifestyle management is and a guide to enable the reader to reach an initial decision as to whether the course was for them and contact details of how to find out more about the course
- Invitation letter signed by Consultants and the Coventry and Warwickshire Cardiovascular Network Director. The letter provided information about who was providing the course, benefits of the course, duration, dates, timing, venue, costs, gold star award upon completion, costs, contacts details of project lead and a guide as 'what to do next' if interested in the course
- A registration form to be completed if interested and details of who and where to return the form to as well as contact details for further information
- A pre paid envelope

An honorary contract was obtained through UHCW Research and Development Department for the project lead, as they did not work directly with Stroke patients and would need access to the hospital database. Patients were identified through UHCW internal Stroke register with support from UHCW Stroke data analyst who carried out a targeted search through the hospital database. A list of contact details of patients who lived in Coventry and Warwickshire and were 3 months post stroke was compiled. The list was checked for deceased patients who were removed from the list. Also, those that were out of area, living in nursing home or residential care we removed as it was not felt that these were appropriate attendees for this course at the time. Addresses were then written by hand on to each pack which were then posted from UHCW.

#### Inclusion criteria

- 3 months post stroke prior to starting the course(admitted to UHCW between March, April, May 2011)
- Living in Coventry or Warwickshire
- Aphasic, but could communicate with carer support
- Psychologically 'struggling' in some way (self recognition that they needed to learn how to deal with this)

#### Exclusion criteria

- Those with dementia or learning disabilities
- Those unable to communicate in English
- Living outside Coventry and Warwickshire

- Patients admitted June, July, August 2011 (not 3 months post stroke)
- Living in a Nursing Home or in residential care.

A total of 300 packs were distributed for course one. 210 invitations were posted via UHCW and 90 packs were distributed via other agencies, this included 30 packs via the council and 60 packs through community services by local clinical psychology consultants.

21 responses were received indicating interest in participating in the course.

15 stroke survivors and 6 carers participated in the course initially. However, 2 stroke survivors became ill and were readmitted to hospital, of these, one stroke survivor and their carer participated in the second course. The other stroke survivor was not well enough to participate in the second course either (also their carer did not attend the second course).

15, 1:1 consultations were booked for those able to attend which took place over 2 days in Coventry. This was designed to facilitate joint agreement as to whether the Stroke survivor felt they would benefit from the course in consultation with Thistle staff who led the 1:1 and telephone consultations.

4 telephone consultations were arranged with those not able to attend on either of the two dates provided.

13 stroke survivors and 4 carers therefore completed the full course.

**Additional methods used by Network as part of the evaluation process included:**

- Observational notes taken of all sessions
- Brief feedback forms distributed to all staff and participants following each session. This included views about what they had learnt and what had been different for them since the previous week.
- Video recording of sessions toward the end of the course to enable participants to say in private what they thought of the course and to ascertain what changes they had made. The vast majority of stroke survivors and carers took part in 1:1 video feedback opportunity.
- It is anticipated that 'select' clips from the video footage will eventually be put onto the Coventry and Warwickshire Cardiovascular Network Website and Coventry University Website.
- Photographs were also taken at various sessions (consent forms developed for photography and video recordings were distributed and signed)

- The Coventry and Warwickshire Cardiovascular Network Associate Director visited the groups on several occasions speaking to staff, participants and course providers about how things were progressing and their experiences

It was not the original intention to offer the course to every carer, rather only those survivors that needed a carer present and those who said that they preferred to have the carer present. However, as the course progressed it proved to be popular and beneficial to Stroke survivors and their carers. Subsequently, when course 2 was organised, carers were actively encouraged to participate if they wished.

### **Reasons for not participating in course 1**

1 person did not wish to participate having attended the consultation

1 person had learning disabilities

1 person was not able to attend the dates that the course would be running

2 people wrote in and said they did not wish to attend but thought it was a good idea

2 people had been 'accidentally' contacted but had since died.

### **Course 2 - Supported self management**

The course structure, venue and recruitment strategy was changed for course 2 in light of the learning generated from course 1, also as a cost saving measure.

A targeted approach was adopted for recruitment as it was decided that we would run the second group with less participant numbers, partly to support our own facilitators in running the course and it was held in a smaller venue. Anticipated sample size for course 2 was 6 stroke survivors and 3 carers. This enabled our newly trained course facilitators to practice with a small group and perhaps be a more accurate reflection of group sessions run by the NHS.

- Course facilitators who participated in course 1 sent invitation packs to stroke survivors whom they had contact with and felt would benefit from the course. Packs were therefore sent from UHCW, community rehabilitation in Coventry and South Warwickshire Rehabilitation hospital.
- One participant from course 1 also identified a contact but she decided not to participate as she had made a full recovery.

11 stroke survivors and 7 carers expressed an interest in the course and returned a reply slip. 6 stroke survivors had a 1:1 consultation.

1 stroke survivor had another stroke the day before the consultation

1 stroke survivor did not have a consultation but agreed to participate following conversations with the project lead and researcher but subsequently dropped out as she felt unable to participate due to her speech difficulties. Her carer was most disappointed as he was keen to be involved.

1 stroke survivor declined because they decided to take up a course offered by the Stroke Association. However, they subsequently changed their mind and 'turned up' on the day.

1 Stroke survivor dropped out having attended the first few sessions.

7 stroke survivors and 5 carers completed course 2

It was interesting to note that carers seemed to benefit immensely from the course. Many wanted to 'help' in some way. One of Stroke survivors for instance, mentioned that 'The Opal Centre' was a good venue, and shared contact details of who to contact as he ran a Stoke support group at the centre.

One carer and Stroke survivor found the course so beneficial that they wrote to the local MP and the Health Secretary, Andrew Lansley suggesting that the course be made available to all Stroke survivors and carers as part of the NHS service delivery.

Another provided a lengthy summary to the project lead detailing each week what he and his wife had gained from the course. The course also appeared to have a huge impact on carers' mental health and well being.

## RESULTS

### COURSE 1

Stroke survivors and carers reported that the course was excellent and all participants had made some changes in their daily lives as a result of tools and techniques they had learnt and adopted.

Indeed, the participants of course 1 found the programme so useful that they 'secretly' arranged to write a special thank you note to the course providers and had the comments made into an A3 poster and framed. This gift was presented to the course providers at the last session. A copy was also made for all staff involved in the course as a thank you gesture from the participants.

Group members formed strong friendships and one member suggested that contact details of all participants be collated and distributed among the group. A list detailing name, telephone number and email contact was put together and given to all participants. The group intends to meet up and keep in touch with each other. This will become a self supporting support group in the community.

Staff and participants all spoke highly of the course and many expressed that it was 'excellent'. Two participants stated from the outset that they felt they would not gain anything from the course as they felt that they were much further ahead in their recovery than other participants, yet both attended all 10 sessions, completing the course and reported making changes in their lives.

### Stroke survivors

#### Expectations of course:

"To resume a near normal life a possible"

"To have a better quality of life"

"Share stories"

"Getting ideas from others"

"To go out more. I live on my own I feel lonely, but if I go out I fall over because people bang into stick and you can fall over"

"To get on a bus hopefully"

"To help others and help myself"

#### Some comments: What did you learn today?

"That I was actually coping quite well, although it is very hard work indeed (wk 2)"

"We all share similar problems and feelings" (wk2)

"How to manage stress and symptoms, to break the cycle" (wk 3)

“Prioritising and getting things done that are meaningful done first (wk 6)  
“Learnt how to cope better with my speech difficulties” (wk 6)  
“To do the important things first” (wk6)  
“To take control of the situation” (wk7)  
“My communication style is definitely passive, and I wish I could change it to more assertive style” (wk 7)  
“How to deal with negative thoughts and to achieve better communication” (wk7)  
“To listen to what my body is saying and being able to say ‘no’ in a sympathetic way” (wk7)  
“Stones are more important than sand, deal with them first” (wk7)  
“How mind over matter can create positive or negative feelings” (wk8)  
“It’s all about PATS not NATS” (wk8)  
“The importance of reinforcing the thinking and how it can effect lifestyle” (wk9)

Some comments: what had been better since the previous week?

“Before now I felt the door was closed; now I feel it has been opened, it has certainly lived up to my expectations”  
“To control breathing and do exercises to help relax and sleep” (wk 2)  
“X been promoted to 3 wheeled walking frame from four” (wk2)  
“Got on a bus” (wk2)  
“A feeling of family unity, how we can help each other just by being part of the group” (wk2)  
“Group therapy is very helpful” (wk3)  
“My breathing is much better” (wk 3)  
“Slept for 5 hours, best in long time” (wk3)  
“Sense of achievement, relaxation” (wk3)  
“Feeling more purposeful” (week 3)  
“I have learnt to pace myself (wk6)  
“Pacing oneself and breathing exercises producing calmness” (wk 6)  
“Satisfaction in working although only a few hours” (wk 6)  
Working in the garden” (wk6)  
“Feeling less tired” (wk6)  
“I am more relaxed” (wk 6)  
“Not so many tears – breathing” (wk6)  
“For the first time since my stroke this morning I walked 8 steps with the help of only a walking stick” (wk7)  
“To practice what I have been taught” (wk 7)  
“Being calm when on the move” (wk 7)  
“My post stroke feelings are allowing me to put myself before others in certain situations” (wk7)  
“I have thought more about the importance of day to day activities, this has helped me cope” (wk8)

“I had a more positive approach to my walking” (wk9)  
“Sharing experiences with others” (wk9)  
“My ability to cope with stressful situations” (wk9)  
“Exercise is giving a sense of achievement” (wk9)  
“Putting into practice mindfulness” (wk9)  
“Still no tears” (wk9)

#### Some comments reported by participants (wk 10)

“It enables me to sleep”  
“It’s made me more inspired and motivated to keep going”  
“First time in 6 months my desk is clear, I have been able to concentrate”  
“You have to set targets, I must, I can, I will”  
“Seeing other people have achievements make me want to achieve”  
“Without the course, I don’t think I would have made the changes, I don’t know what will happen when the course ends”.

#### Words to describe the sessions:

‘Inspiring’, ‘motivating’, ‘excellent’, ‘look forward to it’, ‘blessing’.

#### **Carers**

“That I am tired and exhausted and I need to take some action to get hope into the picture again”  
“Gave us confidence in the course and the belief that considerable benefit was to be gained from it. It made us enthusiastic about attending the course.  
“Having now attended 8 sessions, I found it tremendously beneficial”  
“I have been better rested and less stressed...I feel better now as I don’t feel guilty when I go out for 2 hours a day” (wk8)  
“I found the importance of positive thinking and idea of contingency plans very useful. The manual has been very useful, particularly relaxation and belly breathing” (wk9)  
“I did not originally intend to attend, as I thought it was inappropriate for a non-stroke survivor to participate, however, the team told me I was very welcome. I wish I had attended the previous sessions” (wk9)  
“It has impacted positively on the quality of our lives”

#### Attendance

The number of carers who also participated gradually increased from 4 carers to 6 in course 1. This was because they had learned from their partners how useful the course was and asked if they could also take part. Due to sickness the number of participants did reduce, however, 13 stroke survivors and 4 carers completed the course.

A register of attendance was kept. None of the staff missed any sessions. Attendance by Stroke survivors and carers was overall very good. Although there were some absences, these were largely due to Stroke survivors being ill or being readmitted for Stroke, seizures or mobility problems missing several weeks of the course.

One stroke survivor and their carer who attended the first three sessions but subsequently unable to attend due to hospitalisation, was offered the opportunity to attend course 2 which they accepted.

## **COURSE 2**

### Course structure

It was decided from the outset that the second course would be run with a much smaller group of participants in order to make the whole process more manageable for our new facilitators and also, because it was felt that the group sessions would in future be much smaller within an NHS setting.

Input from the course providers (Thistle Foundation) was also reduced to 5 sessions to enable our newly trained staff to take a more active role in facilitation and leadership. Our newly trained staff also had access to a further half day of mentoring support from the Thistle Foundation.

Unlike course 1, lunch was not provided, however, an opportunity to meet at the end of the session was incorporated and participants were requested to bring a light lunch with them.

However, the course was oversubscribed with 18 participants expressing in interest in attending course 2, this included, 11 stroke survivors and 7 carers.

Participants and carers from course 1 were very keen to provide support for course 2. They were slotted in to relevant sessions where they had an opportunity to share their experiences with the group. One carer attended 6 of the 8 sessions and 3 stroke survivors attended single sessions and spoke about their experiences.

### Attendance

A register of attendance was also kept for courses 1 & 2. Overall, course attendance was very good. Attendance by staff was excellent, despite some staff using their own time to attend. 4 members of staff supported the 2<sup>nd</sup> course.

Attendance from Stroke survivors and carers was slightly problematic with course 2. Despite concerns about the course being over subscribed, participants did 'drop out'. However, like course 1, lack of attendance was primarily to do with ill health and continued health problems as opposed to lack of interest in the course:

- In 3 cases, the patient was ill from the start of the course and was not well enough to attend.
- One stroke survivor attended only the first session due to speech difficulties, the stroke survivor felt unable to continue.
- Another stroke survivor only attended the first two sessions but then decided to withdraw as she found it challenging.

#### Views about the course

The second course, like the first, provided much support, inspiration and a valuable means of coping and getting on with life after a Stroke for Stroke survivors and their carers.

Indeed, participants were already speaking positively having only attended one session the previous week.

A number of people for instance, were already talking about feeling “uplifted” as a result of attending the first session. Some had even managed to go out socially which lifted their spirits.

For instance, at week 1, participants reported wanting “to have a better quality of life” and “to be more confident”.

In the final session, participants reported that they were:

“able to things they were able to do before”

“go out in groups”

“relaxing was getting easier”

“staying calm and reacting less”

“it shows that you can do more”

“the group has taught me a lot of things like the need to be positive”

“planning”

“putting first things first” and thereby learning to prioritise what is important

There were high levels of satisfaction and feelings of improved performance from both stroke survivors and carers.

#### **Facilitators**

Feedback from facilitators was also very positive throughout the course despite concerns about changes to the structure of course 2.

Feedback from facilitators was also positive, both in terms of the benefits for Stroke survivors and carers but also in terms of the benefits they themselves experienced as a result of participating in the course and changes in their working practices.

Overall it was felt that all participants have made positive changes, it helped people discover their personal strengths and resources proving to be a useful support network even after the course was completed.

One facilitator commented:

“One of the most striking things for me is that we saw people who have been discharged from existing therapy services - and they may have reached all therapy goals and as professionals, we would feel that is a good outcome”.

Other comments include:

“It (course) has the potential to change the emphasis of patient expectations – that they expect the therapists to “fix their problems”

“The approach of the course is the complete opposite, its supplies them with the means to move forward”

“I enjoyed all aspects, especially experiencing deep relaxation and the group’s feelings about what makes a good listener”

“The great benefits of relaxation and breathing and putting them into practice myself, mindfulness and its advantages”

“Taking part in presenting and positive feedback, listening to positive experiences from participants – profound!”

“My strengths in presenting and facilitating”

“About putting most important things into my diary first and letting everything slot a mind of its own”

“Looking at what is really important in life and how to manage this”

“Relaxation sessions – great for staff too”

“Importance of not reacting, give things thought first”

“Watching the group interact with each other without much prompting” (enjoyable)

“I enjoyed listening and being part of the inspirational accounts the participants shared about their experiences and how the course has helped them move forward”

“Watching reactions to sand/stone demonstration” (prioritising)

### **Lessons learnt**

A considerable amount of time was spent enlisting support from GEH and SWFT and UHCW. This involved writing letters, obtaining electronic signatures and approval from consultants. Despite the support of consultants it was unfortunate that requests for packs to be sent out to Stroke patients were not met due to demands and pressures working within an acute trust setting. However, this turned out to be for the best, as our facilitators had developed good relationships with their clients and recruitment to the second course was far more cost effective.

### **SUSTAINABILITY**

The Coventry and Warwickshire Cardiovascular Network, in collaboration with Community Neuro Rehabilitation Services, and UHCW will embed the learning into practice.

This will be done by generating funding through different sources; HIEC, Warwickshire County Council, Coventry City Council and the Coventry and Warwickshire Cardiovascular Network. Future funding will be used to deliver 4 SFBT 2 day courses over a two year period for other staff groups, embedding the methodology across the service and providing a wider pool of possible facilitators. Embed the process for referral and establish a clear pathway across the NHS and Social Care. Deliver education awareness events to raise the profile of the availability of the Lifestyle Management course, who would benefit from attending and the methodology. Develop a ‘train the trainer’ course in conjunction with the Thistle Foundation and develop our own Stroke specific course material with an evaluation process for feedback and improvement.

The local Community Neuro Rehabilitation service have already started to use the approach in their daily practice. UHCW have purchased 50 manuals directly from Thistle Foundation and are already applying the practice with other conditions such as Fatigue. They will be conducting their own evaluation of using the course with different conditions next year.

### **CONCLUSION**

Overall the project and the courses proved to be hugely successful with both the participants and staff.

Looking at best hopes or expectations, many participants had achieved what they hoped to get out of the course or were now much further ahead in their journey in terms of reaching their goals.

The course demonstrates that positive self talk, group work, with motivation and inspiration can genuinely affect people's mind-sets to improve their health and well being and cope better.

Facilitators in this project came from different disciplines such as speech and language therapy, community rehabilitation and occupational therapy. The methods used demonstrated that it can be tailored across disciplines and that many of the tools, techniques and approaches that are part of the course can be learnt and used by professionals from different backgrounds. It may be that, having prior knowledge of Stroke is not an essential criterion for learning and implementing solution focused brief therapy into practice.

The learning generated is already being implemented in practice and the service is well on its way to being embedded into service structures.

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