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# National Stroke Foundation Hospital Peer Support Program

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**A report on the Hospital Peer Support  
Program Pilot June 2008.**



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Tim Rechner – Stroke survivor and member of Boroondara Stroke Support Group  
Marc Skolnic – Stroke survivor and member of Boroondara Stroke Support Group and Australasian Aphasia Association



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## Executive summary

The Hospital Peer Support Program (HPSP) was developed and piloted by the National Stroke Foundation (NSF) as a strategy to provide timely access to psychosocial information and peer support for stroke survivors and carers as they transition from hospital to home. The program incorporated peer role models as powerful facilitators in delivering important information that the medical model of care often cannot provide. Such information included the transition home from hospital, what to expect from life after stroke and strategies to ensure quality of life.

Recent research by the NSF revealed that many stroke survivors reported they were under prepared (both mentally and physically) to return home<sup>1</sup>. Less than a third of stroke survivors felt satisfied with the information they received about stroke, stroke support groups and community services before leaving hospital. Only 23 % of carers reported satisfaction with the information they received about services community groups and stroke support groups.

Stroke survivors and carers also describe the importance of peer support early in the recovery journey<sup>2</sup>. Peers are highly accepted by fellow stroke survivors and carers and are able to provide social support, experiential knowledge and a social comparison<sup>3</sup> that the medical model of care is unable to provide. Hospitals however are often hesitant to permit unsupported peers to meet their patients due to concerns that the information provided may be inaccurate, inappropriate and/or potentially overstep professional boundaries.

In 2007 the NSF developed the HPSP with the support of an expert advisory committee consisting of stroke survivors, carers and health professionals. The HPSP provided one hour information sessions within six Melbourne metropolitan hospital sites. The sessions were co-facilitated by a NSF health professional and Peer Role Models (PRMs) and delivered psychosocial information about transitioning home from hospital to eligible stroke survivors and carers prior to discharge home. The pilot phase of the program ran from September 2007 to February 2008. Ninety four information sessions were offered. Only 47 (50%) information sessions were delivered reaching 83 stroke survivors and 38 carers.

The program incorporated a number of components: the development of a Peer Training Program (PTP); recruitment and training of PRMs (stroke survivors and carers from the community); development of the HPSP; engagement of hospital sites; recruitment of stroke survivors and carers within these sites; delivery of the HPSP information sessions; and evaluation via pre and post information session questionnaires, follow up phone interviews post-discharge from hospital and focus groups with the PRMs and hospitals' champions (health professionals who helped with the delivery of the program at a local level).

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<sup>1</sup> National Stroke Foundation (2007) Walk in our shoes

<sup>2</sup> National Stroke Foundation (2007) Walk in our shoes

<sup>3</sup> Solomon, P., (2004), Psychiatric Rehabilitation Journal, *Peer support/Peer provided services underlying processes, benefits, and critical ingredients*, Spring 2004, V. 27, N 4.



An evaluation process looked at the effectiveness of the PTP and considered the perceived value of the peer supported information session on stroke survivors and carers transitioning from hospital to home and the feasibility and sustainability of the program within the participating hospitals.

Nine recruited stroke survivors and carers completed the PTP to become peers and co-facilitate the program's information sessions. Evaluation of the training program indicated PRMs experienced a positive shift in stroke knowledge and increased confidence about co-facilitating the information sessions. Following the delivery of the HPSP, peers identified the training as a key factor of their success and reported they would not work as PRMs without this valued training. The peers also reported co-facilitation with the NSF health professional was crucial for support and their overall confidence in facilitation.

Prior to commencing the program, the hospitals' health professionals expressed concerns that peers may provide inaccurate and/or contradictory information and potentially overstep professional boundaries. Health professionals' concerns were alleviated by the knowledge that all peers would be trained and would co-facilitate the information sessions with the NSF health professional. After the HPSP it was felt that trained peers still required some support to ensure provision of accurate and appropriate information.

Despite the risk of PRMs providing inaccurate information, stroke survivors and carers attending the hospital information sessions considered their involvement to be a crucial component of the HPSP. Stroke survivors and carers valued talking to and hearing from the PRMs and, once discharged home, recalled their story before any of the key messages delivered in the session.

Another crucial component of the HPSP was the delivery of psychosocial information focussing on the transition home from hospital, what to expect from life after stroke and strategies to ensure quality of life. The information was delivered by both PRMs and the NSF health professional. The findings of the program indicated that both stroke survivors and carers valued receiving psychosocial information that may not otherwise be delivered by the medical model of care. Stroke survivors and carers also valued receiving contact details for the community services that could be accessed after leaving the supportive hospital environment. They reported this information provided the much needed reassurance and confidence that there was always someone they could turn to if needed.

An important aspect of the chosen model of delivery was the follow-up telephone interview. This provided stroke survivors and carers with the opportunity once at home to consolidate information shared during the information session and reinforce key messages.

The piloted model of delivery did have some shortcomings as indicated by 50% of offered information sessions being cancelled. The commitment of the hospital's champions was a key factor in the recruitment of the stroke survivors and thus the number of information sessions being delivered. In addition to this the availability of suitable patients on the days the information sessions were scheduled was also crucial to the delivery of the session. On one of the acute sites in the pilot, only 8% of admitted patients during the pilot were able to attend a session. This was perceived as due to the short length of stay<sup>4</sup> on the acute site



resulting in quick patient turn over which significantly impacted the stroke patients' ability to attend a weekly information session. This may represent an anomaly for Victorian acute facilities only and needs further exploration across the states.

Post program evaluation indicated that the participating hospitals would find it difficult to allocate people resources to independently deliver the HPSP information sessions. It also indicated they would find it difficult to recruit stroke survivors and carers from the community and deliver the PTP. It was unclear if these findings would be similar for regional and remote hospital sites across Australia and requires further exploration.

Further modification to the PTP is required to further develop future peers' skills in delivering accurate information to stroke survivors and carers in hospital. Further exploration is required to look at the different length of stay in acute hospitals across Australia and how this will impact on recruitment rates. The ability of different hospital sites to allocate the resources required to find community stroke survivors and train them to become peers and to independently run programs like the HPSP, needs further exploration.



## Introduction

This report presents the results of the Hospital Peer Support Program pilot.

### Hospital Peer Support Program

Recent research by the NSF revealed that many stroke survivors reported they were under prepared (both mentally and physically) to return home<sup>5</sup>. Less than a third of stroke survivors felt satisfied with the information they received about stroke, stroke support groups and community services before leaving hospital. Carers were even less satisfied with their preparation to go home. Only 23 % of carers reported satisfaction with the information they received about services community groups and stroke support groups. The Hospital Peer Support Program (HPSP) was developed and piloted by the NSF as a strategy to provide timely access to psychosocial information for stroke survivors and carers as they transition home from hospital. Psychosocial information included details of the local stroke support groups and their benefit, community services available, and information about some of the difficulties and frustrations typically faced by stroke survivors and carers when they first transition home from hospital including strategies to overcome these.

Another key component of the HPSP was employing peer role models as powerful facilitators in delivering important information. Stroke survivors and carers describe the importance of peer support early in the recovery journey<sup>6</sup>. Peers are highly accepted by fellow stroke survivors and carers and are able to provide social support, experiential knowledge and a social comparison<sup>7</sup> that the medical model of care is unable to provide. As Robinson (1998) states, 'experiencing a common circumstance or being in a common predicament can be a powerful component of healing'<sup>8</sup>. Peers can provide much need psychosocial information, peer support, encouragement, positive peer role modelling and strategies to cope with commonly faced challenges at home and in the community that is validated from their personal experiences of life after stroke. Hospitals however are often hesitant to permit unsupported peers to meet their patients due to concerns that the information provided may be inaccurate, inappropriate and/or potentially overstep professional boundaries.

This program was developed in response to consultation and feedback from stroke survivors and carers about the information and support they received after stroke. Stroke survivors and carers reported experiencing difficulties with finding information about stroke that might promote recovery and assist with dealing with the challenges they face when they leave hospital and return home and to the community. Stroke survivors and carers also

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<sup>5</sup> National Stroke Foundation (2007) Walk in our shoes

<sup>6</sup> National Stroke Foundation (2007) Walk in our shoes

<sup>7</sup> Solomon, P., (2004), Psychiatric Rehabilitation Journal, *Peer support/Peer provided services underlying processes, benefits, and critical ingredients*, Spring 2004, V. 27, N 4.

<sup>8</sup> Robinson R., & Murdoch P., (1998) Guidelines for Establishing and Maintaining Peer Support Programs in Emergency Services 2<sup>nd</sup> edition, Chevron Publishing Corporation



describe the importance of peer support early in the recovery journey. Many hospitals however are often hesitant to permit unsupported peers to meet patients due to health professionals' concerns that they may provide inaccurate and/or contradictory information and potentially overstep professional boundaries.

In 2007 the NSF developed the HPSP with the support of an expert advisory committee consisting of stroke survivors, carers and health professionals. The program provided one hour information sessions co-facilitated by a NSF health professional and Peer Role Models (PRMs). They provided eligible stroke survivors and carers preparing for discharge home with peer support, encouragement, positive peer role modelling, psychosocial information about the transition home from hospital and early stages of the stroke recovery journey, and strategies to cope with commonly faced challenges. The pilot phase of the program ran from September 2007 to February 2008 across six Melbourne metropolitan hospital sites.

### **Core Program Objectives**

The pilot program aimed to explore how the information and support needs of stroke survivors and carers preparing for discharge home might be best delivered focusing on the feasibility and sustainability of the chosen model of delivery.

### **Core Program Activities**

This program incorporated three core activities with a number of components:

1. The development and delivery of a Peer Training Program, including recruitment of stroke survivors and carers from the community.
2. The development and delivery of the Hospital Peer Support Program, including the engagement of hospital sites and recruitment of stroke survivors and carers within these sites.
3. Evaluation via pre and post information session questionnaires, follow up phone interviews focus groups.



## **Section one: Peer Training Program**

### **Introduction**

This section will describe the development and evaluation of the PTP. It also describes the recruitment of peers who were required to co-facilitate the HPSP information session by delivering important psychosocial information and support.

### **Development of training program**

The NSF was responsible for providing training and support for all PRMs. The training aimed to further develop their knowledge of stroke and the hospital setting, to strengthen their understanding of the needs of stroke survivors and carers transitioning from hospital to home, and to facilitate confidence to present relevant information and answer questions as required.

### **Content**

The PTP content included information about stroke; stroke risk factors; early signs of stroke; the social, emotional, physical and cognitive impacts of stroke; medical management; understanding grief and loss; emotional responses from participants; supporting the stroke survivor and family; understanding good communication; confidentiality; professional boundaries and good time management. The training also provided participants with the opportunity to explore their own personal stroke recovery journey reflecting back on the initial stages and to present their story in front of a supportive group.

### **Format**

The PTP was delivered in two morning sessions. Education and training was provided via PowerPoint presentations, written information, question and answer sessions and brainstorming activities. Participants were required to complete homework tasks exploring their personal stroke recovery journey and reflecting on their needs at the different stages of their recovery journey. All participants presented their personal story at the end of the training and were provided with feedback from the NSF health professional.

### **Recruitment of peer role models**

Peers were recruited through a number of Victorian Stroke Support Groups and advertisements in local papers. The most effective recruitment strategy involved the NSF health professional visiting four Victorian Stroke Support Groups to provide information about the program and identify potential PRMs.

### **Participation**

Twenty five stroke survivors and carers expressed interest in participating in the PTP. Seventy six percent of interest was derived from visits to stroke support groups, with 20 % from newspaper advertisement and 4 % via word of mouth.

Of the 25 expressions of interest, 16 potential peers attended a PTP session with 12 completing the training and 9 co-facilitating hospital information sessions.



Nine potential peers who expressed interest in participating in the HPSP declined attendance to the training. Four declined due to transport issues, one failed to attend, two had conflicting medical appointments, one reported conflicting personal priorities and one was no longer interested. One carer was unable to get respite for her stroke survivor.

Four participants attended an initial training session but did not complete the program. Two reported over committing themselves, an educational opportunity arose for one and one considered his current life goals were not compatible with the aims of the program.

Three potential peers completed the training but did not participate in the delivery of the program. One presented with severe expressive aphasia resulting in inability to formulate sentences when under pressure/stress, one had over committed himself and the third reported their preferences of week day and site did not match program days and sites.

## **Peer Training Program evaluation**

### **Post-Peer Training Program feedback**

Peers who completed the training program were requested to evaluate its value via two post-training session evaluation questionnaires. Participants reported the positive impact of the PTP:

- 86% reported the training improved their understanding of stroke
- 72% reported the training improved their understanding of their personal stroke recovery journey
- 93% reported the training session improved their understanding of the needs of stroke survivors and carers

Fourteen percent of the peers reported they had some fears and anxieties about being a PRM before the training. Post PTP evaluation indicated these fears and anxieties had been alleviated.

- 90% reported they felt confident to present to stroke survivors and carers and to present in front of a group
- 100% were confident to answer questions by stroke survivors and carers
- 90% reported the training session prepared them for participant's different emotional responses and to cope with challenging behaviours

### **Post-Hospital Peer Support Program feedback**

PRMs were invited to attend a focus group at the completion of the HPSP to provide feedback about their experiences, their perspective on the program and discuss whether the training had adequately prepared them for their role of co-facilitating the HPSP. All participants reported the training was beneficial to them. The opportunity to meet other stroke survivors and carers, practice their story in front of a group and hear others' stories were most appreciated. Suggested improvements to the PTP included bringing carers to the training session so the different perspectives of the journey home could be taken into



consideration; further focus on the initial stages of the stroke recovery journey home; and more role playing.

### **Peer Training Program modifications**

Prior to commencing the HPSP, the hospitals' health professionals expressed concerns that peers may provide inaccurate and/or contradictory information and potentially overstep professional boundaries. The training aimed to ensure PRMs were knowledgeable about stroke, its assessment, and treatment; the roles of the different health professionals; professional boundaries; and topics or questions that were to be referred back to the treating health team. Learnings of the program indicated the health professionals had expressed valid concerns. PRMs would at times provide inaccurate information and/or overstep professional boundaries. This risk was managed by the NSF health professional supporting the peers and assisting with correction of information. These experiences identified ways in which the training program could be improved including:

- More detailed module on professional boundaries
  - Increased role playing on how to redirect medical questions
  - Opportunity to observe appropriate and inappropriate answering of medical questions (via DVD)
- More detail module on appropriate communication methods
  - When it is or is not appropriate to ask personal questions
  - How to ask personal questions in a non-confrontational manner
  - Opportunity to observe appropriate and inappropriate asking of personal questions (via DVD)
  - Affective listening skills
- More detailed module on the initial stages of the stroke recovery journey

### **Hospital Peer Support Program co-facilitation**

This section will describe the PRMs role in co-facilitating the HPSP, their perception of the benefits stroke survivors and carers derived from attending an information session, barriers to successful delivery of the program, the challenges PRMs faced and suggested improvements to the program from the peers perspective.

#### **Role of the Peer Role Model**

The PRMs identifies three key functions in their role:

- To offer hope and positive peer role modelling
- To provide information about the short term issues faced in the initial stages of returning home and the long term positive outcomes



- To convey important messages – “the stroke survivor is not a victim” and “over time the stroke survivor and carer will adapt and develop strategies to overcome challenges and enjoy life”

### **Perceived benefits of the Hospital Peer Support Program**

The PRMs reported stroke survivors and carers attending an information session expressed a general sense of appreciation for the information and support provided. This was indicated by the levels of engagement, the questions asked, the warm ‘thanks yous’ and ‘good byes’ received and the general interest in the peers’ stories.

The opportunity for the stroke survivors and carers to make a personal and often emotional connection with someone who had similar experiences and who was coping and enjoying life was perceived as the major benefit of the information session by the PRMs. This was perceived as particularly important for stroke survivors returning home independent of a carer. Many peers reflected on their own recovery journey and reported they wished a similar program had been offered to them during their hospital admission.

PRMs reported that they derived value from their role in co-facilitating the HPSP and were keen to continue.

### **Barriers to successful delivery of the program**

PRMs identified a number of factors that they felt impacted on their ability to be effective in the delivery of the messages of the HPSP.

- Stroke survivors and carers personal readiness to hear and identify with the information presented
- The compatibility of the stroke survivor and PRMs in terms of age, level of disability and commonality of the care experience
- The acuity and complexity of the stroke. Stroke survivors in the rehabilitation setting were perceived as more receptive to the information provided than stroke survivors in the acute setting with a mild strokes or transient ischaemic attack (TIA).
- The cognitive skills of the stroke survivors
- The presence of a carer to assist with retention of the information presented
- The personality of the stroke survivors and carers attending the information session
- Stroke survivor fatigue
- Stroke survivors’ reduced insight resulting in diminished ability to ‘hear’ the information at that time
- Stroke survivor narrow focus on the physicality of getting home



## **Peer Role Models' Personal Challenges**

### ***1. Communication method***

The biggest challenge reported by the PRMs was adapting their communication methods to stay within the professional boundaries of their role. The peers discussed the challenges of speaking only about their own personal experiences and situation and not commenting on the stroke survivors' and carers' personal experiences and situation; avoiding giving medical advice; ensuring they interacted appropriately and asked personal questions at appropriate times. They reported these new communication methods had to be learnt and practiced but the rationale behind the constraints were understood and considered reasonable. They reported relying on the support of the NSF health professional to support them in complying with the program's expectations.

### ***2. Dealing with the frequent cancellations of the program***

PRMs expressed their disappointment with the number of information sessions that were cancelled. The peers reported that they looked forward to the information sessions and would organise their busy day or week around them and thus appreciated ample confirmation. They felt that the hospital sites were not embracing the program due to the belief the hospitals used a 'medical model of care' as opposed to the more 'holistic model of care' used by the program. PRMs felt that participation in an information session needed to be made compulsory or a routine part of discharge planning to ensure all stroke survivors and carers had access to the particulars of the information provided and the positive peer role modelling.

### ***3. Other challenges***

Other challenges faced by the PRMs included tailoring the information they provided to meet the different needs of stroke survivors and carers in both the acute and rehab setting; travelling to the hospitals which were dispersed across Melbourne and finding disabled parking at some of the hospital sites.

## **Suggested improvements to the information session**

PRMs reported the information session generally ran for just over an hour which was considered too long. It was felt an improved model would be to present the information in two parts, the first consisting of the peers' story and a week later a second session to provide an opportunity to review previous information and discuss the contents of the Stroke Survivor Kit. The limitations to this suggested model were identified as stroke survivors being discharged prior to the second information session would miss important information.

Another suggested improvement was to match the PRMs and stroke survivors on age, levels of disability and experience of the care setting. This has the potential to relieve some of the pressure peers felt to adapt their story to cater for the specific needs of stroke survivors and carers attending the information session. Matching PRMs to the stroke survivors may also improve the stroke survivor's ability to receive the provided information. This would however require training a much larger pool of peers and increased time to organise the logistics of this model of delivery.

PRMs felt it was important that a carer attend the information session as carers were more likely to ask questions, identify with the information presented and repeat the information to their stroke survivor at more appropriate times as needed.



## Section two: Hospital Peer Support Program

### Introduction

This section will describe the development, implementation and evaluation of the Hospital Peer Support Program (HPSP). This section will also describe the engagement of hospital sites and champions.

### Development of information session

#### Content

The HPSP content was developed with advice from an expert advisory group and in response to consultation and feedback from consumers about the information and support received and needed by stroke survivors and their carers after stroke. The content of the information session did however change as the program developed and additional information needs were identified. Changes reflected common questions asked by stroke survivors and carers. Topics covered included:

- Challenges with everyday activities, such as toileting with assistance, activities of everyday living
- Fatigue
- Mood, depression and the cycle of grief and loss
- Isolation
- Driving eg. suspension/loss of license
- Changes to relationships and friendships
- Stroke support groups
- Hobbies/interests
- Strategies to deal with deficits, especially subtle mental changes
- Fear of secondary stroke
- Secondary stroke prevention
- Recognising the signs of stroke
- Carer worries, anxieties and changes in lifestyle
- Community networks, support and information sources available to stroke survivors

The most common questions asked during the information session were to the PRMs about their experiences with recovery, psychosocial adjustment, risk factors and secondary prevention. The questions generally reflected areas that the stroke survivor or carer were concerned about in their own recovery journey. Other questions frequently asked were about driving, medical management of stroke, community services and assistance available, return to work, changes in relationships with family and friends, returning to hobbies/interests and community access.



## Format

The NSF health professional and the PRMs co-facilitated the information sessions. Sessions occurred in a confidential room on the ward and were generally 60–90 minutes and were generally scheduled for mid morning or mid afternoon. The formats of the information sessions were generally consistent:

1. Brief welcome and introduction by the NSF health professional
2. Invitation to participate in the pre-session questionnaires
3. PRMs' story with opportunity for questions
4. NSF health professional providing and talking through the Stroke Survivor Kit<sup>9</sup>
5. Provision of Carers Australia kit as necessary and general NSF fact sheets and consumer booklets
6. Invitation to participate in the post-session questionnaire
7. Invitation to be contacted post-discharge home and consent to be contacted forms completed.

The original goal for this program was to conduct weekly information sessions at the three acute sites and fortnightly sessions at the three rehabilitation sites over a six month period. The frequency of the sessions were however dependant on the availability of suitable patients on the ward at that time.

## Resources

All stroke survivors attending the information session received a Stroke Survivor Kit, a FAST<sup>10</sup> pen, FAST magnet and FAST bookmark. Initially all carers attending the information session received a Carers Australia Kit but due to difficulty getting these resources during the second half of the program only a few carers received a Carers Australia Kit. A number of stroke survivors also received the following National Stroke Foundation resources:

- Long term recovery booklet
- Sexuality after a stroke fact sheet
- Mobility and exercise after a stroke fact sheet
- Medications after a stroke fact sheet
- Communication after a stroke fact sheet
- Thinking and sensing after a stroke fact sheet
- Depression after a stroke fact sheet
- Diet after a stroke fact sheet

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<sup>9</sup> The National Stroke Foundation **Stroke Survivor Kit** is designed to help people who have had a stroke, their family and carers to adjust to their life after stroke. It is focused on the transition from hospital to home. The desired outcomes from the implementation of the Kit are for survivors of stroke to regain a sense of control over their recovery; to equip stroke survivors and their families and carers with knowledge about help that is available and how to access it; and to provide a place for them to record information.

<sup>10</sup> **FAST** stands for **F**acial weakness, **A**rm weakness, **S**peech difficulty, **T**ime to act fast and is an easy way to remember and recognize the signs of stroke or TIA.



## Implementation

This part of the report describes how the HPSP was implemented including recruitment of the six hospital sites, recruitment of stroke survivors and carers and the eligibility criteria used.

### Recruitment of hospital sites

Five Melbourne metropolitan hospital sites including six wards were recruited to participate in the program through direct liaison with the NSF health professional. Ethics approval was obtained where needed. Health professionals who helped with the delivery of the program at a local level were called 'champions'. They either volunteered to be involved in the program or were selected by their managers. The majority of champions were from a nursing background (66% were Nurse Unit Managers). When the champion was unavailable a second staff member would fill the position. The champions' role was to assist in the logistics of program delivery and to recruit stroke survivors and carers.

### Recruitment of participants

Champions identified stroke survivors on the ward who were preparing for discharge and fit the inclusion criteria. Champions were required to inform and invite stroke survivors and family/carers to attend an information session and provide an information brochure. The brochure contained the contact details of the NSF's health professional for any further questions. The champion's commitment to the program was crucial in the recruitment of the stroke survivors and carers and thus the number of information sessions being delivered.

Posters were also located on the ward to inform and invite participation although at many sites this was not regularly updated.

### Eligibility criteria

All stroke survivors were considered eligible if they met the following criteria:

- Had a confirmed diagnosis of stroke
- Expect to be discharged home to the community or low level residential aged care facilities
- Aged 18 years or over

The stroke survivor's family members and/or carers were encouraged to attend the information session with their stroke survivor.

## Evaluation

This section provides details of the number of sessions facilitated and numbers of stroke survivors and carers attending. It also provides a participant profile; stroke survivors and carer's reported preparedness to return home; impact of the information session as reported in sessional evaluation and telephone interviews; the stroke survivor and carer's recall of the information session and the resources looked at once home. This section also discusses the champions' perceived value of the HPSP.

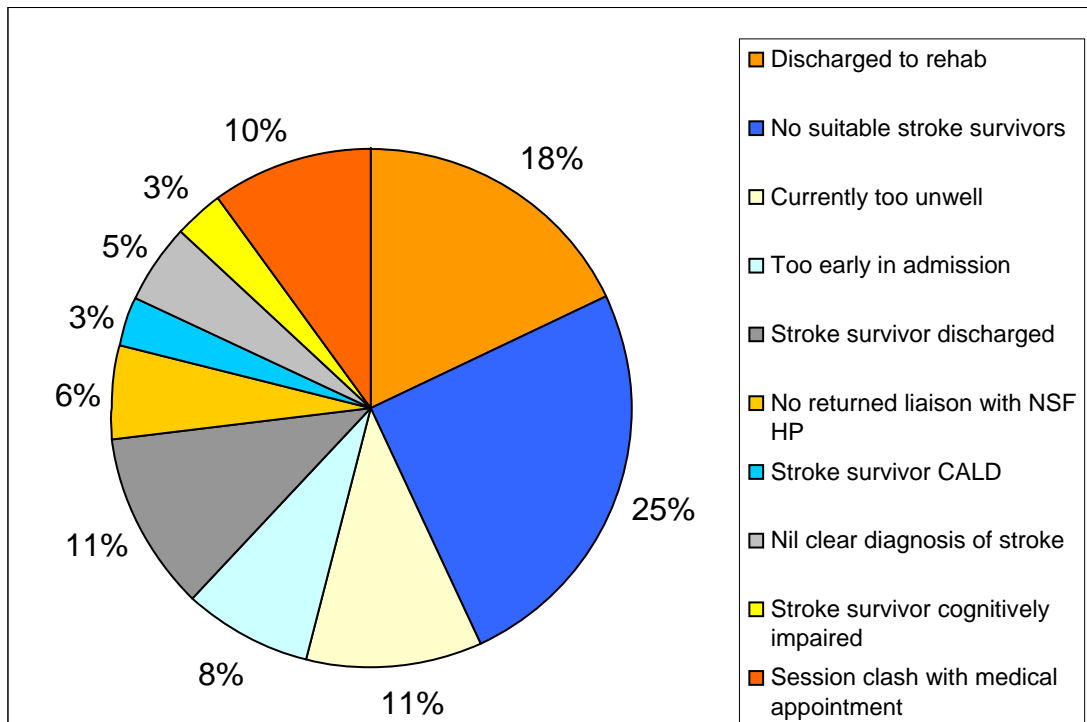


### Number of participants and sessions

Ninety four information sessions were offered over six months; 47 (50%) were delivered reaching 83 stroke survivors and 38 carers.

The high numbers of cancellations were mostly due to lack of suitable participants or discharge to a rehabilitation as per Figure 1.

Figure 1: Reasons for session cancellations



Successful delivery of the program varied between sites. The Acute 1 site (stroke unit) achieved the second highest percentage of sessions delivered (64%), highest number of stroke survivors accessing an information session (28) and second highest number of carers (10) as per Table 1 (following page). These statistics were deceiving, however, as 92% of its 372 admitted stroke survivors during the six month pilot period were unable to attend an information session. The high percentage of eligible stroke survivors who were unable to attend an information session at this site may reflect the short length of stay in the acute ward resulting in patients inability to attend an information session offered only once a week.

**Table 1: Hospital, stroke survivor and carer participation**

Hospital	Weeks in program	Number of sessions offered	Number of sessions delivered	Number of stroke survivors	Number of carers
Acute 1 (stroke unit)	26	25	16 (64%)	28	10
Acute 2	19	18	9 (50%)	9	5
Acute 3	16	14	0	0	0
Subacute 1	24	14	10 (71%)	24	12
Subacute 2	22	15	9 (60%)	18	8
Subacute 3	14	8	3 (37%)	4	3
TOTAL		94	47 (50%)	83 (74 completed pre-surveys, 64 post-surveys)	38 (32 completed pre and post surveys)

## Participant Profile

Seventy four (89%) stroke survivors completed pre-session questionnaires with 64 (77%) completing post-session questionnaires. Thirty two (84%) carers completed both the pre-session and post-session questionnaires.

### Gender

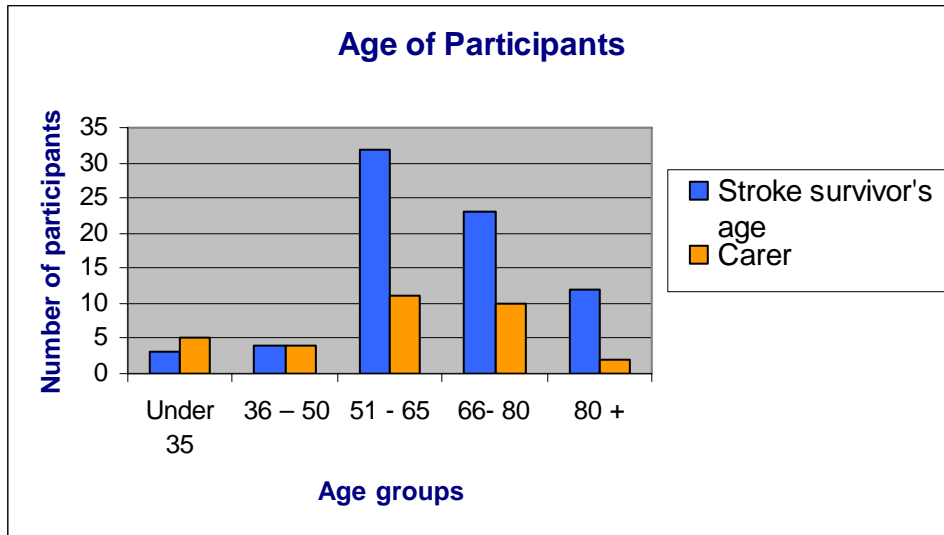
Almost an equal number of male and females participated in the program (51% female; 49% male), however 65% of carers attending an information session were female.

### Age

The largest age group of participants for both stroke survivors and carers was in the age range of 51-65 years.



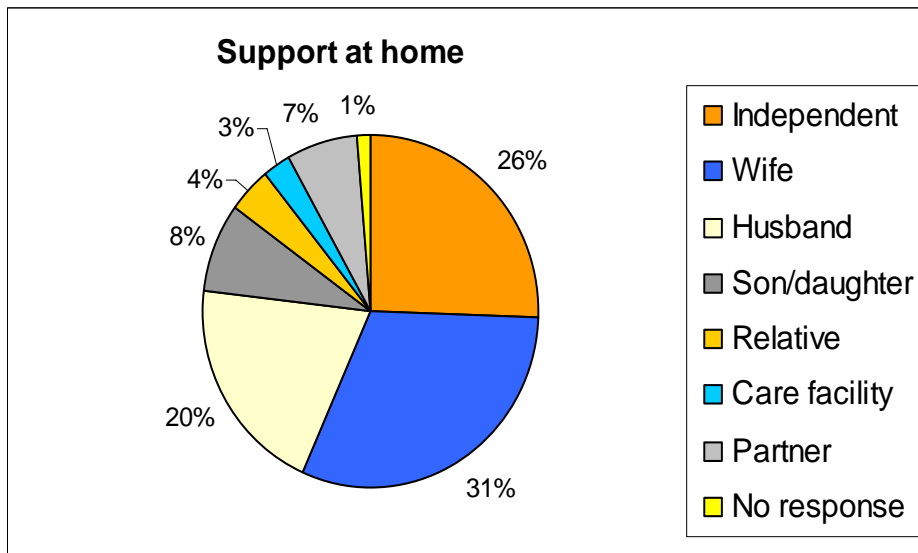
**Figure 2: Participants' ages**



**Support at home**

Fifty one percent of stroke survivors were returning home to their spouse.

**Figure 3: Support at home**

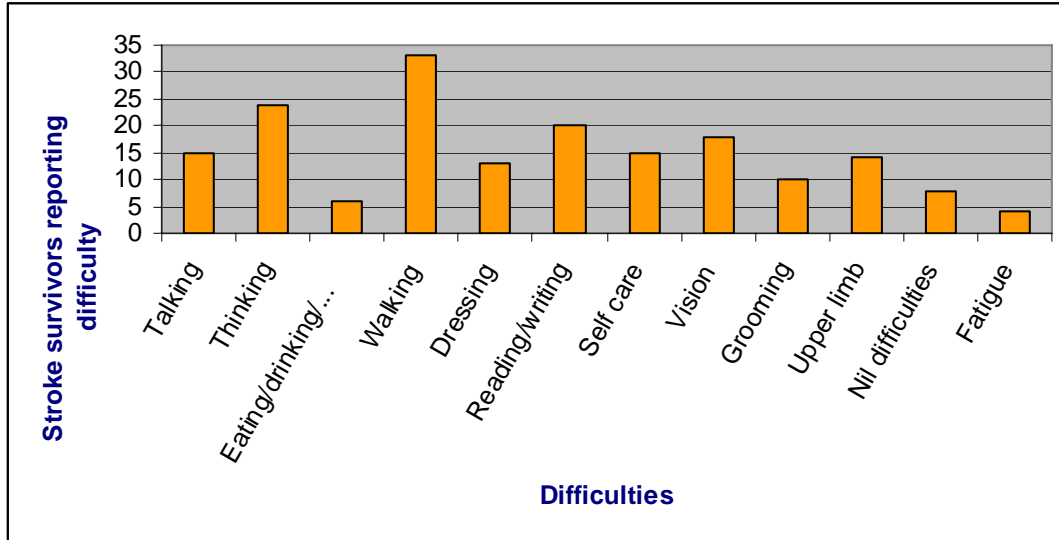


**Difficulties post-stroke**

Sixty percent of stroke survivors reported having more than one difficulty post-stroke.



Figure 4: Difficulties experienced by stroke survivors post stroke

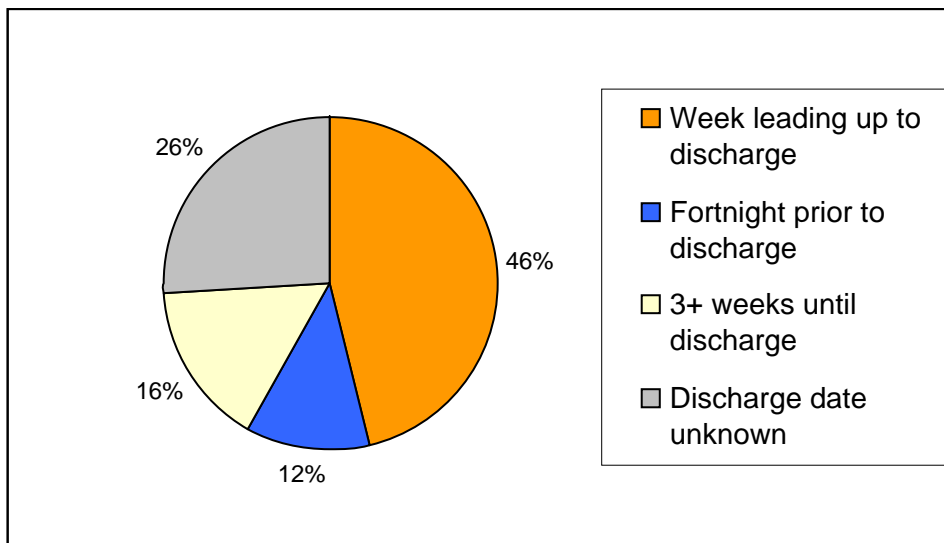


Seventy two percent of the stroke survivors had not experienced a stroke before.

**Time of attendance to information session**

Participants most frequently attended an information session within one week of stroke onset (32%) reflecting recruitment from the acute hospitals. Regardless of time of stroke onset, 46% of stroke survivors attended the information session in the week leading up to their discharge home.

Figure 5: Time of attendance at an information session





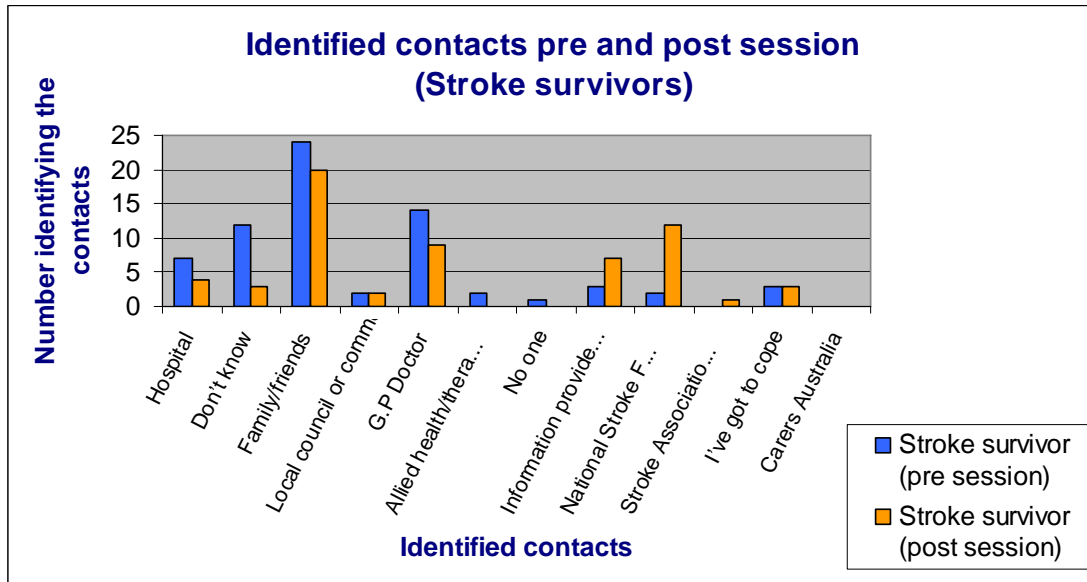
### Sessional evaluation

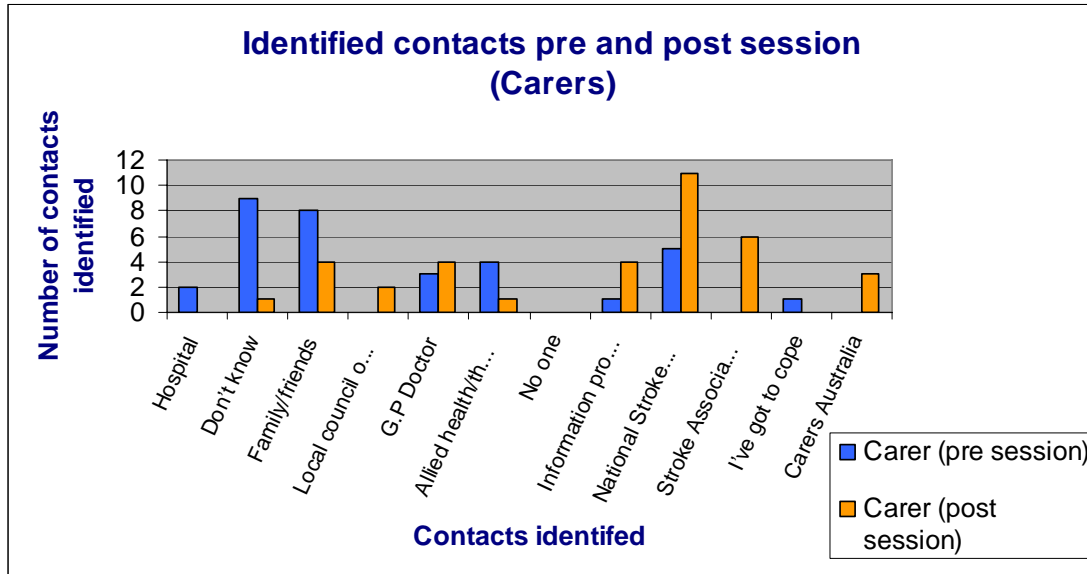
Quantitative and qualitative evaluation was completed using sessional questionnaires, telephone interviews and focus groups.

The results of the HPSP indicate that 87% of acute stroke survivors and 67% of rehabilitation stroke survivors felt prepared to go home prior to the information session. Carer figures were similar for discharges from a rehabilitation setting (68%) but lower for discharges from an acute setting (61%). These results did not indicate a difference between levels of preparedness pre- and post-information session for either stroke survivors or carer. These findings were consistent with stroke survivor and carer reports that feelings of preparedness were generated by the treating team and support from family and friends. This indicated that the information and support provided by the HPSP did not directly influence levels of preparedness.

Despite the limited changes in preparedness to return home pre and post information session, the information session had positive outcomes in regards to knowledge of community services and support. Stroke survivors and carers were asked pre-session who they would contact for more information about stroke in general. Sixty five percent of stroke survivors were able to identify someone they would contact but 35% reported "I don't know". Post information session, 98% of stroke survivors identified someone they would contact. Pre information session, 63% of carers were able to identify someone to contact but 37% reported "I don't know". Post information session 97% of carers identified someone they would contact. Refer to Figure 6 for identified contacts.

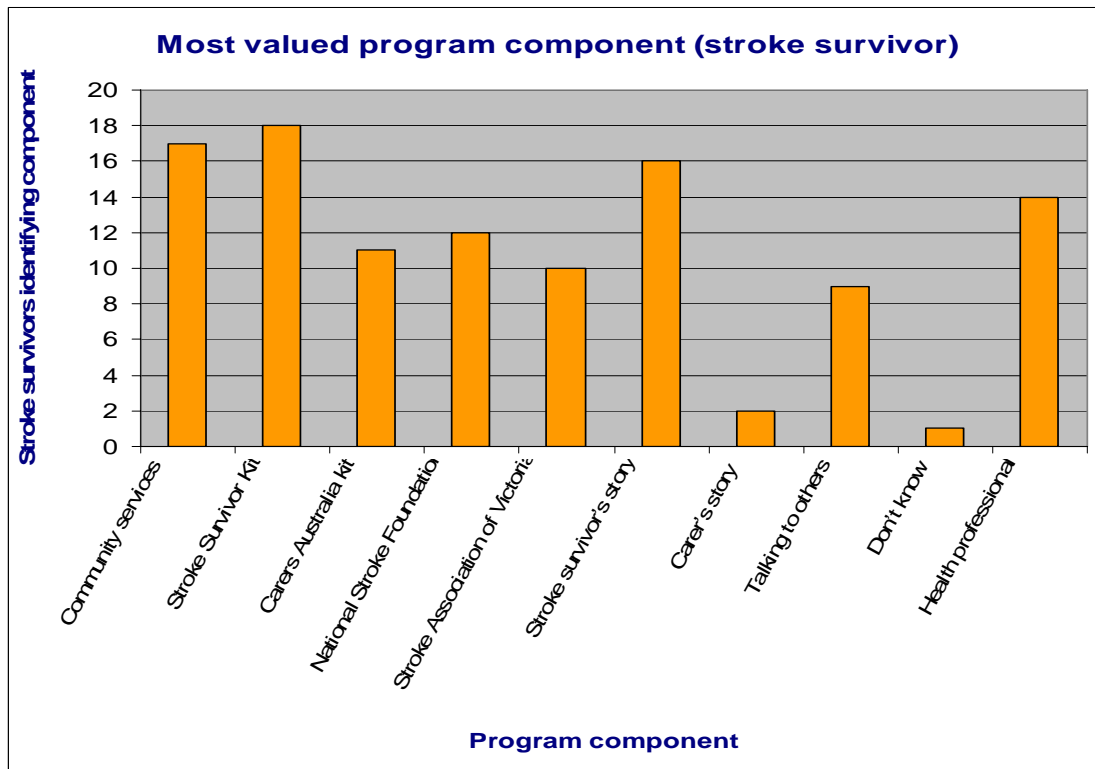
Figure 6: Identified contacts for support pre and post information session

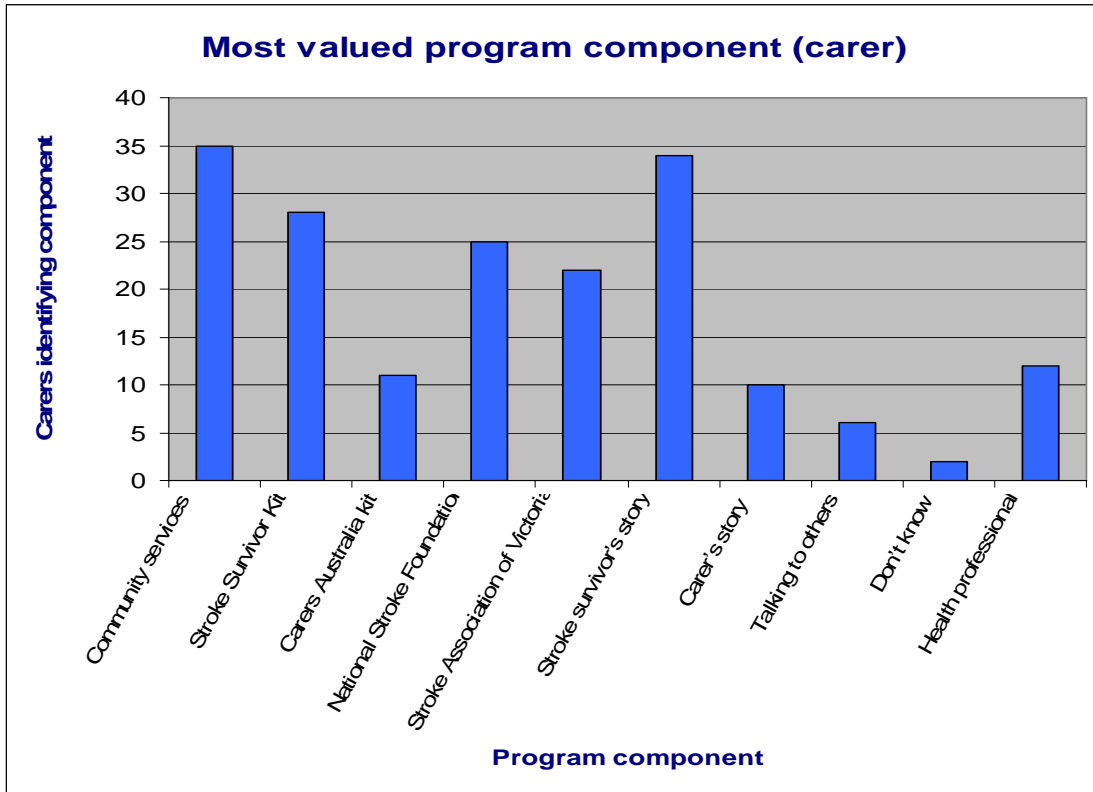




Stroke survivors' and carers' post information session reports indicated that they derived value from the information session. Getting a Stroke Survivor Kit, hearing about community services and hearing the stroke survivor's story were the most valued components of the information session for both stroke survivors and carers. Refer to Figure 7 for more detail.

**Figure 7: Value of the components of the information session**





### Post-discharge follow up telephone interviews

Two to four weeks post discharge home stroke survivors and carers were followed up via a telephone interview. They were asked a number of questions including whether they recalled the information session.

#### Recollection of the program

Seventy two percent of stroke survivors reported they could recall the information session and were able to provide some accurate information about the session. The majority were able to recall the PRM and some specifics about his/her story (68%). They also recalled the written resources provided and the NSF health professional. Stroke survivors who were unable to recall the information session reported they had memory problems or had experienced information overload in hospital.

*“What was the other chappy's name? He was a gardener. When he was talking about overcoming things, like what he went through with losing his job and stuff, to get back on with life and not panic. I was fine when I was in hospital, it's since I've come home”*

*“The man's story. How wonderful it was to hear a man share his story in a humble way. I recall he had 4 strokes and lost his friends and marriage. I can't recall what the health professional talked about. The information in the bag (Stroke Survivor Kit) was good. I'm using the magnet”.*



Ninety five percent of carers recalled the information session, in particular the PRM (46%). They also recalled the Stroke Survivor Kit; the provision of contact details of community support and information services; and specific information about what to expect when they returned home.

*“Hearing his wife's story, how she felt. It really helped me with what to expect. And to know if we needed help, there were numbers I could use. It was what I expected, it's when you get home it hits you. Very informative and very useful”*

*“The fact it could happen again. I hadn't thought of that. I didn't think she'd go home and this could happen. Signs to look out for and the factors of going home, and the ups and downs. We hit a brick wall and then go up again. I didn't jerry then when you told me, but I register now”.*

### **Perceived program value**

Both stroke survivors (89%) and carers (100%) identified the opportunity to hear from and speak to a PRM as the most useful component of the program.

*“It was interesting and it made me think that just getting home is not the end of it”*

*“Very enlightening & hope he helps me to understand the signs of my husband not coping & getting depressed”*

*“Very relevant. It was reassuring to hear he had same thoughts and feelings after stroke”*

When a PRM had been unavailable, stroke survivors and carers were asked if they would have found the opportunity to talk to a peer useful. Eighty six percent of stroke survivors and 16% of carers felt hearing from a peer would have been useful to them.

*“My mum would have liked to talk to a stroke survivor, definitely. When she walked away she said it would have been valuable. I think it's extremely important, it's the connection. You were very experienced and informative but tis the connection and bonding with someone whose had that experience”*

Eighty four percent of stroke survivor and 95 % of carers reported the information session was useful to them, although only 66% stroke survivors and 58% of carers reported it helped them with their return home. Stroke survivors reported that the information session was useful for a number of reasons, firstly the opportunity to hear from someone who had been though a similar experience and done well; the direction, increased awareness, preparation and understanding the session provided; the community support and information services' contact details; and finally the opportunity to talk about their stroke and be heard.

*“Just to talk about it, other than to the doctors and medical stuff. The affects on everyday life and knowing there is someone to support you once the medical advice is over”*

Stroke survivors (87%) and carers (95%) described a sense of confidence that the program gave them in knowing that there was someone they could turn to if they needed. They



attributed this confidence directly to their participation in the program and the written resources provided.

*"It gave confidence, reassurance, better understanding and with (peer role model) to know it's not the end of everything but the beginning"*

Four stroke survivors reported on the program in a negative manner. Two stroke survivors reported the session was not useful to them for two key reasons, timing and not being worried about returning home. One stroke survivor reported the program was 'scare mongering'. One stroke survivor did not agree the information session was useful to him because he had enough of a support network at home.

*"Mainly timing and I don't think I was taking it in"*

*"I was a bit worried about the emphasis on transition home. It made me think again where I'd been confident, it made me doubt my ability to make the transition. It was a bit of scare mongering. It shouldn't be a frightening prospect. Just the fact that it had been spoken about at all. Until then I hadn't thought of myself as a stroke survivor just a patient in hospital. There was a lot of emphasis on stroke."*

Learnings from the follow up telephone interview indicated that often it was not until the follow up phone contact was made with the NSF health professional that the stroke survivors and carers participating in the program had true realisation of the information they had heard. The telephone follow up provided a vital opportunity to consolidate the information shared in the information session and reinforce key messages. Stroke survivors and carers often used the telephone interview as an opportunity to get advice or further information about the services they could be receiving in the community using this much like the NSF 1800 Stroke Line.

### **Use of resources**

Stroke survivors and carers attending an information session were provided with a Stroke Survivor Kit and access to all of the NSF consumer literature. When available a Carers Australia Kit was provided.

The telephone interviews revealed 66% of stroke survivors and 63% of carers had looked at the information provided. Most stroke survivors and carers looked at the information once they returned home.

*"Yes. It was very good. I read it when I got home. I didn't have time in hospital"*

Of the stroke survivors and carers who reported they had looked at the information very few reported they had used the information. It was not determined what information the stroke survivors or carers had specifically looked at. Despite this a significant number of stroke survivors and carers reported that having the kit and knowing that contact details of community support services were accessible should they need them was valuable.

*"It's good knowing that there is help available, you're not alone. There are agencies and the Stroke Foundation to help"*



## Champions' focus group evaluation

All champions were invited to attend a focus group at the conclusion of the program to provide their perspective on the program. The aim of this focus group was provide feedback on their role as champion, the impact of the HPSP on the ward, the logistics of the information session, the perceived value of the HPSP, the issues with recruiting stroke survivors and carers, and ideas on how to improve sustainability and feasibility of the program. The champion's feedback was vital towards assessing sustainability of the program running in the hospital setting and suggested improvements. One champion from an acute site and one from a rehab site participated in the focus group.

### Role of the champion

The champions perceived their role as performing three key functions:

- Facilitation of the ward's health professionals to engage in the program
- Recruitment of the stroke survivors and carers
- Assist with the logistics of running the program

### Recruitment of participants

A significant difference between the acute and rehab setting was the ease of recruiting the stroke survivors and carers. It was reported on the acute setting that stroke survivors were very receptive to attending an information session as they had a strong need for information. Only two stroke survivors invited to attend an information session declined, one due to her age and past experience of a strokes and another due to disinterest. The rehabilitation experience was described as different with the champion taking on a more persuasive role. It was perceived that due to the length of stay in the rehabilitation ward that these stroke survivors perceived themselves as well informed and not needing more information.

### Perceived feasibility and sustainability of the program

On the acute ward it was felt that the Hospital Peer Support Program (HPSP) would be best facilitated by an external consultant to avoid the program being delivered in a medical format. Stroke survivors on the participating acute stroke unit were generally admitted for 3–4 days and were thus perceived to be actively seeking more medical information from their treating team such as understanding stroke, medications and secondary stroke prevention. An external consultant was perceived to have more flexibility to provide social and emotional information. It was reported the participating acute stroke unit would also have significant issues with finding people resources to independently facilitate the program.

The champion from the rehabilitation setting felt that the HPSP could be replicated with ward staff taking it on as a project, although finding the resources to do this would be challenging. Although the ward could identify some potential PRMs from past patients they would not have the resources to train them.



### **Barriers to successful implementation of the program**

The champions at both sites identified a number of barriers to successful implementation as outlined below.

- Poor engagement of health professionals
- Sole responsibility for the program – If the champion did not facilitate the session it would not occur as demonstrated by the lack of referrals from other health professionals and during times when champions were unavailable or busy with other commitments there was no initiative to assist with the program.
- Culture of health professionals – if they do not have clear ownership of a project they are unlikely to take on additional roles due to their limited time and resources.
- Impact of concurrent ward activity such as ward rounds, team meetings, the limitations on family visiting times, and the additional work required on days with high discharge numbers.
- Poor access to program – There was a mismatch between program availability and the timing of admissions and discharge of potential participants.

It is interesting to note that both champions reported they did not feel championing the program was a burden to them as it only required 30 mins per week to facilitate.

### **Perceived benefits of the program**

Both champions felt the information session was of value to their patients. Both had received positive feedback and reported that the most valued component for participants was the knowledge that there was someone to help them when they got home if needed. Speaking to a peer role model was not mentioned at either site.

Both champions would like to see the program continue although they would ultimately change the timing on their ward. It was felt by the acute setting that providing the information session to patients going on to rehab facilities would also be beneficial.



## Discussion

Recent research by the NSF revealed that many stroke survivors reported they were under prepared (both mentally and physically) to return home<sup>11</sup>. Less than a third of stroke survivors felt satisfied with the information they received about stroke, stroke support groups and community services before leaving hospital. Carers were even less satisfied with their preparation to go home. Only 23 % of carers reported satisfaction with the information they received about services community groups and stroke support groups.

Another key component of the HPSP was the delivery of this psychosocial information from experienced peer stroke survivors and carers from the community. Stroke survivors and carers describe the importance of peer support early in the recovery journey<sup>12</sup>. Peers are highly accepted by fellow stroke survivors and carers and are able to provide social support, experiential knowledge and a social comparison<sup>13</sup> that the medical model of care is unable to provide. Hospitals however are often hesitant to permit unsupported peers to meet their patients due to concerns that the information provided may be inaccurate, inappropriate and/or potentially overstep professional boundaries.

The Hospital Peer Support Program (HPSP) was developed and piloted by the National Stroke Foundation (NSF) as a strategy to provide timely access to psychosocial information for stroke survivors and carers as they transition home from hospital. The development and delivery incorporated peer role models as powerful facilitators in delivering the important information that the medical model of care often cannot provide.

Six hospital sites were recruited across metropolitan Melbourne reaching 83 stroke survivors and 38 carers. Despite all sites initially being keen to embrace the program, 50% of sessions were cancelled. The high numbers of cancellations were mostly due to lack of suitable participants.

A crucial component of the HPSP was the delivery of psychosocial information focussing on the transition home from hospital, delivered by both a Peer Role Model (PRM) and a NSF health professional. The findings of the program indicated that both stroke survivors and carers valued receiving this information that they may not otherwise receive from the medical model of care. Stroke survivors and carers most appreciated receiving contact details for the community services that could be accessed after leaving the supportive hospital environment.

The second crucial component of the HPSP was the PRMs who provided support, encouragement and positive role modelling. The findings of the program indicated that stroke survivors and carers attending the information session reported value in talking to

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<sup>11</sup> National Stroke Foundation (2007) Walk in our shoes

<sup>12</sup> National Stroke Foundation (2007) Walk in our shoes

<sup>13</sup> Solomon, P., (2004), *Psychiatric Rehabilitation Journal*, Peer support/Peer provided services underlying processes, benefits, and critical ingredients, Spring 2004, V. 27, N 4.



and hearing from the PRM and once discharged home, recalled the peer and his/her story before any of the key messages delivered in the session. The majority of stroke survivors and carers who did not have the opportunity to hear from a PRM reported post-information session and post-discharge home that hearing from a peer would have been useful.

It was important to note that the follow up telephone interview was an important component of the HPSP. It provided stroke survivors and carers with the opportunity once at home to consolidate information shared during the information session and reinforce key messages.

Many hospitals are often hesitant to permit unsupported PRMs to meet patients due to health professionals concerns that peers may provide inaccurate and/or contradictory information and potentially overstep professional boundaries. The HPSP overcame these challenges by ensuring all PRMs successfully completed a Peer Training Program (PTP) delivered by a NSF health professional experienced working in the hospital setting. Learnings indicate the PTP was crucial to facilitate peers' knowledge of stroke, professional boundaries, roles and responsibilities and their general confidence to deliver the important psychosocial information.

Prior to commencing the HPSP, the hospitals' health professionals expressed concerns that peers may provide inaccurate and/or contradictory information and potentially overstep professional boundaries. Health professionals concerns were alleviated by the knowledge that all PRMs would be trained and would co-facilitate the information sessions with the NSF health professional. After the program it was felt that trained PRMs still required some support to ensure provision of accurate and appropriate information.

Post program findings indicated that the PTP required modification to further develop PRMs' skills in accurately delivering their messages and respecting professional boundaries.

The model of delivery presented with some shortcomings as indicated by the high cancellation rate due to no suitable patients. In addition the length of stay in Victorian hospitals is shorter than other states thus the impact of shorter length of stay on participation rates requires further exploration.

The champions were crucial in the operation of the HPSP especially in the recruitment of the stroke survivors and carers and thus the number of information sessions being delivered. The role of champion was not considered a burden as it required only 30 minutes per week to facilitate. The champions engaged in the program reported that an external health professional was the best person to deliver the psychosocial information as the treating team often presented information via a medical model. They also reported their sites would find it difficult to allocate people resources to deliver the HPSP information sessions and would be unable to recruit and train stroke survivors and carers from the community to act as PRMs. It was unclear if these findings would be similar for regional and remote hospital sites across Australia and requires further exploration.



## Conclusion

The Hospital Peer Support Program (HPSP) indicated that stroke survivors and carers transitioning home from hospital valued receiving psychosocial information that may not otherwise be delivered by the medical model of care. Stroke survivors and carers most appreciated receiving contact details for the community services that could be accessed after leaving the supportive hospital environment. They reported this information provided the much needed reassurance and confidence that there was always someone they could turn to if needed. Delivery of this information is considered a crucial part of the discharge process.

The follow up telephone interview provided stroke survivors and carers with the opportunity once at home to consolidate information shared during the information session and reinforce key messages.

Stroke survivors and carers reported they valued the opportunity to hear from and talk to a Peer Role Model (PRM). Hospitals are often hesitant to permit unsupported peers to meet patients due to concerns about the information that may be provided potentially overstepping professional boundaries. The program overcame these challenges by ensuring all PRMs successfully completed a Peer Training Program (PTP) delivered by a health professional and were supported in co facilitation of information sessions by the NSF health professional. Findings of the program indicated that the training required modifications to ensure peers were consistently delivering accurate and appropriate information in the information session.

Future plans for delivering the HPSP will need to explore the different resources available to acute and rehabilitation sites across city, regional and remote Australian hospital sites in regards to the ability to recruit and train PRMs and deliver the program's information session. Further exploration is required to determine the different length of stay in acute hospitals across Australia and how this could potentially impact recruitment rates.



## Appendix 1

### Project activities and timelines

