‘Caring for the Carers’ – the establishment of a support group for carers of stroke survivors

Keywords:
Carers, stroke, support groups, experience based design, values clarification

Duration of the project:
March 2010 – March 2011

Project leaders:
Anne Marie Tunney, Lecturer in Nursing and Practice Development, University of Ulster and Northern Health and Social Care Trust
Patricia Holley, Stroke Specialist Nurse, Northern Health and Social Care Trust

Contact details:
annemarie.tunney@northerntrust.hscni.net
patricia.holley@northerntrust.hscni.net

Summary of project
Based on the identification of an unmet need and an acknowledgement of the benefits to be gained, a support group for carers of stroke survivors was established in one area of an integrated health and social care Trust within Northern Ireland. Members of the group were provided with the opportunity to meet with others who had similar experiences and through discussion were able to support and learn from each other. Activities enjoyed by the group included attendance at social events, information sessions delivered by various healthcare professionals, relaxation sessions and personal health checks. They were also given the opportunity to contribute to suggestions for enhancing service delivery to both stroke survivors and their carers. A quarterly Carers Newsletter, edited by members of the group, has been published and carers have been involved in providing information to the general public on aspects of stroke survival and lifestyle. The initiative has been positively evaluated and the group continues to grow steadily both in number and level of activity. It is hoped to roll out the initiative to other services within Northern Health and Social Care Trust.

Background
It has been estimated that 15 million people have a stroke annually (Larson et al., 2008) and within Northern Ireland (NI), it has been estimated that 4000 people survive stroke annually (Northern Ireland Chest, Heart and Stroke Association (NICHSA), 2008). Smith et al. (2004) have highlighted that more than a third of these are dependent on an informal carer. Carers are people who, without payment, provide help and
support to a family member or friend who may not be able to manage without this help because of frailty, illness or disability (Department of Health, Social Service and Public Safety in Northern Ireland (DHSSPSNI), 2006). Within NI it has been estimated that there are over 185,000 unpaid carers and that 55% of these are aged 45 years or more (Evason, 2001).

The impact on the carer of this role has been documented extensively in the literature. Within NI it has been found that 61% of carers have some health problems (DHSSPSNI, 2006). Caregivers have been found to experience many negative physical and psychological outcomes (Schulz and Beach, 1999) which often have an effect on their social interaction (Anderson et al., 1995). Depression, exhaustion, anxiety and a profound sense of loss among caregivers have been identified (Berg et al., 2005, Greenwood and Mackenzie, 2010) particularly within the first month of caring and the early stages of this role.

Recently within NI there has been more recognition of the important role of carers and this has been reflected in government legislation and policy which has been adopted at local level within health and social care Trusts. A strategy for carers was published by DHSSPSNI in 2002 which recognises that carers have an important part to play in rehabilitation and it suggested they should receive the necessary support to allow them to continue to fulfil this role without damaging their own health and wellbeing.

One such method of providing this support is through the provision of support groups. DHSSPSNI (2006) have recommended that all ‘can help with the provision of information about services and how to cope with caring’ and reassure carers that ‘they are not alone in feeling the strains and stresses of caring’ (p.12). The literature contains many references to the benefits for patients from attending support groups but there is little to suggest that carers may also benefit from attending such groups. Positive outcomes from attending carers support groups include improvements on measures of care giving burden and reduction in depression (Chou, Liu and Chu, 2002), increased knowledge and improved morale and a decreased sense of loneliness (Winefield, Barlow and Harvey, 1998).

The availability of local support groups for carers within NI is geographically sporadic and their aims and objectives are variable with some being structured and educational whilst others function mainly as a means of social interaction.

The catalyst for this project was a comment made by a carer to the stroke specialist nurse within Northern Health and Social Care Trust (NHSCT): ‘There is plenty of help available for those who have had a stroke but little
available for carers’. Further investigation of the issue by the stroke specialist nurse revealed that whilst there was a local carers group it was generic in nature and therefore not specific to the needs of carers of stroke survivors. Further informal discussion between the stroke specialist nurse with carers of stroke survivors suggested that, locally, there was a need to establish such a group.

Aims and objectives of the project

The overarching aim of the project was to establish a support group which would meet the expressed needs of carers of stroke survivors. The project leaders felt however, that as this was a support group for carers, then they should be the ones to determine the shape it would take. It would have been easy for the leaders to set their own objectives but these may not be in keeping with what was required by the carers. An initial aim was therefore created by the project leaders which was to engage with carers to enable them to set their own objectives for the group, thereby establishing a greater sense of ownership and promoting sustainability.

Methods and approaches

The project was led by NHSCT stroke specialist nurse supported by NHSCT and University of Ulster (UU) practice development nurse. The project was supported by the Patients First Programme facilitated by the Foundation of Nursing Studies (FoNS) in partnership with the Burdett Trust for Nursing. A number of approaches were used to initially establish the group and then to firstly, enable the group to identify its own objectives and secondly, to meet these objectives. These included:

- A questionnaire to establish baseline local interest in the formation of a group and to explore what format it should take
- A claims, concerns and issues exercise with the support group members
- Enabling carers to create a ‘wish list’
- A values clarification exercise with the support group members
- The establishment of a steering group and a working group
- An experience questionnaire and listening lab using the Experience Based Design (EBD) approach
- A staff workshop on discharge planning
- Activities to publicise the group

These methods and approaches and their outcomes will be discussed below.

Baseline questionnaire – needs analysis

In order to establish the feasibility of establishing a support group for stroke survivors and to ascertain what would be the most suitable venue, time and format for the group, a baseline questionnaire was developed and forwarded by the stroke specialist nurse to a random (n = 20) sample
of carers in one area of the Trust. Anonymity and confidentiality were assured and a stamp addressed envelope was included to maximise response rate.

There was a 100% response rate with 75% of respondents indicating that they were interested in joining the group. The remaining 25% indicated a willingness to join but indicated that they would have difficulty attending the group because of lack of support to care for the stroke survivor in their absence. Respondents indicated that they wanted to meet monthly with meetings lasting no more than 1–2 hours and there was a 50:50 split as to what would be the most suitable time of day for the meetings – morning or evening. Respondents expressed a wish that the meetings would take place within the hospital with 93% indicating that transport would not be a problem. 66% indicated that they would be able to leave the person they were caring for with another person whilst they attended the meeting. 93% wanted the format of the group to be a combination of discussion and social interaction with an educational component. Three respondents wanted the meetings to be ‘light hearted’ with one respondent stating that they would like ‘information about help when the patient first comes home from hospital as this is the time when they felt most alone.’

Based on these responses, it was decided to hold the support group meetings every six weeks within Causeway Hospital from 10am – 11.30am. A date was set for the first meeting and communicated to respondents. The stroke specialist nurse agreed to facilitate the group initially but there was the expectation by the project leaders that this role would eventually be taken over by one of the group in line with recommendations that local carer support services are best run and managed when carers themselves are ‘involved in the management process’ (DHSSPSNI, 2006, p 26).

**Claims, concerns and issues (CCI)**
The inaugural meeting was attended by ten carers and was facilitated by the stroke specialist nurse. The project leaders provided a general introduction to the group and gained agreement from the group members to use information collected throughout the group e.g. comments, views and observations for evaluation purposes. It was important, since this was the first meeting of the group, that an ice breaker was used to help members get to know each other. Members of the group were invited to introduce themselves and to state how long they had been a carer and who they cared for.

A claims, concerns and issues exercise has been recommended as an effective technique when establishing groups and setting agendas (RCN, 2007). It has the added advantage of allowing stakeholders, in this case the carers, to shape the group which helps to create a sense of ownership.
(Titchen and Manley, 2006). The project leaders were introduced to this tool at one of the FoNS’ workshops for project leaders run as part of the Patients First Programme and it was felt that it would help to lay the foundations for establishing an effective group dynamic and to promote inclusivity within the group as all members would be given the opportunity to voice their thoughts in a safe environment. The CCI exercise, an approach based on Fourth Generation Evaluation (Guba and Lincoln, 1989), was explained to the carers and used to determine their claims, concerns and issues around the establishment of the support group.

The claims (positive or favourable assertions) identified by members were that it (the group) was a chance and/or opportunity to:
- Meet people with similar experiences
- Form networks
- Receive information
- Have access to health care professionals for advice

The concerns identified were primarily around the membership of the group including that:
- Numbers would diminish because it may be difficult to get the message out there that the group had been established
- Some carers would be unable to attend since they did not have anyone to look after the person they cared for whilst they attended the meetings
- Men might be reluctant to join

The issues emerging were primarily about the sustainability of group membership, enlisting new members and possible ways to facilitate other carers without respite to benefit from the group. This prompted a brainstorming exercise around publicising the group with various suggestions being made including use of local media, production of a newsletter and printing of posters and leaflets for display in local areas.

**The carer ‘wish list’**
The project leaders felt that the members should agree the aim and set the objectives for the group. This activity was carried out at the second meeting of the group.

In order to get a sense of what the expressed needs of the group were and to act as an ice breaker, members were asked to think about what would be an ‘ideal’ world for them – they were asked to think about what they were currently wishing for and to write their thoughts on a post-it and to stick these on a wall (see Appendix 1). Members were then invited to view the post – its which were later analysed by one of the project leaders using a content analysis approach. Four themes were identified:
- Me time
• Loss of self identity and inability to look to the future
• Help and support
• Emotions and coping

The main theme to emerge was a desire for ‘me time’. Thoughts included in this theme were:

‘I wish I had time to play with my son’
‘A little free time to relax’
‘Quality time with my husband’
‘Space to myself’
‘One day a week to myself’

A sense of loss of self identity was evident from the responses and a desire to go back to the way things were prior to the stroke:

‘I wish I could have my life back to the way it was before the stroke’
‘I wish I could be wife, mother and friend today instead of carer’

There was also reference to ruined plans for the future:

‘We had planned a trip to Canada and I wish we could go’

There was a desire for help and support:

‘More support and information in the early days’
‘More family members to help’
‘More help to ease my burden’

Finally, responses were themed around emotions and coping:

‘I wish I was not so angry’
‘It’s hard to see my sister getting weaker’
‘I wish my day was over’

The central focus of the comments was around the importance of support and a need to share experiences in order to prevent loneliness.

**Values clarification exercise**

The second half of this support group meeting was devoted to a values clarification exercise. It was considered important by the project leaders that the group had a shared vision, i.e. that the group members agreed on what they wanted from the group. One method to achieve this is to invite group members to explore their values and beliefs. A template derived from the work of Warfield and Manley (1990) was used to clarify values and beliefs around the purpose of a support group and thus inform the development of a shared common vision for the group. As well as
helping participants to agree a vision for the group it also provided them with the opportunity to identify enablers to the establishment of the group, potential barriers and ways to overcome them.

The exercise is usually completed individually followed by group discussion and it is recommended that 30 – 60 minutes are allowed for the process; however, due to time restrictions, the project leaders adapted this process. Following an explanation about the exercise, group members were given a pre-printed template (see Box 1) to be completed at home and to be returned to the project leaders in a stamped addressed envelope. Members were informed that the project leaders would then theme the received responses and use these to firstly, create a vision statement for the group, and then to draft objectives which would be presented to them for discussion and agreement at the next group meeting.

**Box 1 Statements used in the values clarification exercise**
(Adapted from Warfield and Manley, 1990)

- I believe that the ultimate purpose of our carer’s support group is …
- I believe the purpose can be achieved by …
- I believe my role in our carer’s group is …
- I believe that factors that will help us to achieve our purpose are …
- I believe that factors that will hinder us from achieving our purpose are …
- Other values and beliefs I consider important in relation to our carer’s group are …

All members returned the completed template and from the responses the following vision statement was created:

‘The purpose of the Causeway Carers Support Group is to meet together with people in a similar position and to support and receive support and learn from each other. This will help us to cope by relieving tension, having fun and giving us ‘me time’. New friendships will be formed through chatting and interaction. Advice and shared information from visiting speakers will help us to grow together.’

From the responses to the values clarification exercise, a set of objectives were also drafted for the group and therefore for the project and these were unanimously agreed and adopted by the group. The objectives were:

- To offer opportunities for carers to share their experiences of caring
• To engage carers in exploring how services for stroke patients could be improved
• To provide information for carers enabling them to learn new ways to enhance elements of their caring role
• To enable carers to lend each other support
• To provide a social outlet for carers in a relaxed atmosphere
• To enhance discharge planning so that carers difficulties can be assessed in a timely fashion and carers can be better prepared to balance their competing needs
• To explore ways of sustaining the group

Establishment of a steering group and a working group
In order to meet the objectives identified by the support group members it was necessary to establish two main groups. At an organisational level, it was important to secure the support of senior managers within the organisation to ensure that the project had strategic direction and was aligned to corporate objectives, whilst maintaining a focus on the needs of the service and to advise on sustainability. To this end, the project leaders established a steering group, chaired by the head of nursing for research and development (NHSCT). Membership consisted of nursing, service improvement and governance leads. Three meetings were scheduled to take place over the duration of the project, complemented by status summary reports which were to be circulated to the group three monthly. However, due to changes in personnel and service delivery demands only one steering group meeting took place. Terms of reference were agreed at this meeting and minutes circulated to those who could not attend.

In line with organisational project management processes, a working group was also established with the purpose of supporting the development and implementation of the support group. The group consisted of the project leaders, a carer representative, a ward manager (rehabilitation ward), a carer co-ordinator (NHSCT) and a support worker from Northern Ireland Chest, Heart and Stroke Association (NICHSA).

The first task of the working group was to plan a programme of events for the next 12 months which would meet the expressed needs of the carers, taking into account the agreed objectives of sharing experiences, lending each other support, social interaction, exploration of services and receiving up to date information.

It was decided that each meeting, which lasted an hour and a half, would commence with refreshments with a chance to socially interact, followed by an educational component with guest speakers talking about a topic of interest to the carers. This would then be followed by a period of discussion on the topic of the day giving carers the chance to share their experiences and to learn from and support each other. Taking into
account topics suggested by the carers and from discussion, a list of topics was drawn up and incorporated into a 12 month planner to be agreed by the carers (Appendix 2). Once agreed with the carers, speakers were confirmed. The project leaders realised after a few sessions had taken place that it would be helpful to evaluate each session as this would contribute to further planning and overall evaluation of the project. These will be discussed later in the report.

Publicising the group
One of the concerns identified by the group during the claims, concerns and issues exercise was around sustainability of the group. It was felt by the group that creating an awareness of their existence was vital to its success.

A photograph of the carers group was taken at the first meeting and published in the local newspapers with a small paragraph about the group. Posters and leaflets were drafted by the project leaders and presented to the carer’s for approval. Carers, however, felt that the pictures chosen for illustration did not effectively capture the ethos of the group and that some of the wording was confusing. Amendments were made and content agreed with the carers. The posters and leaflets were printed and displayed in local public areas including health centres, libraries, pharmacies and community centres.

A sub-committee consisting of three carers and the NICHSA representative was established to form an editorial board for the publication of a quarterly newsletter for dissemination to carers in the local area. Two newsletters have been produced to date. These contain information about the group, useful snippets of information pertaining to carers, recipes and competitions with small prizes provided. This initiative has promoted ownership among the carers with a sense of responsibility and pride evident.

During Stroke Awareness Week the members of the carers group volunteered to ‘man’ a stand in the foyer of the hospital and they drew up a rota to ensure that at least one of them was available at all times to inform the general public about carers support and to hand out relevant leaflets about aspects of stroke care. Additionally during this week, the local radio station ran an advertisement to publicise the group.

The EBD approach
Two of the objectives set by the group were ‘to engage carers in exploring how services for stroke patients could be improved’ and ‘to offer carers the opportunity to share their experiences’. It was felt by the project leaders that in order to achieve these, it would be necessary to take participants on a reflective journey through their experiences. It was
acknowledged by the project leaders that this process was likely to evoke many emotions.

It was decided to use a process designed by the NHS Institute for Innovation and Improvement (2009) known as ‘the experience based design approach (EBD)’. This approach uses patient and staff experience to design and improve healthcare services. It involves helping people (patients, carers and staff) to explore their own experiences of a healthcare service and then enabling staff to work with users to understand their experiences and to consider how they could be improved.

Due to the time constraints of the project and service demands it was not possible to use the whole ebd approach; however, the carers were given an opportunity to look at their journey through the health care system when their relative was admitted following a stroke and this included both the physical and emotional aspects of the journey.

The practice development nurse facilitated this exercise with the carers support group. Permission to use the resources provided by NHS Institute for Innovation and Improvement was secured through Foundation of Nursing Studies and members gave written consent for the session to be audio taped to ensure that valuable information was not lost following a full explanation of what was involved. The project leaders were aware that this process was likely to evoke many emotions and made it clear to the carers that they could opt out of the session at any point. They were also made aware that they could be supported through referral to an appropriate member of staff should the need arise.

A number of tools are available to enable experiences to be captured within the resource pack for the EBD approach. It was decided by the project leaders that two of these would be suitable for the purpose of this project, the:

- Experience questionnaire
- ‘Listening lab’

The experience questionnaire
The experience questionnaire allows respondents to identify on paper how they felt at different stages of their journey through the healthcare system. A template provided by NHS Institute for Innovation and Improvement was adapted to suit the context of the project with the following stages of the journey identified:

- Admission process
- Inpatient stay
- Discharge
- Follow up and support
A further two sections were also added to capture the carer’s experiences of the:

- Attitude of staff
- Information provision

A number of ‘emotion’ words were suggested to capture emotions at each stage with carers circling the most appropriate one(s). There was also space for carers to insert their own words. They were then invited to write a short sentence on the experience which led to them selecting their words (see Appendix 3).

The carers were each given a copy of the questionnaire to complete individually, which took approximately 20 minutes.

**The ‘listening lab’**
The next stage of the process was the facilitated ‘listening lab’ which was audio taped for later thematic content analysis. Carers were asked to share the words selected on their questionnaire and to discuss how these words described their experiences. This process took 50 minutes.

**The carer’s experiences – responses to questionnaire**
The experience questionnaires provided a wealth of information about the carer’s experiences of their journey through the healthcare system (see Appendix 4). The outcome of this exercise revealed a number of words which described the concerns and worries which carers experienced throughout this journey.

- **First contact with health services**
The most common emotions experienced at first contact with the health services were ‘fear’ and ‘worry’. The reasons given by the carers for picking these words were attributed to the fact they didn’t know what was happening or what was to follow as this was a new experience for most of them. The quick and professional actions of health care professionals e.g. the ambulance crew, prompted the selection of such words as ‘safe’ and ‘relieved’

- **The admission process**
The responses to this section revealed a sense of loss of control of events and also a real sense of loneliness. The most commonly selected emotion was ‘worried’ with a sense of ‘frustration’. The long wait to be given information on what was happening was a central feature of many of the responses

- **The inpatient stay**
A sense of ‘exhaustion’ and ‘worry’ was evident from the responses and there was a suggestion that this was exacerbated by the fact that there was ‘mixed messages from staff’ and ‘no one to tell you
anything’. However, there were also undertones of relief in the selected words with carers selecting ‘supported’ and ‘safe’ more frequently than in the previous sections. One carer attributed this to the fact that there was an open visiting policy on the ward.

- Discharge
  A return to a sense of panic was evident at this stage because the stroke survivor was being discharged and perhaps the carers no longer had the safety and availability of healthcare professionals on an ongoing basis. Words chosen included ‘scared’, ‘worried’ and ‘isolated’ and comments suggested that this was because of what they perceived as a lack of preparation for discharge and a ‘lack of help from social services’. There was also a sense of fear evident and a perception that carers were being ‘left on their own’ to care for their loved one.

- Follow up and support
  The sense of ‘being on my own’ and ‘responsible’ was also evident in this section. One respondent indicated that she did most of the organising of follow up and support ‘on my own’. There was also a suggestion that carers didn’t know where to go for help and support. However, on the positive side, there was praise for input from the voluntary sector – ‘NICHSA was a Godsend’ and a recognition of the value of the support group – ‘I got involved in the carers meetings’.

- Information provision
  ‘Poor’ and ‘sparse’ were the most commonly selected words to describe information provision with one carer highlighting that although booklets were available ‘what was really needed was someone to talk to’.

- Attitude of staff
  Despite criticism that information was often sparse, in general, carers described the staff as ‘caring’, ‘helpful’ and ‘attentive’. However, a caveat to these answers was that ‘these qualities were displayed by only some staff’.

The carer’s experiences – ‘listening lab’ discussion
Much of the rich information elicited from the experience questionnaire (discussed above) was elaborated upon during the audio taped discussion, i.e. the ‘listening lab’. The audio tape was transcribed and a thematic content analysis was undertaken by one of the project leaders (Appendix 5). This was done through highlighting the ‘emotion’ words and phrases which frequently appeared in the transcription. These words and phrases were then grouped under themes. A number of themes emerged which
are outlined below. They will be explored further at a discharge planning workshop for staff and at subsequent carer’s group meetings.

- **A sense of being alone**
  This was a central component to the discussion and was commented on by a number of carers. It was evident at each stage of the journey. Carers talked about being alone physically and emotionally when their relative suffered the stroke and it was apparent that this loneliness was felt both physically and psychologically – ‘I was just on my own … had to drive to the hospital not knowing’. Even when people were physically around, e.g. in the hospital, participants still referred to a sense of being alone – ‘I’m sitting here on my own’. This sense of being alone threads through to discharge and coping and led to ‘mental’ and ‘physical’ exhaustion. ‘Fear of the unknown’ and ‘fear for the future’ was also notable during the discussion

- **Lack of information**
  The most commonly cited reason for this sense of being alone loneliness and fear appeared to be the difficulty in getting information about the stroke survivor’s progress with one carer referring to it as ‘begging and begging’ for information and again this featured from admission throughout the entire journey. Because for many carers this was a new experience, this added to their sense of frustration and anxiety. Several times, the phrase ‘didn’t know what was going to happen’ was used. Additionally, there appeared to be a fear of ‘bothering busy staff’ throughout the discussion – ‘they were far too busy’, ‘I wanted to ask’, ‘so much they had to do’, ‘hadn’t time to sit down and talk to you’. For some, this perceived ‘coldness’ resulted in a number of emotions. One participant revealed how she started to think the worst because ‘no one was telling her anything’ and left her thinking ‘is he going to die?’ There was also evidence of anger – ‘to them it’s routine’, and frustration - ‘I just wanted someone to come and talk it over’. The feeling of being treated as just another relative was apparent and as one carer suggested ‘someone just needs to be there to explain’ with another stating ‘even if they’d give you 5 minutes’

- **The effect of stroke on relationships**
  Carers gave many examples of how the stroke had an effect on their relationship with the stroke survivor. They mentioned the ‘devastation’ caused resulting from ‘the loss of what they had’. They commented on things being ‘never the same again’ and the ‘cloud’ that is always there. The physical expression of love and closeness and how it had changed was commented on – ‘you can’t get that holding close’, ‘at a distance’. One carer described the change in relationship with her mother saying ‘I lost everything that day’. They also talked about how emotions of the stroke survivor had
changed with ‘tempers and tantrums’ putting a strain on their relationship resulting in them becoming ‘angry and cross’. Some of the carers referred to how they now had to take on a more assertive role within the relationship – ‘head of the home’ but they also acknowledged the emotional and physical strain that this caused – ‘keeping up appearances’

• The effect on the carer
A further theme to emerge from the discussion was the effect that caring had on the carer. There was a clear indication of being overwhelmed by being catapulted into this new role with no warning or preparation. ‘I just cried and cried’ describes the emotional turmoil caused and there was also a sense of helplessness noted, ‘I coped as well as I could’. This helplessness was evident in the statements ‘begging and fighting’, ‘you get tired and exhausted, it was getting to me and I was nothing to nobody’. The sacrifices which the carers have had to make were also discussed, ‘there’s nothing else getting into your life’, ‘it’s not about you or tomorrow or your children’ and there was an indication that carers wanted to ‘be appreciated’

• Loss of privacy
Carers talked about how they lost privacy within their own life as a result of their caring role. Some attributed this to the number of visits from healthcare professionals – ‘home was like a hospital’, ‘horrific’ and one carer summed this feeling up very well – ‘district nurse at the doorbell, doctor at the back door, carer trailing teabags all over the kitchen floor whilst I try to eat breakfast with my family’

• Ongoing support
The discussion around this topic demonstrated the frustration experienced by the lack of follow up and support. ‘Follow up was nil’ and once again the sense of loneliness was apparent in the comments. One carer saw the quest for support as ‘a fight’ which resulted in her mother perceiving herself as ‘a real burden lying here’

• Positivity for advances in stroke care
Despite the many concerns and issues raised by the discussion, there was also acknowledgement that services had improved in many ways since these carers had experienced health care. There was praise for the fact that there is now a stroke specialist nurse in post who is ‘so helpful’ and is available to speak with carers either in person or on the telephone

Evaluation
Evaluation of the project was carried out through:
Verbal feedback from social activities
One of the objectives identified by the carers was that the group meetings would promote social interaction. In order to achieve this, carers attended a reflexology session, had a visit to a local garden centre and went Christmas shopping in December. Comments on the enjoyment derived from these activities were captured and summarised on paper by the stroke specialist nurse and included an acknowledgement of the tremendous benefits of ‘me time’ with one carer commenting that it was ‘just lovely to have someone making a meal for her rather than having to do this herself’.

Observation of group dynamics
The practice development nurse was able to observe the group dynamics whilst the stroke specialist nurse facilitated the sessions. She observed that the initial meetings were friendly and as time progressed a sense of cohesiveness was evident. This observation was supported by a comment made by one of the carers, ‘when we first met and I looked around the room I wondered how we would get along, now we are like one big happy family and I know if any of us had a problem or just needed to chat we could lift the phone to anyone in the group and find support’. A clear sense of participation was observed with all members contributing to discussions. It was apparent that members felt comfortable with each other and this was evidenced by the way in which they freely shared their experiences in an open and honest way. The presence of comforting touch was noted between carers when this sharing became difficult and empathy was demonstrated. There was real concern for members of the group who were experiencing a particularly tough period over the course of the project. There was also evidence that the group were communicating with each other outside the carers group meetings, supported by comments such as ‘I’ll ring you’ or ‘I’ll call in’. There was also a therapeutic relationship in evidence between the stroke specialist nurse, the NICHSA representative and the carers which was obviously appreciated by the carers. This was evidenced through observation of conversations taking place whereby individual concerns and troubles were being addressed by the health care professionals.

Group meeting evaluation
Evaluation of the group meetings took place using a mixture of verbal discussion, observation of interaction and questionnaires distributed to carers at the end of identified sessions. Responses were collated by the project leaders. The format for the evaluation questionnaire was based on a simplified version of John’s model of reflection (1995) where carers...
were guided to think about what went well, what didn’t go so well, what new knowledge they had acquired and how this might have an influence on them personally and/or in their caring role.

- Health check up meeting
  A nurse from NICHSA attended this session and carried out checks on carer’s blood pressure, blood sugar levels and cholesterol levels. She also provided verbal and written advice on healthy diet and lifestyle:
  - Enjoyed most – carers indicated that they appreciated having their cholesterol, blood sugar and blood pressure checked. Apart from the obvious benefits of the physical health checks, carers also referred to the sharing, comradeship and ‘getting a laugh’ through attending the session. A number of them also stated that they had particularly enjoyed the scones which had been made by one of the carers!
  - Enjoyed least – the responses to this question were few indicating that the session had been a success. One carer referred to the temperature of the room being too hot.
  - New information learnt – carers reported that they now knew what their blood pressure, blood sugar and cholesterol levels were and for those who were discovered to have higher than normal levels, they appreciated the fact that they were given advice on lifestyle changes and were encouraged to go to their GP. One participant stated ‘I learnt that my blood pressure was raised and I should have it checked by my practice nurse’
  - Following today, will you do anything different? – carers referred to changes they would make to their diet and lifestyle which suggests that they had taken the advice of the NICHSA nurse who was performing the tests.
  - Improvements – carers indicated that they would have liked to see more people attending.
  - Summary – carers were asked to provide one sentence that summarised the meeting. Words used included ‘good fun’, ‘meeting everyone again and chat’, ‘it’s time out for me to meet people in the same situation’

- The experience questionnaire and ‘listening lab’ meeting
  The same template was used to evaluate this session:
  - Enjoyed most – the elements of meeting, sharing company, talking openly and learning were evident in the responses; ‘It was good to share and learn from others’ and ‘we all understood each others problems and heartaches’ sums up the responses.
  - Enjoyed least – there were mixed responses to this question. For some, the meeting had been emotionally draining, ‘the
tears and remembering how frightening it all was when T had his stroke’, ‘Depressing – brought back what happened’. However, the meeting had been cathartic for others with responses including, ‘I enjoyed today – it’s a pity it couldn’t have been longer’ and ‘I enjoyed it all’

- New information – rather than new information learnt, carers dwelt on the fact that emotionally they had benefitted from the session. A number of carers commented that they had learnt they ‘weren’t on their own’, ‘some people are worse off than me’ and ‘that some people are going through much the same as me’
- Anything different? – carers demonstrated a true sense of selflessness in their responses saying that they would like to try harder to reach out more to others who were in a more difficult situation and to just take one day at a time
- Improvements – there was only one response to this question with one carer saying that a box of tissues would have been useful as many of them had become tearful during the discussion
- Summary – the responses to this question demonstrated the value that carers were getting from being a member of the carers group, for example ‘I feel we are really bonding well and will help each other when we can’, ‘we were all as one’ and ‘very interesting and easy to talk to other people in the same situation!’

From the evaluations of the individual sessions and from observation of the group dynamics it was evident that the carers had gained a number of benefits from being a member of the group. This is summed up by the comment, ‘I like the fact that there is no other group in this area that I am aware of that is specifically for carers of stroke survivors which is important’.

**Final evaluation**
An overall evaluation of the initiative took place at the end of the project. Using a short questionnaire, devised by the project leaders, carer’s were invited to submit their comments about the project (see Appendix 6). There was an 86% return rate.

- **Main reasons for joining the group**
  The main reasons cited for joining the group were a desire to meet with others in a similar position and in doing so to make new friends through sharing experiences. A further reason was a desire for ‘me time’ with one carer stating ‘to be able to get away from my caring responsibilities for a couple of hours’. Carer’s wanted to be able to help others who may be new to the role and to learn more about how they could cope better with some of their own problems
Experiences of being a member of the group
All responses were positive and carers referred to being able to meet with others to discuss how they cope with their problems. Many referred to the benefit of sharing with others who really understood what they were experiencing, of ‘being themselves’ and not just ‘a grumpy old woman’. One carer mentioned the unique bond that they now shared as a group and it was gratifying for the project leaders to note that their support was helpful. Some found the talks to be interesting and most referred again to the importance of ‘me time’ to sit and talk.

Contribution of group membership to role as a carer
Carers were asked if being a member of the group had helped them in their role as a carer. Once again, the sense of comradeship was evident in the responses with carers referring to the informal support network established, ‘we can phone others in the group if we need to – having someone to listen and not being alone’. It was evident that carers appreciated the provision of emotional support in a safe environment. One carer also commented on how the group had helped her to be more confident as a carer with another alluding to the fact that help available now is much better than what it was when her husband took his first stroke. Once again the supportive contribution of the project leaders was commented upon.

Enjoyed most
Carers were asked to comment on what they had enjoyed most about being a member of the group. The word ‘friendship’ was used frequently in responses. A further theme in the responses was the value derived from listening to the variety of speakers throughout the year who provided ‘useful tips’. The social benefits of group membership were also referred to, particularly the ‘getting out of the house for a few hours and having a cup of tea made for you’, the ‘scones, tea and sympathy’ and being able to ‘relax for a while’.

Any other comments
Finally, carers were invited to provide any other comments relevant to the evaluation. Some used this as an opportunity to suggest future activities for the group including walks and further social activities. A suggestion came from one of the carers that it would be ‘good to form a small voluntary group to provide practical help to other carers in the form of shopping, telephone calls and baking’. It was encouraging to see evidence that the carers wanted the group to continue, ‘I would miss it if it ever stopped’, ‘I sincerely hope it continues and grows’, ‘It would be awful if the group couldn’t go on’. There was also an acknowledgement that the numbers needed
to increase and a suggestion that ‘so many need what this group has to offer – an invaluable support’

Finally there was a heartfelt thanks to the project leaders for their work during the project.

**Discussion**

The aim of this project was to establish a support group for carers of stroke survivors which met their expressed needs and this has been achieved through the setting up of the Causeway Carers Support Group. The need for such a group was reinforced by DHSSPSNI (2006) who identified that social well being is maximised by the feeling that there is someone who will listen. The meetings are attended regularly by a core group of women (n=20). Whilst one of the hopes of the group was to encourage men to join the group, this did not happen. This may be due to the fact that women are more likely than men to be carers (DHSSPSNI, 2006). Additionally, it was hoped that membership would have increased throughout the lifetime of the project. However, it was disappointing that during this time only one new member joined the group. She was recruited through ‘word of mouth’ rather than through the more costly approaches to recruitment adopted by the group. It was also interesting to note the effect that this new member had on the group dynamic. Her first meeting was to the experience questionnaire and ‘listening lab’ session which, on hindsight, may not have been appropriate since members shared their thoughts, feelings and emotions of being a carer and were only able to do this because they had developed cohesiveness through being open and honest with each other. Although the new member readily shared her own experiences, it was observed by the project leader facilitating the meeting that some of the group were uncomfortable and reticent in speaking. Whilst it was difficult to attribute this to the presence of the new member, previous to this, members appeared to communicate much more freely.

With regards to the objectives set by the group, the majority of these have been met. The main objective was that through participation in group meetings, the carers were given the opportunity to share experiences and to support one another. This has been facilitated through participation by members at each session. A further objective was a desire for more information. The meetings achieved this by providing the carers with some new information which will help them physically, psychologically and financially in their caring role. Carers listened to a talk on availability and entitlements to benefits which helped them to personally assess their own benefit entitlement. A report by Evason (2001) highlighted that only 9% of carers in NI are in receipt of Carers’ Allowance despite the fact that many more are entitled to this but remain unaware.
The need for carers to be aware of their own health needs has been strengthened by the DHSSPSNI (2006) who issued a framework for support services to carers. It emphasised that health promotion activities should be carried out within all Trust areas for carers. To this end, as part of the support group programme, carers were able to avail of a personal health check.

The quest for information was also highlighted by the outcomes of the experience questionnaire and ‘listening lab’ supporting the assertion that carers want to be fully informed of condition management and treatment outcomes and to have this delivered to them at each point in their journey with the stroke survivor. It has been noted that uncertainty can have an effect on psychosocial adaptation in illness (McCormick, 2002) and that lack of information can add to carer uncertainty which can lead to increased anxiety (O’Connell et al., 2003). A study by Wallengren et al. (2010) reinforced the outcomes of the ‘listening lab’ which suggested that information needs change over the course of the journey.

Another objective for the group was the desire to share experiences in order to support each other. The various emotions elicited by the experience questionnaire and ‘listening lab’ are not uncommon to those cited in the literature. Greenwood et al. (2008) refer to carer depression and anxiety especially in the immediate post stroke period (Greenwood and Mackenzie, 2010) and Kerr and Smith (2001) and Hinojosa and Rittman (2007) refer to mood swings and survivor behaviour. In addition, as also uncovered in the ‘listening lab’, relatives often want support in coping with their own emotions, a fact alluded to by Mak et al. (2007).

With regard to service improvement, as a result of working closely with this group of carers, the stroke specialist nurse aims to use the comments made by the carers to develop information packs specific to the identified phases of the journey which will supplement the provision of verbal information.

There were a number of challenges presented to the project leaders during the project. An area of dissatisfaction experienced was the recognition that there were a large number of carers who would have benefitted from joining the group but were unable to do so as they did not have access to respite care. It is hoped that in the future the role of the volunteer may be expanded to include the provision of respite to allow carers to attend support group meetings.

The project leaders were also faced with some personal and professional challenges. One of these was around facilitation style. It was important to remember that, whilst they were committed to completion of the project, the progress and purpose of the group had to remain within the control of the carers. The challenge, therefore, was creating a balance between
meeting the carer’s needs and facilitating the project. Based on the theory of organisational behaviour (Hersey and Blanchard, 1996), the initial approach to facilitation adopted by the facilitators was largely directing through activities such as structuring, taking control, instructing and telling group members what to do. As time progressed and the group became more cohesive, the facilitation style moved to one of encouraging and supporting with more emphasis on consultation and advice. This ‘letting go’ process was particularly challenging for one of the facilitators whose background was practice development with professional staff. She found that her role in facilitating the project required her to ‘let go’ of the desire to control change and to let other people put their ideas into practice. Barrett et al. (2005) cites that the consequences of being unable to let go are an unmanageable workload and this had to be borne in mind. For the other project leader, the ‘letting go’ was in relation to the decision regarding the purpose of the group. Her initial thoughts were that the purpose of the group would be educational; however the group members thought differently as they wanted more emphasis on social interaction. Additionally, it was noted that group members were slow to take ownership of the running of the group which may have been due to over reliance and dependence on the project leader. However when a more encouraging style of facilitation was adopted, it was noted by the project leaders that some of the more assertive group members started to take on a leadership role within the group.

Another challenge for one of the leaders was the management of emotion evoked by the experience questionnaire and ‘listening lab’ meeting. This necessitated her moving out of her comfort zone and in doing so, sacrificing a structured approach to the session. One of the important lessons learnt from this experience was that facilitation can be unpredictable and sometimes success depends on moving the focus from tools and techniques to being open minded and to expect the unexpected.

**The future**
This project has reaffirmed the need to provide a support mechanism for carers of stroke survivors. It has identified a number of areas where service improvement can be made reaching from first contact with health care services right through to discharge and post discharge.

It is important that carers are identified at the earliest possible opportunity to ensure that they get the best support and advice possible. Within this project a discharge planning workshop is still to be organised which will enable carers, ward staff and social workers to explore the current assessment of carer need, documentation and provision of post discharge support services for stroke survivors with a view to enhanced provision. A comprehensive carers assessment is vital as a first step towards identifying what support a carer requires and the workshop will provide participants with the opportunity to explore the newly introduced
NISAT (Northern Ireland Single Assessment Tool) which includes a section for carer assessment (DHSSPSNI, 2005). The outcomes of the experience questionnaire and listening labs which identified where services could be redesigned will be used at this workshop.

With regard to sustainability following the life of the project, it is hoped that the group will continue under the chairmanship of one of the carers, the NICHSA representative or the carers co-ordinator (NHSCT). DHSSPSNI (2006) recommended the appointment of a carer liaison or co-ordinator post in each health and social care trust with a remit for bringing about improvements for carers. It is therefore hoped that this remit will extend to the sustainability and roll out of the initiative across the Trust. The stroke specialist nurse will also continue to provide advice and support to the group on an ‘as required’ basis. It is hoped to eventually move towards a ‘combined’ model for the support group. This would allow patients, carers and staff to meet together so that improvements in service delivery can be identified and plans made to action these. It is also hoped that the strength of this group would be such that it can lobby Government for funding and resources to bring about improvement and to promote regional recognition for the important role of the carer.

To this end, a celebratory event to publicise and celebrate the work took place within the NHSCT and was attended by the FoNS practice development facilitator, project leaders, senior managers, carers, practice staff, student nurses, members of NICHSA, Stroke Association and Health Improvement staff. The project was presented by those involved including the carers who provided a panel discussion on their experiences of being a group member. Professor Kader Parahoo also presented his research entitled, ‘The needs of carer’s of stroke patients in the community’. The day generated some useful discussion with one of the most useful outcomes being the setting up of a committee including carers and senior managers with the aim of establishing a user support group which would hopefully attract some trust funding.

**Conclusion**

This project introduced an initiative to address an unmet need within a health and social care trust. Led by a stroke specialist nurse and practice development nurse, a support group for carers of stroke survivors was established with the aim, vision and objectives set by the members. A number of activities have been enjoyed by the carers which met their objectives for information, advice and social interaction. The various activities which took place over the year have effectively allowed the carers to gel together as a group and to support and learn from each other in a safe environment. They have also been supported to identify areas for service improvement through the sharing of experiences. Friendships have been formed and the hope is that the group will now
become self facilitating with the stroke specialist nurse providing an advisory role. The contribution of voluntary organisations has been beneficial through the involvement of a representative of NICHSA on the working group and further organisational support for the initiative was achieved through the contribution of the carer’s co-ordinator (NHSCT). It is hoped that the membership of the group will steadily increase and that the vision for the group will continue to be realised.

**Recommendations**

Although this was a small scale project it resulted in a number of recommendations for future work:

- A piece of research should be conducted which will compare the outcomes for carers participating in either a structured or unstructured support group

- A set of referral criteria should be developed by the stroke specialist nurse to ensure that all patients who have been admitted to Causeway Hospital with a diagnosis of stroke will be referred to the stroke specialist nurse; this will be disseminated to all wards and departments

- A database of carers and stroke survivors should be established so that they can be followed up at three months post discharge with an invitation to attend the support group

- This initiative should be ‘rolled out’ to other areas of NHSCT

- The possibility of incorporating some training into the programme for further support groups which may be established within NHSCT as whilst the aim of this carers group was not about training, it must be acknowledged that many carers require some training and resources to carry out their role

**Acknowledgements**

The project leaders would like to acknowledge the immense help and support from Theresa, Diana and Kate – Practice Development Facilitators, Foundation of Nursing Studies. The contribution to the project from members of the Causeway Stroke Carers Support group is also acknowledged and it is recognised that without them this project would not have been possible.

**References**


Appendix 1. The Carer’s Wish List

‘I wish I could have my life back the way it was before the stroke’

‘We had planned a trip to Canada and I wish we could go’

‘Sometimes that my sister could be more mobile – it’s hard to see her getting weaker’

‘I wish the day was over’

‘I wish I could be wife, mother and friend today instead of carer’

‘I wish I had more help to ease my burden and have a few hours to myself’

‘More support and information in the early days’

‘I wish I had more space to myself’

‘As an only child I wish I had more family members to help if needed’

‘I wish I had more help to ease my burden and have a few hours to myself’

‘I wish I was not so angry’

‘I wish I had space to myself’

‘I wish I had time to play with my son’

‘I wish I had 5 hrs- 1 day a week to myself’

‘A little free time to relax… someone to speak to when feeling down… carers money doesn’t take the stroke patient where they would like to go, e.g. garden centre’

‘I wish I could have quality time with my husband’
# FOUNDATION OF NURSING STUDIES PROJECT

‘Caring for the carers’ – The establishment of a support group for Carer’s of stroke survivors.

## TEMPLATE FOR CARER SUPPORT GROUP MEETINGS

<table>
<thead>
<tr>
<th>Date</th>
<th>Information session</th>
<th>Discussion themes/project work</th>
<th>Newsletter subgroup</th>
</tr>
</thead>
<tbody>
<tr>
<td>2/7/10</td>
<td><strong>RECREATION DAY</strong> (Reflexology)</td>
<td>Establish sub group to meet over summer</td>
<td></td>
</tr>
<tr>
<td>10/9/10</td>
<td>Health promotion for carer’s</td>
<td>First edition</td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>(NICHSA Health promotion nurses)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22/10/10</td>
<td>The experience questionnaire and</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>listening lab – emotions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7/12/10</td>
<td><strong>RECREATION DAY</strong> (Christmas shopping)</td>
<td>Second edition</td>
<td></td>
</tr>
<tr>
<td>7/1/11</td>
<td>Discussion of way forward for group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25/2/11</td>
<td>Speech difficulties – the stroke patient.</td>
<td>Common communication problems and coping</td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>(Alison Moss – SALT)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18/3/11</td>
<td>The ‘burden’ of care – carer’s needs.</td>
<td>What’s available locally for patients and carers?</td>
<td>Third edition</td>
</tr>
<tr>
<td></td>
<td><em>(Siobhan Blair – Ward Manager – Rehab)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Problems encountered –</td>
<td></td>
<td>Fifth edition</td>
</tr>
<tr>
<td></td>
<td>- Incontinence</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Swallowing</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>(Teresa Quigg and Claire King – Stroke Module)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25/3/11</td>
<td><strong>CELEBRATORY EVENT</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The **ebd approach™**

Developed by the NHS Institute for Innovation and Improvement

This Experience Questionnaire will help you think about how you feel at different stages in your journey as a carer.

<table>
<thead>
<tr>
<th>How did you feel?</th>
<th>Recovery</th>
<th>Why did you feel like this?</th>
<th>Why?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Circle the words that best describe your feelings at each stage or write your own words below.</td>
<td>happy</td>
<td>The nurse was very supportive and talked me through everything I was nervous about, like how it all went. I had a few questions that had been worrying me – she did her best to find out the answers.</td>
<td>We’d like to know why you felt like this. Was it friendly staff, a nice conversation or a long wait?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Nervous Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Write your own words here</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Using patient and staff experience to design better healthcare services

[www.institute.nhs.uk/ebd](http://www.institute.nhs.uk/ebd)

Adapted by the Foundation of Nursing Studies and attributed to the NHS Institute for Innovation and Improvement
<table>
<thead>
<tr>
<th>First contact (GP, Ambulance, A&amp;E)</th>
<th>Admission process</th>
<th>Inpatient stay (visiting)</th>
<th>Discharge</th>
<th>Follow up and support</th>
<th>Attitude of staff</th>
<th>Information provision</th>
</tr>
</thead>
<tbody>
<tr>
<td>happy supported</td>
<td>happy supported</td>
<td>happy supported</td>
<td>happy</td>
<td>happy supported</td>
<td>helpful</td>
<td>helpful</td>
</tr>
<tr>
<td>safe</td>
<td>safe</td>
<td>safe</td>
<td>safe</td>
<td>safe</td>
<td>distant</td>
<td>sparse</td>
</tr>
<tr>
<td>good</td>
<td>good</td>
<td>good</td>
<td>good</td>
<td>good</td>
<td>understanding</td>
<td>embarrassed</td>
</tr>
<tr>
<td>comfortable</td>
<td>comfortable</td>
<td>comfortable</td>
<td>comfortable</td>
<td>comfortable</td>
<td>disregarding</td>
<td>poor</td>
</tr>
<tr>
<td>scared</td>
<td>worried</td>
<td>worried</td>
<td>burdened</td>
<td>in pain</td>
<td>caring</td>
<td>unapproachable</td>
</tr>
<tr>
<td>worried</td>
<td>lonely</td>
<td>lonely</td>
<td>worried</td>
<td>worried</td>
<td>aggressive</td>
<td>confusing</td>
</tr>
<tr>
<td>lonely</td>
<td>sad</td>
<td>sad</td>
<td>lonely</td>
<td>lonely</td>
<td>responsible</td>
<td>isolated</td>
</tr>
<tr>
<td>sad</td>
<td>thankful</td>
<td>exhausted</td>
<td>sad</td>
<td>sad</td>
<td>on my own</td>
<td></td>
</tr>
<tr>
<td>out of control</td>
<td>frustrated</td>
<td>nuisance</td>
<td>confused</td>
<td>useless</td>
<td>responsible</td>
<td></td>
</tr>
<tr>
<td>helpless</td>
<td>angry</td>
<td>overwhelmed</td>
<td>responsible</td>
<td>isolated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>hopeful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Write your own words here**

<table>
<thead>
<tr>
<th>Write your own words here</th>
<th>Write your own words here</th>
<th>Write your own words here</th>
<th>Write your own words here</th>
<th>Write your own words here</th>
<th>Write your own words here</th>
<th>Write your own words here</th>
</tr>
</thead>
<tbody>
<tr>
<td>Why did you feel like this?</td>
<td>Why did you feel like this?</td>
<td>Why did you feel like this?</td>
<td>Why did you feel like this?</td>
<td>Why did you feel like this?</td>
<td>Why did you feel like this?</td>
<td>Why did you feel like this?</td>
</tr>
</tbody>
</table>
**THE EBD APPROACH –Experience Questionnaire Summary**

**FIRST CONTACT**

RESPONDENT 2 ‘Supported, scared, worried, helpless’

RESPONDENT 3 ‘Scared, worried, lonely’
   Didn’t know what happened...wasn’t present when he took the stroke.

RESPONDENT 4 ‘Safe’ ‘Relieved’
   The ambulance arrived quickly and ambulance crew were very professional.

RESPONDENT 5 ‘Scared, worried, sad’
   Knew what was ahead as I had assumed my mum had taken a stroke

RESPONDENT 6 ‘Good’
   Didn’t know what would be next

RESPONDENT 7 ‘Scared’ ‘Never involved with stroke patient’

**ADMISSION PROCESS**

RESPONDENT 2 ‘Supported, worried, thankful’

RESPONDENT 3 ‘Worried, lonely’
   Didn’t have anybody with me

RESPONDENT 4 ‘Overwhelmed’
   Little knowledge of stroke and was not sure what was happening to my husband.

RESPONDENT 5 ‘Worried, lonely, sad, thankful, frustrated’
   Long wait to hear what was going on... no admission to rehab – mum in surgical ward for 2 weeks

RESPONDENT 6 ‘Comfortable’
   Nobody was there to tell you anything.

RESPONDENT 7 ‘Frustrated’
   When Jean was brought in for tests nothing showed up and she was sent home and then she had another stroke.
INPATIENT STAY

RESPONDENT 1 ‘Happy, worried, sad, exhausted, lost’
Did not expect this after what seemed good recovery after aortic valve replacement.

RESPONDENT 2 ‘Happy, supported, safe, exhausted’
Visiting was brilliant….. because I could come into Rehab anytime and stay as long as I could.

RESPONDENT 3 ‘Worried, exhausted’
He was moody and cried a lot.

RESPONDENT 4 ‘Worried’
We were both very worried and ignorant of stroke.

RESPONDENT 5 ‘Worried, lonely, sad, exhausted, expensive, lost’
Mixed messages from staff….. never wanted to tell you anything.

RESPONDENT 6 ‘Worried, exhausted’

RESPONDENT 7 ‘Supported’

DISCHARGE

RESPONDENT 1 ‘Scared, responsible’

RESPONDENT 2 ‘Happy, worried, lonely, confused, scared, isolated’
Charlies thought process was not the same…. helping Charlie was like looking after someone I didn’t know…. the bond between us was not there.

RESPONDENT 3 ‘Burdened, worried, angry, isolated’
Didn’t get much help from social services.

RESPONDENT 4 ‘Worried, responsible, isolated’

RESPONDENT 5 ‘Burdened, worried, lonely, sad, scared, responsible, angry, isolated’
Time for home with no aids, house not adapted.

RESPONDENT 6 ‘Confused, scared’

RESPONDENT 7 ‘Responsible’
As Jean lives on her own.
FOLLOW UP AND SUPPORT

RESPONDENT 1 ‘On my own’
Very poor...practically non existent.... My daughter (a nurse) rang all relevant depts. to try to get physio and speech therapy... I did most myself.

RESPONDENT 2 ‘Supported, worried, lonely, on my own’
Chest, heart and stroke was a Godsend.... it gave Charlie time out and it gave me time to think.

RESPONDENT 3 ‘Worried, lonely, on my own, responsible’

RESPONDENT 4 ‘On my own, responsible’
We had very little follow up or support for first 6 months.

RESPONDENT 5 ‘Worried, lonely, sad, useless, on my own, responsible’
Did not know where to seek health leaflets and had no time to read them.

RESPONDENT 6 ‘On my own, responsible’

RESPONDENT 7 ‘Comfortable’
Shelagh was very supportive.... I got involved in the carers meetings

ATTITUDE OF STAFF

RESPONDENT 1 ‘Caring’

RESPONDENT 2 ‘Helpful’

RESPONDENT 3 ‘Distant’

RESPONDENT 4 I felt they did not care and had little time... because of the attitude of staff I felt they just went through procedure.

RESPONDENT 5 ‘Helpful’
Some staff were very good

RESPONDENT 6 ‘Helpful, understanding, caring, attentive’

RESPONDENT 7 ‘Understanding, caring, attentive’
As I was in Dublin Hospital for 5 and a half weeks I knew most staff who were very loving and gave me the hugs I needed.
INFORMATION PROVISION

RESPONDENT 1  ‘Helpful’

RESPONDENT 2  ‘Confusing’

RESPONDENT 3  ‘Sparse, poor’
  7 months on and no one

RESPONDENT 4  ‘Unapproachable’
  We were given many helpful booklets but really needed someone to talk to.

RESPONDENT 5  ‘Poor’
  Very little information.

RESPONDENT 6  ‘Sparse, poor, confusing, helpless’

RESPONDENT 7  ‘Sparse, poor, helpless’
  It is frightening initially to be alone with a stroke patient and poor information and poor information about Stroke Club which has been a Godsend.
**Transcription of EBD process**

<table>
<thead>
<tr>
<th>Fac</th>
<th>We’re just going to have a wee chat about the different components of this and the first thing really is about first contact. Now as W has already said to us that some people will have had experience with first contact, others not... so does anyone want to kick off with telling us about some of the experiences that you had with first contact with care services? What were your thoughts and feelings? Right Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Z</td>
<td>Well my first contact I thought was excellent because Tom suddenly had this.... whatever had happened to him and I hadn’t a clue what was wrong but when I phoned the doctor they put me straight through to the ambulance and the ambulance was there very very quickly which was wonderful because I just didn’t know what was going on.... the crew were very professional, you know and reassured me so much that I sailed into hospital thinking everything was going to be OK – they took over and I felt that was very good. I didn’t enjoy the next process at all because I hadn’t a clue what was happening to Tom.</td>
</tr>
<tr>
<td>Fac</td>
<td>Was that the admission process?</td>
</tr>
<tr>
<td>Z</td>
<td>That was the admission process : this was in AandE of course and the environment to me was so strange because I am not used to AandE – there were lots of nurses and lots of cubicles and lots of fuss going on and then I’m left with Tom in this little room and just was really really frightened because I couldn’t talk to him.... it was really really frightening – that bit wasn’t good.... so I have put down that I was overwhelmed which was quite true because of lack of knowledge about stroke... I mean I know so much more now it wouldn’t be nearly as bad but I just didn’t know what was happening.</td>
</tr>
<tr>
<td>Fac</td>
<td>And had you ever had experience of anyone having a stroke in the past?</td>
</tr>
<tr>
<td>Z</td>
<td>Not at all.... I was so ignorant about stroke.... I don’t know about the rest of you.... it really was this is why it was always my hobby horse to get</td>
</tr>
</tbody>
</table>
awareness to get the public aware of how simply it can happen and the signs like that FAST thing that we had you know its good.

Fac  OK – anyone else want to share your experience of first contact and the admission process – we can put those two together.

Y    Well I was frightened.

Fac  Yes Y– well what frightened you?

Y    Frightened because when I saw Hugh sitting with the hand limp and the foot out to the side, I’d a good idea it was a stroke he had and I was frightened and wondered was he going to die, was he going to survive and I was so relieved to see the ambulance coming and they did come very quickly. I dialled 999 and they came very quick and when I went into the hospital with him I was worried, I was sad, I was overwhelmed, I was frightened and I didn’t know what was going to happen and it was a long wait because we went in about 9 o clock and I didn’t come home to nearly one in the morning and it seemed to be endless you know because we stayed on because you had to wait until somebody saw him and somebody else came.

Fac  Did you find that you were regularly given information?

Y    Yes although there wasn’t much information to give you at that stage so because there was still no movement in his right side and he was mumbling away and I couldn’t make out a word of what he said and there wasn’t much information really to give you at that stage... it was more the next day when we saw Dr G and after that but that first night you came away and you just didn’t know what was going to happen.

Fac  Yeah – Z did you want to come in there?

Z    I just think it would have been... I think that the staff are excellent but because they are dealing with it everyday they don’t know what the patients carers are thinking... you know to them its routine and they kept on saying to me its either a clot or a bleed and I wanted to ask which would be better but you know....

Fac  What stopped you from asking those questions?

Z    Just because they were far too busy. You just sit there like a wee wife by
the bed praying Y – I was praying the whole time. I don’t know about or anybody else but you are **overwhelmed** and very **frightened**.

| **Y** | You felt there was **so much they had to do** they hadn’t really **time to sit down and talk to you** at that stage. I didn’t know there could be a bleed or there could be a clot. I wasn’t familiar with that at that stage. |
| **Fac** | Right anyone else want to come in? |
| **X** | Well I wasn’t actually with Tommy when he had the stroke. **I just got the phone call** to tell me to go to Coleraine Hospital.... he was playing in the band. |
| **Fac** | Was it night time? |
| **X** | Yes and **I was just on my own** and I had to drive to the hospital not knowing..... |
| **Fac** | You didn’t know what you were going to be confronted with? |
| **X** | No.... I thought it was just his diabetes because he’s diabetic and he had been admitted 6 months before that.... he had collapsed the night and.... |
| **Y** | You see **I was fortunate** because Hugh took it at a friend’s house – we had been asked in for a cup of tea so my friend was there and there were two friends actually there – so at least **I had people around me**. Yes **I wasn’t left on my own**. |
| **W** | To be alone and having to drive...... |
| **X** | Well he was in the pub you know playing and it was actually the wee girl that was in the bar said to the fella that owned the bar – that fellas having a stroke ‘cos her father had had a stroke – so he phoned for the ambulance and then he rang me and he said to me ‘X now don’t get alarmed’ – he didn’t tell me – he just said Tommy had taken not well and we got the ambulance for him and he’s in Coleraine Hospital. So, of course we went in and there he was lying – I knew the minute I looked at him because his arm.... so it was **frightening** sitting there on my own. |
| **Z** | This driving in in the car and I was following the ambulance and I thought what is happening and I just prayed. |
| **X** | Well everything’s going through my head – what has happened and there’s |
so much diabetes in his family you know. As I say I was sitting there on my leaf alone and then a wee doctor – it was a lady doctor and she came into me and said ‘do you realize what has happened to your husband? I says I do and I thought to myself, I’m sitting here on my own so I rang my brother and it was away about maybe after 12 …. then he got out of bed and come in.

<table>
<thead>
<tr>
<th>Fac</th>
<th>That was good – at least you had someone there with you and did you stay there all night?</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td>Stayed to about 4 o clock and then they told us the next 24 hours was crucial but there was nothing they could do…. they told us just to go on home and if there was anything they would ring…. but of course we didn’t go to bed and then we got hold of my daughter – she was only on a night out down in Kelly’s but my brother went to Kelly’s and found her.</td>
</tr>
<tr>
<td>Fac</td>
<td>That probably scared her as well</td>
</tr>
<tr>
<td>X</td>
<td>This was it and then we got freshened up in the morning and went back up again but he wasn’t talking or anything just he looked at you and just cried all the time you know</td>
</tr>
</tbody>
</table>
| W     | Well X as you say the loneliness – I was in Dublin where he had the aortic valve surgery 12 days ago and they said they had to rush him back to Theatre – they didn’t think they’d actually get him back alive because so much blood had gathered behind the heart – they had to open him again and he was in intensive care – thankfully. I had left him at 5 o clock, gave him a kiss to go down because they had a wonderful café there and I used to take an hours break…. so at five to six and when I came back, normally they’d have said to me – just you walk on in you know and I was told – no wait and you wait and you wait and you start thinking what’s wrong….. nobody tells you anything. Initially it was a lovely wee nurse came down to tell me that he’d had a stroke and well I just cried and cried and she told me come on to see him. I said I cant go now, I don’t want him to see me crying but she said he wont even know you’re there and he was unconscious and initially paralysed from the neck down so he was very
critical and I was in Dublin **on my own**…. that was **lonely** – well then when I rang my family, Jane and Paul came down in the early hours of the morning to be with me but as you said that **loneliness** – I was there I was **frightened**, I didn’t really **understand** about a stroke – the surgeon I think he said if it…. the next 24 hours are crucial and if he doesn’t deteriorate anymore then he has a chance of survival but he said at the moment and he put his hands like that – they didn’t expect him and as I say it was that being **alone**, being **frightened**, **didn’t understand** really a stroke – I used to think someone had a heart attack – that’s awful, they’ve only had a stroke.

<table>
<thead>
<tr>
<th>Z</th>
<th>And that’s oh so wrong</th>
</tr>
</thead>
<tbody>
<tr>
<td>W</td>
<td>Yeah and until I experienced, I didn’t realize just how <strong>devastating</strong> a stroke is not only to the person… how it takes away from their life but also for the carer, the wife, the sister, the support, <strong>what it does to you</strong>…. it really, you’re never when I say <strong>never the same again</strong>…. your life is never the same again, you <strong>never can have</strong>, if I can say, the <strong>happiness</strong> – you can never have that happiness, there’s always that <strong>cloud</strong> there and in my case, the person you married……</td>
</tr>
<tr>
<td>V</td>
<td>It’s not the person you married – you <strong>lose the bond</strong></td>
</tr>
<tr>
<td>X</td>
<td>There’s just I don’t know whether you’d call it a <strong>distance</strong>…. you <strong>can’t relate</strong> – the <strong>closeness</strong> is not there anymore. I notice there now if you go to give him a hug there’s more of a…… you know the hands…. you know you <strong>can’t get that holding close</strong>.</td>
</tr>
<tr>
<td>V</td>
<td>The <strong>emotions</strong> have <strong>changed</strong> completely</td>
</tr>
<tr>
<td>X</td>
<td>Yes that’s right</td>
</tr>
<tr>
<td>V</td>
<td>And then you find that very very hard</td>
</tr>
<tr>
<td>X</td>
<td>It’s hard to cope with yes and as I say my husband is terminally ill and that is doubly hard to cope with along with the stroke and his speech – it’s getting worse – everything I noticed deteriorating and so at the moment I find it very <strong>very difficult</strong> …. you know <strong>coping</strong></td>
</tr>
<tr>
<td>Fac</td>
<td>Anybody else want to share?</td>
</tr>
</tbody>
</table>
Well for me we were having a family wedding – my mummy’s grand
daughter was getting married on Friday and me and mummy were relatively
close. She had been to town that Saturday doing as she’d always done – we
were comparing nail polishes and getting confetti into the clutch bags and
we went to bed on that note. I heard a sort of moaning noise which I
thought was my young child and I went up the corridor and the baby was in
bed sleeping. I went into mummy’s room and she tried to tell me she had
been to the bathroom and somehow her legs weren’t working right and I
shouted for my husband – ‘Come up here’ you know mummy just felt a bit
limp. We got her lifted into bed and suddenly her speech just went and my
first initial thought was ‘Oh God, please not another time’.. My father had
a stroke and I would be very good in a situation you know when it’s all go,
you know I can cope well and I coped as well as I could. I went and rang
the doctor on call. He reassured me – well he sort of reassured me a bit
but really he done nothing for me. He said he’d call an ambulance but
expect it to be an hour to an hour and a half.

He said, is she a religious woman? Read her the Bible and I thought – Sod
you and the Bible. You know I just wanted someone to come and talk
over you know and mammy was trying to tell me whatever she was trying
to tell me – her speech by this stage had gone and something that was
unbeknownst to be her mouth was dry and I was giving her water through a
straw – I could’ve choked her you know – I didn’t know we just tried to
reassure her and I kept hugging her and telling her I loved her and
reassuring her it was OK and she was going to be fine – but I was terrified
– I was absolutely terrified. The ambulance crew arrived about an hour later
and because I had the baby to also see to I let mammy go in the ambulance
and I sort’ve got myself together and came down here. I came into Casualty
– mammy was in this bed – still couldn’t communicate to me – again my
own thoughts – I thought she’s had a stroke and I tried to get somebody
and say what’s going on, what’s happening. ‘There’s nothing
happening yet…. you just need to take time’. Well that was about 8 o clock in the morning – I was still here at 1 o clock the next morning in Casualty. There were no beds for mammy and still nobody had confirmed to me what really was wrong with her or what it was. She was then moved from Casualty into what was like a medical ward and she lay there for 2 weeks and the whole time she was lying there I was thinking there’s gonna never be any hope because a medical ward is not for somebody with a stroke. You know mummy waited for scans, she waited for opinions and 2 weeks down the line there was nothing….. and that’s when my anger started. I just got so angry because I thought you know, well as everybody thinks your loved one is…. I need help… I need mummy to get help… I need these things to be happening and nothing was happening. And again, anybody I went to ask it was ‘we don’t know yet’… ‘in time we’ll let you know’. Then when she got to the Rehab ward… I suppose it was really then that I thought ‘Oh God, she’s had a stroke’ and because I knew from my father having a stroke that all the signs were there but there was no speech – no speech came to mammy so this lady that was playing with me that Saturday with the nail polish had become…. she’s become what she is today…. not mammy, not the mammy I want her to be, knew her to be and really for me, I believe that I lost everything that day.

W You do lose that…. that’s what I was saying.

U That emotion as you say…. mammy shows no emotion…. you know if I told her I had cancer or I was going to Las Vegas she’s expressionless – it doesn’t seem to register but that was just my experiences and again all I feel I needed was someone to come – I’m a realist – all I wanted was for someone to come and say ‘Your mummy’s had a stroke – she’s had a bleed on the brain’ – this is the process and that was never there. Seven months on my mummy was still lying here and rather than begging and fighting the whole time – you get tired, you just get exhausted and you’re tired and you’re frustrated and you’re angry and then I felt it was getting to me – I felt I was nothing to nobody – you know I wasn’t even a mummy.
to my own wee child cos I never seen him. My baby was going to Antrim to
be looked after at 6 o clock in the morning and I was meeting him coming in
the door at 7 o clock in the evening and I was just hoping that Tony would
hurry up to get here and I was home at half ten and he was in his cot ready
to get up at 6 o clock the next morning. And really, talking it out, I still feel,
I still feel angry and that’s 7 years on – sorry 5 years on but you know I
still feel that somebody needs to be there to explain that to you and I
mean I had first hand of a stroke – so it really wasn’t that scarey as such to
me but like, listening to some of you ladies saying that you never knew
anything about it – it must have been terrifying for you all. You know, for
me, I sort’ve knew what a stroke involved but it didn’t make it any easier.

Naw I don’t think it would make it any easier

And it was the fact of you were really begging and begging people... to
me that should be everybody’s right to know about their loved one and
what’s happening. I mean, I didn’t... it was like ‘Can I take mammy out in a
wheelchair... am I allowed... and what about her swallow today.... have you
tried her swallow. You know I was going in when mammy’s speech came
back a bit – I was going in and mammy was saying ‘I haven’t been to the
toilet today’ and I’d have been saying ‘Why haven’t you been to the loo?’
‘They’re just busy’ I thought God it’s somebody’s human right to go to the
loo – until one day sort of alarm bells were ringing with me and I thought
my goodness – you know you haven’t been to the toilet all day – I had to go
that evening at visiting time and say ‘I would like you to check why mummy
hasn’t passed any water today’ You know it was me who had to say ‘Can
you’s put in a catheter or is there any way you can start to get her kidneys
going again?’ Nobody had noticed that. So to me, them people is left in
them beds and despite, I know everybody is busy and there were some
nurses who were very good in the unit but there were a lot who
didn’t care.

Another thing I didn’t like – Tommy’s only in his 50’s and the ward he was in
was 70’s, 75’s and they were all lying – wouldn’t even speak or nothing –
but then they got him one of those electric wheelchairs and then he was fit to go outside. And they had a wee garden round the back and I got him out on Bank holidays but there again I had to come up for him about 9 o clock myself, take him out, put him in the car – you know there’s **no help no help whatsoever.**

<table>
<thead>
<tr>
<th>U</th>
<th>Aye and meanwhile when this is all happening there’s <strong>nothing else getting into your life</strong> – you’re like a Zombie going about.</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td>And I was trying to keep up my work too cos I needed the money – I was working 8 – 5 – coming in, seeing to the dinner and getting here for 7 o clock. If you were a minute late, ‘what kept you?’ And he never was like that – Tommy never cared about time but you see the minute he had the stroke it was....</td>
</tr>
<tr>
<td>U</td>
<td>I think that’s because their world becomes so small, you know their world – there’s only them in their world, in their bubble and I find that about mummy yet – if I was to sit with mummy 23 hours a day it’s never enough. Their world becomes so small – there’s no one else in their world – you know <strong>its not about you or tomorrow or your children or whatever</strong> – it’s about them and much as you love these people <strong>you still want to feel needed</strong> and want to be <strong>loved</strong> or <strong>appreciated.</strong></td>
</tr>
<tr>
<td>W</td>
<td>Yes it’s <strong>hard to take</strong> at times isn’t it? I mean you do what you do because you love the person but there’s times.... you <strong>don’t seem to have a life.</strong></td>
</tr>
<tr>
<td>V</td>
<td>Sometimes you <strong>question why</strong> it has happened to us</td>
</tr>
</tbody>
</table>
| U | Even when I look at you ladies sitting in here and I think my mummy should be sitting here .... it’s not that I want youse to be unhealthy but you want the best for them and I want mammy to be sitting here talking with everybody elses mummy and then you **struggle and you struggle** and as V says you’re **on your own** – you’re trying to be **everything to everybody** and you’re **mentally and physically exhausted.** And then you’ll get this dickhead, excuse my expression, come up to you and they’ll say ‘God isn’t your mum looking great’.
| W | Oh yes, I was going to say that.... **that annoys me** |
| U | ‘You’re that good to her and you take her out and it’s only 10 o clock in the morning’ and you think you don’t know I’ve been up since 5 o clock to get her looking that well. |
| W | They’ll say ‘arent they great, aren’t they wonderful’ You feel like saying – ‘No they’re not- you should be with them 24 hours and see the other side – all the **tempers and the tantrums.**' |
| U | They say ‘she’s that good, she never complains’ and you think God **if they only knew** – she’s just given me dogs abuse all night and I’m saying but I don’t feel how you feel about my mammy and you have this **anger inside you.** |
| W | Yes there’s times you get **angry** and **cross** |
| V | Yes the person with the stroke wouldn’t be looking as tidy and well if it wasn’t for you. |
| U | And because my mammy cared so much about her appearance – that’s all I ever wanted – I am remembering you know when they get to the stage where you can take them out of the ward for a walk and I used to put the baby on one side of mammy in the chair and walk that corridor and the only thing was my wee boy loved to get to the end to the machine to buy a packet of sweeties. I can remember taking her into the toilet down below and you know, she loved lipstick and I said ‘here put your lipstick on today mammy’ and she’s sitting there and it’s just like this lipstick going everywhere and you cant really correct that because you want her to feel as normal. |
| Fac | And it would have been unwise if you had taken over and tried to clean it up |
| U | And another thing I found so **frustrating** – you know even from the start here and everywhere or most places was ‘Does she take milk?’ ‘Does she like?’ and I thought Why don’t you just ask her? ‘Does she take custard?’ as if she was this person lying in behind the chair. |
| Y | I find even yet if we go out to visit people tend to **ignore you.** As if he cant talk to them and he’s left sitting there and they talk among themselves and they don’t seem to bother with him. |
Or because of mammy’s speeches I’ll get ‘I don’t understand a word she says so I don’t go to visit her’. And I think you know if somebody’s blind do you not talk to them or is somebody is deaf – like you know there’s ways. Even if you never knew what somebody said you could still have contact with them. Like a hug, like a touch, mammy can hear – she might not be that able to speak but she can hear. And I just feel in this room there is so much raw emotion still there from everyone of us and you can feel it when everybody speaks – cant you?

You definitely can and I suppose for me, I’m sitting her and I’m just thinking is this wrong that this has been revealed today? all this raw emotion and I’m just conscious of the effect this is having on all of you.

But I think it’s good to be.... it’s good to release it

It’s up to yourselves – I need you to tell me if this is what you want

Well for me, I don’t mind because to me it’s like a release... it’s like a valve – you can get rid of it and you can go out of here and that’s another wee bit gone. And I’m not as raw today as I have been at a previous session.

When you are with your loved one you are keeping up appearances – you know you’re telling your children to make father laugh, talk to your father. And their wee hearts are breaking and you leave them at night and you’re crying going round that ring road.

And I think it’s a woman thing – there’s a drive in a woman to be like an ambassador – to be head of the home – to be mammy.... I can do it all, I don’t need people and we all need people and yet there were people saying to me, well very few people, but the thing people did say ‘Maybe I could come round and give you a hand’ and you thought sure she wouldn’t know how to work with mammy and I had things like even toileting... I used to think sure nobody could leave mammy the way she should be left – you know they all have their dignity and they don’t want a stranger.

Naw my husband wouldn’t have wanted a stranger in although I had the offer of a nurse every morning. I said no, he wouldn’t want that – it’s not for everybody, I’ll cope.
And then you find too that when people start coming into your home.... my home was like a hospital. It was the District nurse at the doorbell now, it was the doctor at the back door, it was a carer – the experience I had with some of my carers was just horrific and still it was like a nightmare – yet when I see the girl I think, Oh God here she comes again, you know. I used to be in bed on a Saturday morning thinking – another 5 minutes and this person will be in through my home. My husband and my wee baby were sitting at the table trying to take their cornflakes and this person was trailing this teabag all round the kitchen while we were sitting there thinking ‘Isnt that terrible’ and mammy was trying to tell her what she needed or wanted and she never answered her – this used to frustrate me – I used to think – she has the right to be looked at and she needs a tablet – would she like a drink?

She’s still a human being

My experience of Ernie being in Dublin – when we got back home the follow up was nil. Absolutely nil. And to people who know the reason he was able to speak so well again was all the work I did with him. Only my daughter whose a nurse did a lot of searching and ringing people and that but still I dunno maybe 6 months or more after he came home before we got any physio or any speech therapy or any help.

And then you have to follow up once you go home – you still have the exercises to do with him

I got nobody.... I was completely alone

There was a list and I had to wait til it came to my turn

And then my fight was mummy was here and she’s been here for some time and she was saying to me ‘I feel a real burden lying here... you know... every day the nurse walks in and says are you still her Mrs F?’

Oh I know

And we were at the stage where what’s next for them? and my thing was well once we got a package settled it’s time for mammy to move home. The other part of my family were saying it’s over my dead body – I was like
**fighting with my own family** – so unbeknownst to me my brother discharged my mum from here and took her to somewhere.... she had lived in her own home for 50 odd years – he had taken her to somewhere totally different – she was like a fish out of water – took her to someone else’s home, played Mr Wonderful and they got a care package – morning and night. It was more than I got. Within 12 weeks down the line they called this big meeting to say we can’t cope, you know she’s going to have to go home to you. Mum came home to me 12 weeks later and **I had nothing**.... not a thing. I hadn’t even a wheelchair – I had to go the Red Cross and thankfully they lent me a wheelchair for a number of weeks until mum got one.... but again it was ‘has your mum had a stroke?’ ‘How did you get a wheelchair?’ You were **on your own totally.**

| X | But I think now, they’re much more aware of strokes and they might be a bit **more helpful**.... I’ve a brother now and they’re getting more help |
| U | The procedure seems easier than what it was 5 years ago |
| X | You know if you saw Tommy – as T knows – you’d think Tommy is so easy going but.... |
| U | And then there’s the **pride thing** – I’m sitting here telling this and I’ll probably go out that door thinking why did I tell all them people.... you **bottle it in though** |
| W | It’s really **good to unload** though |
| U | But you feel like....... |
| Z | How do you two ladies feel when you hear all this.... what we’re all saying is we were **frightened**, we were **lonely**, we **didn’t know** and I think really to sum it up – when this stroke overtakes you it would be nice if there was **someone** even if they’d **give you 5 minutes** – surely that would not be impossible for someone to have that as a caring role – just to sit and say your husband’s had a stroke – we think it might be.... |
| T | I think now that Tricia’s there hopefully people are getting more information |
| U | Well it’s like **fear of the unknown** and I think if you know what the situation is you can cope with it better than being totally **alone and** |
isolated and not knowing.

<table>
<thead>
<tr>
<th>Z</th>
<th>Because then you think the worst – your mind goes ahead of you and you think the worst don’t you</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fac</td>
<td>In answer to your question, Z, from my point of view, this has confirmed to me a lot of what is missing in the health service today and what really concerns me about it is the fact that it’s a commonsense, humane approach that is missing. And I think sometimes when staff work in an area for a long time they become blasé about things so every stroke is the same and they tend to forget there is a family, carers and a whole social circle out there that has been affected by this person and I suppose in terms of what we are doing today, these are the types of things I believe can benefit service delivery. And I know in another Trust they have a group like this with carers, staff and stroke survivors who meet together to discuss service improvements. And as T says people are now beginning to recognize that users of services and carers need to have a voice to help shape services delivered. So to all of you I can only apologise to you on behalf of nursing for the negative experiences you have had and to reassure you that things will improve.</td>
</tr>
<tr>
<td>U</td>
<td>There’s a girl works with me who has had a stroke and she’s only in her 40’s – she had a stroke about 2 weeks ago – I am a trade union representative at work so I was out in her home the other day with the Personnel manager – just catching up on how she was and just listening to her talking about how she was treated here – she did mention Patricia – there’s a girl Patricia down there and she’s lovely – I felt that she was coping alright because she felt she had some strength behind her – support – whereas looking back to us – we didn’t have that.</td>
</tr>
<tr>
<td>Y</td>
<td>You see Hugh has had 2 strokes and there was such a difference after the second one because Patricia was there. And it was so different from the first time because Patricia was so helpful and you knew you could go to her – she said that’s my wee office and if I’m not in, leave me a wee note and I’ll contact you or ring me and she was so helpful and it was so different from</td>
</tr>
</tbody>
</table>
the first time.

<table>
<thead>
<tr>
<th>V</th>
<th>It’s great to know there’s <strong>help</strong> at the end of a phone and understanding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fac</td>
<td>What about the overall experience?</td>
</tr>
<tr>
<td>S</td>
<td>We have the experience of Jean and she keeps getting those wee strokes and we’re aware that every 6 months she’ll be admitted again. She’s in now, went in on Saturday – then she had a big nosebleed on Tuesday night and then she broke her hip in April and was in 5 months. So about every 5 – 6 months she gets mini strokes and every one takes its toll</td>
</tr>
<tr>
<td>X</td>
<td>That’s what happened to Tommy last year</td>
</tr>
<tr>
<td>Z</td>
<td>What about your husband P – you’re very quiet?</td>
</tr>
<tr>
<td>P</td>
<td>He’s doing quite well now but it’s just the same as the rest of you – at the start it was <strong>hard</strong> and <strong>nobody to tell you anything</strong> – then he was admitted – just <strong>worried</strong> – just nobody there to tell you anything</td>
</tr>
<tr>
<td>U</td>
<td>Maybe on a more positive note I know another man who had a stroke and he’s only about 50. It’s quite sad as he was going away to Korea or somewhere. His son was getting married – Billy had another stroke and was down here and he got that new drug – they way he’s far better than he ever was!</td>
</tr>
</tbody>
</table>
Appendix 6

CARING FOR THE CARER’S

OVERALL EVALUATION

1. WHAT WERE YOUR MAIN REASONS FOR JOINING THIS GROUP?

2. WHAT HAVE BEEN YOUR EXPERIENCES OF BEING A MEMBER OF THE SUPPORT GROUP?
   (Might want to talk about how the group has progressed from first meetings to now)

3. HAS BEING A MEMBER OF THE SUPPORT GROUP HELPED YOU IN YOUR CARING ROLE?

4. WHAT DID YOU ENJOY MOST ABOUT THE GROUP OVER THE LAST YEAR?

5. ANYTHING ELSE YOU WANT TO SAY ABOUT THE GROUP?