



'Caring for the Carers' – The Establishment of a Support Group for Carers of Stroke Survivors

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Project background

It is estimated that 4,000 people survive stroke annually in Northern Ireland and that more than a third of these will be dependent on a carer. Carers are defined as 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. They have been found to experience a range of physical and psychological problems particularly in the early stages of this caring role. Preliminary investigation revealed that although a local 'carers group' was in existence, it was generic in nature and not specific to the needs of carers of stroke survivors.

A national strategy for carers in Northern Ireland recognises that carers have an important part to play in rehabilitation. Furthermore 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 is through the provision of support groups.

Aim and objectives of the project

The project aimed to establish a support group which would meet the expressed challenges faced by of carers of stroke survivors in the Northern Health and Social Care Trust. The objectives were:

- To use an experience based design (EBD) approach to identify and understand the needs of a carer of a stroke survivor
- To promote a sense of self ownership by carers with the support group and facilitate its sustainability
- To engage carers in exploring how services for stroke patients could be improved

Key activities and outcomes from the project

A feasibility survey was undertaken (n=20) to establish local interest in the formation of a carers group and the format it should take. Of this cohort 75% demonstrated an interest in joining, with the other 25% indicating a willingness to do so, but an inability to attend due to carer responsibilities.

A number of approaches were used to establish the support group and help the carers to identify their own objectives and how these would be met. These included a values clarification

exercise and the production of a vision statement. To support the project, a steering group and a working group were established. The working group developed a 12 month programme of activities to 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. These activities were positively evaluated by group members.

To enable the group to share their experiences and to explore how services for stroke patients could be improved, carers were involved in a reflective experience questionnaire and listening lab. A number of areas were explored in the carer's journey; admission process, inpatient stay, discharge process, follow up and support, staff attitudes and information provision. The EBD approach identified where services could be redesigned and a follow up is planned with both staff and carers.

A sub-committee of carers was established to publish a quarterly newsletter for carers in the locality. Two newsletters have been produced to date.

It is now intended to develop a criteria system for referral to the stroke specialist nurse within the Trust. A database of carers and stroke survivors is planned to enable discharge follow up including offering the option of joining the carers support group.

Implications for practice:

- The establishment of a carers group for stroke survivors addressed a previously unmet need within the Trust and supported significant improvements to the service e.g. carer information and social interaction
- The project team needed to overcome challenges of facilitating the project whilst also 'letting go' to ensure the needs and wants of the carers were met
- Not all stages of the EBD approach were able to be undertaken within the project time frame but those used enabled the sharing of experiences, learning and created a sense of group support for the carers of stroke survivors in the Trust
- Other carers may have benefited from joining the support group but were unable to do so as they did not have access to respite care to facilitate attendance
- There is an opportunity to roll out this kind of initiative to other services within the Trust

A full project report including references can be accessed from: <http://www.fons.org/library/report-details.aspx?nstdid=11369>

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