

PROJECT SUMMARY

Project Title: Long Term Support in Stroke	Date Project started: January 2006
Project Lead (MI): Gaynor Smith	Date Project closed: June 2007
Project Lead (Other): Tom Penman, Connect	

Brief description of aims of project:

This project (run by Connect, the Modernisation Initiative and local people living with stroke) aimed to pilot collaborative working with local people living with stroke to address some of the long term impacts of stroke. A number of local people took on the role of long term support coordinator, whose task it was to:

- Facilitate the creation of a sustainable network of people living with stroke to provide a range of opportunities for sharing knowledge, experience, skills and inspiration
- With the network, identify within and beyond the boroughs opportunities for development of confidence and activity, together with the means of accessing these opportunities
- Create a network of voluntary and public sector organisations offering services and opportunities to people living with stroke

Reason for change:

There is a considerable body of literature describing the long-term life impacts of stroke – which include loss of independence, restricted social participation, depression, and isolation - and the kind of support that people with stroke and their carers require (NAO, 2005; McKevitt et al, 2004). Additionally, South London Stroke register data shows that although 26% of stroke survivors were moderately or severely disabled at 1 & 3 year post-stroke, 55% were assessed as ‘inactive’ at 1 year and 51% at 3 years. (Patel et al, 2006).

Research indicates that the kinds of long-term support that people require and the gaps in provision are:

- Social and emotional support
- Information and knowledge about stroke
- Coordination of, information and communication about, the health and social care system and wider services available for people living with stroke, and
- Practical support not only to manage every day life but also to re-engage with a life that is personally meaningful

What we did (action taken):

People living with stroke were trained and supported to:

- Raise awareness of their long term support issues and needs with local service

providers

- Identify the barriers and facilitators to accessing long-term support opportunities locally
- Trail innovative ways of sharing information, and practical ideas and support for living long term with stroke from their lived experience
- Pilot a network approach to increasing the social participation of local people living with stroke
- Develop ways of collaborative working that enabled people with communication difficulties to participate in a range of ways

Network activities included:

- Mystery shopping
- Reviewing community access
- Lobbying local authorities
- Running stroke awareness events in GP practices for practice staff and patients

Impact, display data baseline to current:

7 local people living with stroke became trained network coordinators

Over 90 local people living with stroke were involved in long term support network events across Lambeth and Southwark

Outcomes / Learning:**The long-term support co-ordinator role:**

- Many of the long term support co-ordinators had life experience prior to stroke of leadership and involvement in their local communities
- It takes time, support and experience often for people to feel that they can play a more active role in developing and delivering services
- With the right support people living with stroke who have communication difficulties were able to take on the role of long term support co-ordinator and work collaboratively with other coordinators, utilising complimentary skills and taking on different tasks.

Engagement:

- The network found it difficult to engage with more isolated people living with stroke, such as in nursing homes.
- GP practice events provide to be the most effective method for reaching previously “unreached” people

Through this project, and other user involvement initiatives, Lambeth and Southwark now has a resource of involved and skilled stroke service users

How has change been sustained:

The learning and skills developed in the Long Term Support in Stroke Pilot project will inform the development of the new Lambeth and Southwark Stroke Service User Involvement Network.

Contacts for further info:

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