

The development of a Peer Support Service for people living with stroke:

A collaborative project by Connect - the communication disability network and the Stroke Modernisation Initiative

the communication disability network



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Abstract

Lack of relevant information, post hospital abandonment, and limited long term support are frequently cited as service gaps by people using stroke services (NAO Report, 2005). Our Health, Our Care, Our Say together with preliminary recommendations from the Department of Health Stroke Strategy strongly recommend peer support and local

networks as a creative way of addressing the needs of those with stroke and other long term conditions. This poster reports on preliminary findings from a project to train and support people with stroke as peer supporters.

What is the Peer Support Scheme?

Figure 1 - Introduction to the scheme for peer supporters and people with stroke referred to the scheme

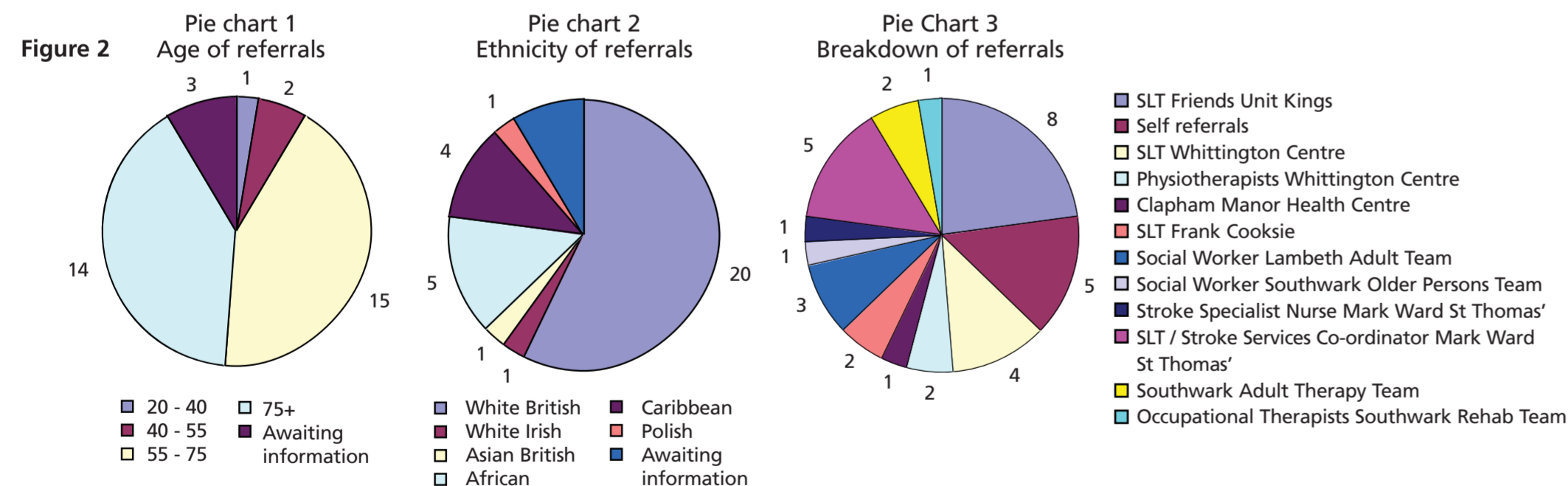
What does the scheme do? In the words of the trained peer supporters...

- 'In stroke care there is a catalogue of things that don't happen - we are an interesting service - we get in before others'
- 'As a peer supporter I hope we offer motivation and hope'
- 'You talk about day to day stuff'
- 'It (the scheme) helps because you have been there and it makes people realise they are not alone'
- 'A network for people to meet'
- 'It's about using your personal experience'

Who uses the scheme?

To date 35 people with stroke living in the London boroughs of Lambeth and Southwark have used the scheme. The age range and ethnicity of people referred to the scheme is shown in graphs 1 and 2.

Referrals to the scheme have come from a range of sources, predominantly from within hospital and community based therapy teams and are represented in figure 2.



Michael, a trained peer support volunteer, meeting a client



Peer support volunteers talking to others about the benefits of the scheme



Peer support group meeting where peer supporters share experiences of their visits

John and Sandra's story

John had his stroke in March 2007. John was a Deputy Head Teacher prior to his stroke. He was first visited by a Peer Support Volunteer whilst in a neuro rehabilitation unit, where he spent three months after his stroke. The referral to the scheme came through his Speech and Language Therapist and he was first visited in the second month of his rehabilitation while he was still trying to adjust to life post stroke.

On his return home John continued to receive visits from two trained peer supporters, Ken and Jane. The visits take place at John's home and normally last around an hour. John's wife Sandra is often present too.

Ken and Jane spend the time with John talking about their own personal experiences of stroke, what they found helpful and how they have got back to everyday living. They have also shared their knowledge and expertise of life after stroke, for example managing transport and driving an adapted car. Sandra and John are very happy with the meetings and Sandra says 'Jane and Ken are very positive people. They have given me hope about the future.'

When asked what they have gained from being peer supporters Ken and Jane both say that they are delighted to be able to help someone else. Jane says 'I wish a scheme like this had existed when I had my stroke'

To date six meetings have taken place and the peer support meetings are ongoing.



Peer supporters with stroke who work on the scheme

- 'I see myself fulfilling a role'
- 'You learn a lot'
- 'I don't want anyone left on their own, I remember what it's like. Families are kind but they don't really understand'
- 'The scheme has given me more courage to ask for things myself and to join in conversation'
- 'Without peer support I wouldn't have developed, I wanted to prove I was ok, this is my own way of doing it'
- 'I get more out of it than I give. Now I feel 'whole' the peer support scheme has made this possible'

Service Providers who refer patients to the scheme

- 'I think the peer support scheme has the potential to make a real difference to patients' levels of anxiety about going home and life after stroke'
- 'Patients have enjoyed speaking to Sharon (peer support worker) as someone outside of the hospital staff who can empathise with their experiences on the ward. Since Sharon has started making regular visits we have had an increase in referrals to the scheme'
- 'Having the peer support volunteers has been great for patients to receive emotional support while in hospital from someone who can truly empathise and understand their situation. The opportunity for this to be continued in the home environment helps with the sometimes difficult transition on discharge and ensures people are put in touch with appropriate support networks'.

Evaluating the project - Benefits of the scheme

To date there have been a range of benefits. Feedback from the three key stakeholder groups suggests the scheme offers:

- Help with the transition from hospital to home
- Support with lifestyle issues post stroke, e.g. parenting, work, holidays
- Relief from isolation
- Confidence partnering
- Emotional support from experienced people with stroke
- Networking opportunities

Evaluating the project - Some issues and challenges to date

- Encouraging service providers to make referrals
- Getting commissioners and planners to give the scheme a higher profile
- Getting sufficient and clear background information on who was to be visited
- Anxiety by service providers about the skills and training of the peer supporters
- Training and support required for service providers to complete risk assessment forms
- Management of communication issues for peer supporters
- No shows for peer support meetings

What do people say about the Peer Support Scheme?

People receiving the scheme

- 'It's really made a difference'
- 'It's giving people the message that there is life after stroke and people shouldn't be intimidated'
- 'The past is important but you have to move forward which is part of what peer support can help people do'

Training the peer supporters - What does it cover?

- The role of the peer supporter
- Skills of a peer supporter
- The volunteering process
- Roles and boundaries
- Difficult scenarios
- Support and supervision
- Health and safety
- Managing supervision and feedback

Conclusions and recommendations

- Peer supporters provide a creative, low cost way to extend information and support services to people with stroke
- There are potential benefits for people who use the scheme and also the people with stroke trained to provide peer support
- Although some service providers were initially reluctant to refer to the scheme referral patterns increased over time
- Visits just prior to going home from hospital and in the community were found to be particularly helpful
- Visits in the acute hospital setting were most appreciated after the very acute phase
- Visits in the acute setting tended to be more chaotic and harder to co-ordinate
- The scheme appeared to benefit both those with stroke and their families