

Developing a resource for parents with stroke

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Abstract

Research, consultation exercises, and clinical practice have highlighted the diverse needs of adults living with stroke and aphasia. For younger people with stroke these include issues of parenting and changed family relationships, for example Parr et al, 1997, Parr 2004; Hilari and Northcutt, 2006. The information and support needs of this group are often inadequately met within traditional stroke services.

About the project

This project was initiated following feedback from people living with stroke in Lambeth and Southwark about the dearth of information available to younger people with stroke. Specifically there was criticism about the lack of information and resources for parents who were facing life after stroke.

This project aimed to collaborate with parents and families living with stroke in contact with the Stroke Modernisation Initiative and Connect to develop a practical resource for parents and families grounded in the lived experience of stroke.

Seven people with experience of parenting after stroke were recruited to the project advisory team. Further contributions to the content of the resource were made by in depth interviews and a join in event for parents with stroke. The advisory team worked with a project worker over nine months to plan and run a join in event for parents with stroke, elicit and illustrate key themes for the booklet and DVD, review and edit the text and DVD digital stories, and support the design and dissemination of the resource.

The project ran between August 2006 and July 2007 and was part of the Living with a Disability strand of work within the Stroke Modernisation Initiative.



Involving people with stroke and aphasia

People with stroke and aphasia were involved from the outset of the project. A team of seven key advisors met monthly throughout the project. The advisory team:

- Planned and supported the join in event
- Selected key themes for the booklet
- Elaborated key themes with stories and tips
- Reviewed and commented on the first draft of the booklet
- Selected themes to represent in the DVD digital stories
- Reviewed and edited the first draft of the DVD digital stories
- Commented on production and design issues relating to the resource
- Supported the launch of the resource in July 2007

The advisory team solicited and drew upon views of their family members in developing their stories and tips. This led to Craig Grant contributing a child's eye view to the DVD resource.

In addition to the advisory team and to capture views of parents with stroke outside London we also conducted in depth interviews with three parents who had children aged from 0 – 14 at the time of their stroke in Bristol.

A final group of stakeholders involved in developing the resource was a group of 15 people with stroke and their partners who attended a join in event in September. The purpose of this event was to surface the range of issues faced by parents and families post stroke and to begin the process of gathering helpful coping strategies which different people had found helpful.

At the conclusion of the project we asked the advisory group to comment on what they had found interesting/useful about their involvement in the project. Comments included:

- "Meeting more people like us"
- Helping other people
- "We hope other people won't have the problems we had, especially the kids"
- "If you can understand it, it's better (not so scary)"

Craig's story



Craig was just twelve when his mother, Catriona had her stroke. He remembers the immediate aftermath of her stroke, of calling the ambulance, about not knowing what would happen. 'After it arrived I was almost ushered away - we were taken next door to our neighbours... later on my dad arrived... only to leave for the hospital and for me and my brother to be shipped off again to our friends' house. It really felt like we were being passed from pillar to post and being passed along like an unwanted package'.

Craig reflects on the importance of keeping children informed and reassured. 'As a child I think I was kept in the dark about the whole thing. I had to fill in the gaps for myself and it also didn't prepare me for what I was to encounter at the hospital later on'. But he now feels the experience has taught him new skills and strengths. 'I'm so much more independent now. I have to plan my own schedule round my mother's rehabilitation whilst also continuing my own life'.

Sharon's story

Sharon Smith had her stroke in 1989 when she was seven months pregnant with her fourth child. Her life dramatically changed at this point - her husband had to care for their three sons and their new daughter and look after Sharon. He 'had to control everything I did, food clothes, everything... he even had to learn me how to brush my teeth. He did a good job'. On the DVD Sharon talks about family relationships and how starting a football club helped her husband bond with their sons. Art and poetry helped Sharon express her feelings. 'I kept all my darker parts for my art'. She explained that finding other people with stroke and aphasia was the key to becoming stronger 'I thought I was the only person in the world who had a stroke and had aphasia but there were loads of us... it made me feel I didn't have to hide myself any more. I am proud of stroke and my aphasia because it's made me who I am now. It's made me feel better to let it out'.



Feedback on the resource from parents with stroke

"The good thing is it's us... not patients... in our lives"

"Sometimes people in hospitals treat us all the same. But we're all different... we have a life"

"You're not on your own"

In the early days, the majority of parenting was left to my husband because I was too busy dealing with getting well again. We were just left to our own devices because there was nothing even remotely like this book and DVD around. It certainly would have been reassuring for us to know that there were other parents, who were in the same situation. The DVD was totally inspiring! Offering six short stories, each one totally different, just reinforced the variety of ways in which a stroke can affect other people and their families. It was nice to see an opportunity for parents with strokes who had

lost their reading ability to feel included too.

On a personal level, I feel sure that having the opportunity of either seeing or reading the DVD or book would certainly have given me some encouragement and guidance. What this does is to offer a clear framework to work from - with enough flexibility to cater for individual circumstance'.

Sue Boazman, who had her stroke in 1989 when her two daughters were just four and two years old.

Key findings - What did parents with stroke say they needed?

Advisory group discussions, interviews and the join in event surfaced a wide range of issues faced by parents with stroke and their families. These issues included:

- Getting information
- Understanding emotional responses and needs
- Managing feelings and attitudes
- Dealing with practicalities – in the hospital and when you get home
- Managing discipline and communicating with your child's school
- Coping with changes in roles and relationships
- Getting support

In developing both the ideas guide and the DVD the advisory group were keen to represent getting on with life and changes for the better as well as the more difficult changes. Positive changes included for example:

- A better work/life balance
- Less stress
- Slowing down and being calmer
- Improved relationships with children
- Children becoming more independent and more considerate

The Having a Stroke Being a Parent Resource

This consists of an Ideas Guide, full of practical tips and advice from parents living with stroke to other parents living with stroke. The resource also contains six stories on DVD – four people living with stroke, the teenage son of a person with aphasia and a partner caregiver. These are in the style of the Patient Voices stories (www.patientvoices.org.uk) three minute segments told from the person's own perspective developed through groupwork and interview with participants.

The resource has been distributed free of charge to people with stroke and stroke service providers in the London Boroughs of Lambeth and Southwark. The resource is available nationally through Connect – www.ukconnect.org

Recommendations and next steps

At the conclusion of the project we asked the advisory group what they would like to see happen with the resource. Their responses included the following:

- For service providers to think about us as people and parents and individuals
- For service providers to involve the whole family in recovery
- For service providers to recognise life goes on, things change, sometimes they can be better
- The need for self help and support groups
- For the resource to be made available to both people living with stroke and their family – 'You may not be ready your family can use it, and you later'
- A future project addressing the needs of younger children and teenagers

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