

**PROJECT SUMMARY**

<b>Project Title: Information Project</b>	<b>Date Project started: March 2005</b>
<b>Project Lead (MI): Gaynor Smith, Linda Briant</b>	<b>Date Project closed: December 2007</b>
<b>Project Lead (Other): Service Users</b>	

<b>Brief description of aims of project:</b>
<p>To provide people living with stroke and the people who care for them with timely, appropriate and accessible information about:</p> <ul style="list-style-type: none"> <li>§ the nature of stroke</li> <li>§ the full range of services available to them</li> <li>§ access to opportunities for life after stroke</li> </ul>

<b>Reason for change:</b>
<p>People living in Lambeth and Southwark with stroke and their carers reported that they did not have access to timely, appropriate and accessible information about the nature of stroke, the full range of services available to them and opportunities. <i>“It was almost as if ‘information’ as desired by respondents symbolised an element of control in a situation over which they had none”.</i> Kate Melvin 2004</p> <p>This is a feeling shared by service users nationally as reported in the Stroke Association’s campaign “Nobody Told Me” launched in November 2006 and highlighted in the DoH consultation document ‘A New Ambition for Stroke’ July 2007.</p>

<b>What we did (action taken):</b>
<p><b>Exploring information needs</b></p> <ul style="list-style-type: none"> <li>• Held two ‘Join in’ events for people living with stroke and their friends and relatives. This was an opportunity for people to talk about their experience of stroke and share their views about improving services and information.</li> <li>• Formed the Stroke Information Advisory Group - a partnership between services users and health and social care professionals. (14 people)</li> <li>• This group mapped their stroke information experience. They identified what information they wanted, when they would have liked to have received it, the most appropriate format and what</li> </ul>

the emotional impact was in receiving or not receiving information. This qualitative data enabled us to develop the optimum Southwark and Lambeth stroke information pathway.

- Used the information pathway to map current information provision in services

### **Getting information to service users**

- Identified models of good practice and accessible information and disseminated throughout the local health and social care economy. Information evaluated by service users is listed in the Stroke Information Toolkit available to download in a PDF format [www.mystrokeservices.org.uk/publications](http://www.mystrokeservices.org.uk/publications)
- Identified information gaps and developed good quality information and resources in a variety of formats (see resources developed).
- Developed information protocols with hospital and community services integrated into the stroke care pathway. Information is given as part of an individual's care plan, personalised and localised.
- Staff given the skills and knowledge to provide information to people with stroke and commitment to meet specific communication needs.
- Supported staff developing information to attend Making Information Accessible (a one day course provided by Connect UK)

### **Resources developed**

For more information about developing the following resources and to download PDF documents go to [www.mystrokeservices.org.uk/publications](http://www.mystrokeservices.org.uk/publications)

- Stroke care pathway – a visual tool to help people understand what happens after a stroke. It also indicates what kind of support is available depending on need.
- Stroke information pathway – An audit tool developed with the help of service users, health and social care professionals and the voluntary sector to focus and map patient and carer information needs.
- Outpatient information prescription service (GSTT) for people who have had a Transient Ischemic Attack (TIA) episode - getting the right information, to the right patient, at the right time.
- Transient Ischemic Attack (TIA) handbook – a personalised information resource about TIA and stroke prevention (staying healthy – self management).
- Ward leaflet/booklet – information about stroke, what to expect and ward information and services.
- Accessible menus – Learning from the Patients as Teachers project indicated the difficulties some stroke patients with aphasia experience in making their needs known whilst in hospital. As a result a team of staff and patients have developed accessible menus and picture boards which are now being used at GSTT and King's stroke units.
- Stroke patient handbook – A flexible "filofax" type patient held record with sections and signposting that span the entire pathway of care. Information can be tailored to the individual's needs and level of comprehension. There are sections for goal setting, appointment records, and contact details. All stroke patients at GSTT and King's receive a copy of the Stroke Patient

Handbook as part of their rehabilitation.

- Forward - a biannual newsletter for all stroke patients on the South London stroke register and stroke programme database. This newsletter is produced in partnership with service users and provides information about stroke news, research and services. (A collaboration between the MI stroke programme and the South London Stroke Register).
- “Having a stroke – being a parent”: Based on the experiences of parents with stroke and aphasia and their families, this publication and DVD aims to provide ideas, inspiration and support for parents with stroke and aphasia, from the early days in hospital to coming home and beyond. Developed in partnership with Connect UK, this resource is free to people living with stroke in Lambeth and Southwark. [www.ukconnect.org](http://www.ukconnect.org)
- A local service directory is available online at [www.mystrokeservices.org.uk](http://www.mystrokeservices.org.uk) to be accessed by staff, service users and carers on local resources and information about stroke.

**Impact, display data baseline to current:****May 2004**

Variable quality of information  
Limited support for people living with stroke

**March 2008**

People living with stroke in Lambeth and Southwark receive timely, appropriate and accessible information about:

- § the nature of stroke
- § the full range of services available to them
- § access to opportunities for life after stroke

Staff given the skills and knowledge to provide information to people with stroke and commitment to meet specific communication needs.

**Outcomes / Learning:**

Well defined and developed information protocols with hospital and community services integrated into the stroke care pathway. Information is given as part of an individual's care plan, personalised and localised.

Involving service users in the development of the stroke information strategy ensured new services and information being developed were patient centred and what local people wanted. A service user advisory group is a very useful way to develop jargon free and accessible information.

The involvement of staff supported clinical engagement, particularly when negotiating new information protocols (it only takes the engagement of one clinician who will then engage the other team members).

Encourage and support awareness raising events with clinical staff when launching new information resources. Invite service users who have experience of stroke to talk to teams and explain what this information would have meant to them. Make it a patient centred experience.

Ensure appropriate clinical governance guidelines are followed and you have sought appropriate corporate sign-off before engaging designers/printers.

Plan your dissemination and agree storage when producing books/DVDs etc. Factor in dissemination costs when deciding where products will be delivered.

Working in partnership to develop "Having a stroke – being a parent" with the voluntary sector (Connect UK) provided additional patient centred expertise and experience. Agreeing Connect UK hold the copyright supported sustainability of these materials post MI project.

Combining resources with the South London Stroke register to produce and disseminate a newsletter for services provided access to a much wider audience and provided richer content.

**How has change been sustained:**

- Procurement processes and budget lines for ongoing purchase and supply of materials is currently being negotiated.
- “Having a Stroke – being a parent” resources disseminated to services in Lambeth and Southwark. Available to purchase nationally from Connect UK.
- Where possible, new materials generated are in printable formats, PDF downloads, and established dissemination methods are being utilised, such as trust intranets, local service directories and the voluntary sector.
- Information giving imbedded as part of rehabilitation process in the stroke care pathway.

**Contacts for further info:**

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