Aphasia/Communication Services

Proposal for the development of Aphasia/Communication Services in Oxfordshire

Background
Stroke is the commonest cause of adult disability in the UK. Families and carers of stroke survivors require support, information, education and preparation at all stages of recovery from stroke (Robinson et al., 2005) to enable them to participate in care in and out of hospital. Patients, their families and carers need user-friendly relevant information and support during the stages of rehabilitation particularly in making the transition from hospital to the community.

Quality Marker 13 of the National Stroke Strategy identifies the need to provide: Specialist Coordinated Rehabilitation starting early after stroke and provided with sufficient intensity reducing mortality and long term disability. Components of the stroke specialist rehabilitation include communication and cognitive difficulties.

Communication problems are one of the most common effects of stroke losing the ability to speak or understand is both frightening and frustrating for the individual, and happens to about a third of people who have had a stroke. There are limitations on provision of speech therapy services in Oxfordshire, and discharge from therapy is often earlier that what is anticipated or desired by an individual with aphasia. Whilst there are considerable means of support and access in the community for those with mobility impairments eg wheelchair access and auditory aids for people with hearing impairments, there is a limited amount of support for individuals who cannot communicate effectively their wants/needs. This reduced access, combined with a lack of knowledge/understanding about aphasia, sets many individuals up for social isolation and at the very least, reduced independence in community engagement.

This proposal sets out to look at and develop ways to improve services to individuals with aphasia, their families/caregivers and the community that serves them. This includes development of services that continue communicative intervention and support for as long as is needed and desired, by the individual with aphasia. The aim is to provide life participating approaches that maximise communicative potential and reduce barriers to social reengagement.

Current provision
Currently there is a Tuesday morning Communication group in existence in Littlemore, with no other known Aphasia groups in Oxfordshire. This service is funded by the PCT. This service is run by a Coordinator who is allocated an addition 4 hours to deal with administration and take new referrals. The current service has been running for approximately 15 years and the contract is renewed annually in April.
SALT input takes place when patient in hospital, with further blocks of therapy 6 to 8 sessions per block taking place once patient is discharged. These sessions take place either in a hospital setting or in the patients’ home

**Proposed Solution**
This proposal will build on the existing Communication Support Group funded by the PCT and provided by the Stroke Association. The aim is to enable the current Communication Group to become a Support Group, thereby freeing up the Coordinator to develop and manage the proposed Communication Service.

The service will support those with communication difficulties following a stroke to attain maximum recovery in communication skills and become as independent as possible. Communication support helps improve quality of life by building confidence, improving morale and giving support to families.

It would help people with communication difficulties to take the first step to regaining independence. It aims would be to:

1. Encourage self-advocacy – each user’s needs and wishes are recognised when devising the work programme.
2. Develop Rehab Services – via motivation and stimulation by helping to improve quality of life – not only for the individuals but also for carers.
3. Develop Support for carers – by supporting families of individuals with long term disabilities following stroke and facilitating training in Supported Conversation for carers and family members.
4. Support would also be extended to carers as their well-being is directly affected by the health of the user. The stress and distress caused by general exhaustion, financial worries and difficulty in communication leaves many people unable to carry out their role as carers.

**The Need for the Service**
Each year over 130,000 people in England and Wales have a stroke. Of all people who suffer from a stroke, about a third are likely to die within the first 10 days, about a third are likely to make a recovery within one month and about a third are likely to be left with disabilities including communication difficulty and needing rehabilitation.

It is very common for stroke to affect a person’s communication skills resulting in dysarthria affecting the ability to produce speech, and aphasia which affects the
ability to use language and to communicate. Aphasia is a life changing condition which impacts on both the individual and others around them. Poor communication can prevent people affected by stroke from getting the care and support they need and reduce their ability to participate in social interaction. It can also hinder reintegration into society and diminish quality of life. There is little public awareness about the devastating impact of communication disability; this can lead to withdrawal, increased anxiety and depression, with a greater dependence on medical, social services and informal carers.

One third of stroke survivors have persistent speech, language and communication problems. More than half of individuals have been described as having dysarthria. A significant number will recover in the first two weeks, but approximately 15% will have significant speech impairment. Annually, 60 people per 100,000 populations will suffer with aphasia following their first stroke (Royal College of Speech & Language Therapists, 2007). Carers will need to be assisted to learn how to understand and respond to altered speech or use of alternative means of communication (Royal College of Speech & Language Therapists, 2007).

They also state that for all stroke survivors with communication difficulties, a seamless transition to speech and language services in the community is essential. People can experience communication difficulties after stroke with few other physical signs, and may be discharged after only a few days on the acute pathway so access to communication support in the community should be timely and seamless.

**How the service will work**

It is estimated that of around 1/3 of people left with disability after a stroke 1/3 of those people will experience some form of communication difficulty. Based on the current figure of 1260 strokes per year in Oxfordshire, we would expect around 140 per year to experience new communication disability. We would therefore expect to receive around 60 new referrals per year with around 60 on the caseload at any one time.

Goals are set for each referral, taking into account the wishes of the stroke survivor and the family, as well as the assessment of the therapist, with whom there is ongoing personal contact to ensure that those concerned are satisfied with the service provided.

The service will include several 8-10 week workshop type blocks of support working in small groups with the focus on Supported Conversation aimed at giving our service users the opportunity to learn and practice the skills in a safe and
professional environment. Service users will be reviewed at the end of each block and will have the opportunity to attend further blocks as necessary.

Blocks of support will move around the county dependent on the needs of the referrals, but there would usually be 2 weekly group activities happening within the county at any one time (once the service was established), with the exception of Christmas and Easter.

Once on the caseload people would be reviewed after every block of support and any continuing needs will be addressed. It may be that they join another block in the county or work one to one with a volunteer for a set time. The coordinator would also encourage peer support during the time that the blocks are not running potentially in the same venue in which the block was held e.g. a café or a library.

Length of time on the service is dependent on the needs of the stroke survivors and carers, and it could be that someone is supported for as little as 8 weeks or as long as a few years.

Below is an example of how the blocks may work covering 3 different localities in the county on a rotating basis across a year. The example shows 8 week blocks.
Service users may also be offered one on one support from a trained volunteer to help them achieve specific goals either in the home or within the local community.

**Examples of tasks a volunteer might undertake**

- Visiting a service user at home to offer conversation support and respite for a carer
- Accompanying a service user to the shops or football match
- Supporting a service user to use the bus
- Helping a family create an individual communication book
To Summarise

The service would be run by the Communication Service Co-ordinator whose responsibility it is to recruit, train, deploy and support volunteers within the service.

Communication Service comprises of 8-10 week workshop type blocks of support working in small groups with the focus on Supported Conversation and 1-1 support either within the service users home or in the local community.

Support would also be given to the families and carers, and where appropriate, carers groups are provided. Communication Service offers a local service to meet local needs. It is flexible within the set guidelines and the service adapts to meet the requirements of individuals and the specific.