

Summary Report:

Stroke Association

Monday 23rd March 2015 | 10:00 am

Bath Bowling Club, Pultney Road, Bath

Attendees:

- Barry Grimes (Communications Manager, BaNES CCG)
- Laura Marsh (Commissioning Manager for Long Term Conditions, BaNES CCG)

The Stroke Association Communication Support Group meets every Monday in Bath and every Tuesday in Midsomer Norton. It provides an opportunity for those who have had a stroke and their carers to support each other, hear talks from experts and socialise. The meeting was attended by approx. 20 patients, carers and volunteers with three members of staff from the Stroke Association acting as facilitators on each table.

Introduction

Barry Grimes presented an overview of the purpose and principles of the **your care, your way** review. He explained the definition of community services and the phases and timing of the review. He also shared some of the themes that have emerged from previous engagement events including:

- The role of system navigators is key to delivery of seamless and integrated services
- There must be strong relationships between organisations and departments within organisations
- The role of voluntary and third sector providers is key
- The behavioural and cultural barriers around information sharing must be addressed
- Primary care is central to the role of community services and GP's recognise they have a key role as "caretaker" in a person's pathway of care

Barry explained that this is a key opportunity for commissioners, providers and our community to be innovative, be imaginative and be bold in helping to shape the outcomes of the review. We want to be proud of what we achieve as a result of the review.

Group Q&A Session

The key themes that were raised from the Q&A session were:

- Access to ongoing speech therapy is very important
- The care provided after a stroke is very good but after a few months the support begins to reduce and you are left to cope on your own
- A crisis can occur at any time so appropriate community services need to be available outside the normal 9-5 window.
- The Communication Support Group is really valuable to people and provides an opportunity to share their experiences with people who have also been affected by stroke. It helps build confidence and reduce social isolation.
- Care navigators would be really helpful for identifying who you need to call to access services or finding out about courses, groups or events.
- It's important that the CCG and the Council avoid using healthcare jargon when presenting to patient groups and that the slides provide some information that has been tailored specifically to the interests of the audience.

Group Discussion and Feedback

Barry introduced some theoretical case studies (Norman and Jean) to encourage people to consider what local services people might use or want to access in the future.

The room was split into four groups (volunteers, carers, stroke clients, aphasic group) with facilitators at each table. Participants were asked to think about what works well currently and what are the key things you feel could make a difference to community services.

Volunteers

What could be done differently?

- Trained befrienders – link to voluntary services
- Go to a church/meeting/day centre
- Assistance with personal care
- Information – navigation – services
- Support/visits at home from nurse re. medication
- More GP involvement
- Painting class – finding a class/maintaining an interest (Age UK, Community learning)
- Involvement with Stroke Association, local group to get more information and meet others
- Transport
- Support with deciding where to live e.g. stay at home, supported housing, care home

Carers

- Transport to hospital appointments
- Community support/neighbours/church
- Lack of information
- Lack of carer support, lack of free time
- Carers card
- Free “carers” personal care
- “Personal assistants” to do daily chores e.g. running house, changing lightbulbs
- Short term respite – free regardless of personal finances
- Holiday with support – change of scenery
- Carers Centre – respite care/sitting service
- Weekly clubs – providing respite e.g. communication groups
- Need for ongoing speech and physio therapy
- Need exercises you can do yourself e.g. using apps on tablet devices like Talk Board, but then see a therapist every 3-4 months
- Therapy assistants to come and supervise therapies (doesn’t have to be a fully trained therapist)
- Ability to go back for therapies if situation changes
- Accessibility of buildings/transport – prevents people getting out and about
- More info on powers of attorney e.g. completion of form, cost if done by solicitor
- Assisted suicide – law changes
- Community Stroke Team (ESD) – only 6 weeks
- Paying for care – lack of knowledge about private services
- Benefits and financial assessments – need help through process
- Cognitive difficulties post stroke – dementia/RICE

Stroke Clients (some aphasia)

Norman and Jean need:

- A care and benefits plan
- Help to organise their future in conjunction with family
- Knowledge that if Jean has to go into hospital, someone can look after Norman
- A community consultant who can coordinate all their services
- Routines and mechanisms to support those (e.g. neighbour keeps an eye daily. If she has to go away, who looks out?)
- Social life
- Circle of friends
- Care
- Purpose
- Keeping her mind busy
- Jean needs support as a carer
- They need support as a couple

- Anything that takes the weight off their shoulders
- She gives a lot to other people/community. It would be good for them to give back to her.
- Welfare officers attached to surgeries to help plan care so people can stay at home
- Community nurse/navigator
- Help with reviewing/checking medication and explaining it
- Nurses/carers with time to do their job plus a bit more
- Better information about community services available
- Services to “enrich” his life
- Contingency plans/a key worker to ensure things run smoothly and head off problems

Aphasic Group

- To be able to look after yourself
- More assistance and information
- Speech and Language Therapy
- Need regular emotional support and peer/group support
- Aphasia support
- Volunteer support
- Support for benefits and forms
- Impact on emotional and psychological
- Exercise groups
- Frustration
- Confidence is really important. It can be lost quickly and takes a long time to build it up again.

Feedback by Email

The following feedback was sent in by someone who was unable to attend the meeting:

“From my experience, a lot of different professional people came out and helped me in the beginning and after a time it fizzled out. Because I had a big stroke, I struggled to do different things in the beginning as my brain could not understand it. With time I wanted to learn but I did not get the chance to carry on. If I had had more speech therapy to help me and someone to help me write then I might not now struggle with sentences.”

A carer’s view: “It is really hard to ask for help. It’s difficult to let someone in on what’s going on in your world. You think you can cope and when you can’t you feel like you have let them down. I think when you can trust someone who doesn’t judge you then it is easier to talk to them. I think it’s really important to talk and it does help if you are talking to someone who has been through a similar situation.”

Next Steps

Barry and Laura thanked everyone for their input and suggestions.

- Attendees took away booklets and leaflets to read and share.
- Further feedback is invited via the website <http://www.yourcareyourway.org>
- Individuals can also feedback by writing a letter, making a phone call or using Facebook and/or Twitter

More information will follow in the coming weeks regarding Phase 2 of the engagement which will include focus groups and workshops in May and June. We will contact all stakeholders involved in our engagement directly once dates and agendas have been confirmed.