

Have your say!

A newsletter for cardiac, stroke and vascular patients & their carers

Welcome...

Volume 1, Issue 6

September 2011

Welcome to the September edition of 'Have your say'. It's been a busy and unsettling year for the NHS what with the restructuring, with restructuring plans and reorganisation as the focus for many employees.

There are many changes still to come over the next two years as the government focuses on 'strengthening the collective voice of patients and the public'. Local Health and wellbeing boards will pick up the responsibility of involving patients and carers in any local engagement work. Local

Patient Involvement Networks known as LINKs will become local HealthWatch and will take on more duties and powers around involvement. None of this will become formal until 2013 so plenty of time to try it out and iron out the teething problems.

As a patient or carer do you feel you are fully involved in the care you receive? Do you get the opportunity to comments on the services you have received? I'd be interested to know your thoughts?
Rachel

Stroke Patient Information Review

South Tees Hospitals NHS have just undergone a review of their stroke patient information. Seven patients and carers attended the event on Wednesday 17th August at the Independent Living Centre in Middlesbrough. The information being reviewed was the current South Tees Patient Information Booklet, the

recently developed North of England Cardiovascular Network (NECVN) booklet and the new Stroke Association booklet.

The comments and feedback from the group was very interesting. They really liked the Stroke Association booklet because they could build the booklet to their specifications. But thought it would be better to

have the information about the stroke at the beginning of the booklet like the South Tees & NECVN booklets. All in all the information gathered will be used to ensure stroke patients and their families get the information they need and a booklet they find useful. Thank you to those who took part.

Joint Care Planning

The National Stroke Strategy was published almost three years ago. Quality Marker 12 within the strategy refers to the need for a 'workable clear discharge plan that has fully involved the individual (and their family where appropriate) and responded to the

individuals particular circumstances and aspirations is developed by health and social care services, together with other services such as transport and housing'.

The NECVN has been working with each locality to help develop their own joint care

plan. Patient involvement is fundamental in making this a success and each of the localities are about to embark on piloting their plans with patients.

I shall keep you up to date with the progress on this piece of work in future newsletters.

So what is the NECVN?

The North of England Cardiovascular Network (NECVN) is a local 'organisation' made up of clinicians, managers and commissioners from primary care trusts, acute trusts, including tertiary care, and the ambulance services, who all work together to improve cardiac, stroke and vascular care for patients in the North of England. We cover a 2.8 million population across:

- *North of Tyne (Northumberland, North Tyneside & Newcastle)*
- *South of Tyne (Gateshead, Sunderland & South Tyneside)*
- *County Durham and Darlington (Durham, Darlington & Bishop Auckland)*
- *Teesside (South Tees, North Tees, Hartlepool & North Yorkshire)*



Map of NECVN area

The Stroke Association Step Into Northumberland

The Northumberland Long Term Peer Support Service is a one year pilot service that is joint funded with NECVN. This is the first service for The Stroke Association in Northumberland and is the first of its kind in the North East region. Access to the service is for all stroke survivors and their carers.

The service offers peer support within a group setting with trained volunteers also offering support with achieving their own personal goals whilst

offering practical and emotional support. We provide information and signpost to other local resources for education, training and leisure interests. There are opportunities for people to try new activities while being fully supported by the coordinator and volunteers. We also ensure that stroke survivors with communication difficulties are supported to access the group and community resources fully.

The first group is now successfully running in Blyth

with groups in Morpeth, Belford, Wooler & Berwick commencing in September.

For further information please contact the coordinators:

Sarah Taylor (South Northumberland) 07534 915763 email: - sarah.taylor@stroke.org.uk

Trish McLaughlin (North Northumberland) 07852 953133 email: - trish.mclaughlin@stroke.org.uk

British Heart Foundation (BHF)

Join the BHF Heart Watch and help us keep a close eye on how cuts are affecting heart patients and their families across the UK.

We're worried that heart patients and those at risk of heart disease could lose out because of Governments and

health providers looking to make cuts and savings.

Tell us about changes to your local services and we'll:

- Collate information so we can see what's happening across the UK. It'll help us when we're talking to the key decision makers, who can make a

difference to the quality of local heart health services.

Provide you with contacts and information on starting your own campaign to protect vital local services.

<http://www.bhf.org.uk/get-involved/campaigning/heart-watch-hub.aspx>

County Durham & Darlington Heart Patient & Carer Group

The County Durham & Darlington (CDD) Heart Patient & Carer Group are a group of 10 people who have been affected by heart disease in some way.

They have been meeting for a year now and work closely with the commissioners and clinicians responsible for heart services across CDD.

Each of the members link into other patient groups such as heart support groups and bring the views of those people to the healthcare professionals to

help improve services.

The group have recently looked at the cardiac rehabilitation workplan and have decided to work closely with the professionals around Heart Failure rehabilitation across the county for all heart failure patients. They would also like to get involved in the patient evaluating of cardiac rehabilitation. Was rehab of benefit and how could the service be improved? The group will also be involved in the transfer from phase 3 rehab

(NHS sessions) to phase 4 (community sessions).

The group have also been asked to comment on the current percutaneous coronary intervention (PCI) service available across CDD and will be working closely with the clinicians and commissioners looking at how we can provide a better service for the patients of CDD.

For more information about the group please contact Rachel Bourne, contact details at the bottom of the page.

North East Stroke Research Network (NESRN) Patient Carer Panel (PCP)

The NESRN PCP was set up in 2007 to ensure that the views and perspectives of stroke patients, carers and the public are included in all NESRN activities. Over the last year Panel members have been involved in a variety of activities including giving advice on research projects, staff training and attending conferences.

A number of local researchers have met the PCP to discuss their potential research studies during the very early stages of development. One study included the use of new computer gaming equipment which Panel members have had the opportunity to try out. Two studies in the latter stages of development have managed to obtain substantial funding.

Some members have been involved in educational videos such as those produced for National Institute for Health Research. You can view this



on http://www.crncc.nihr.ac.uk/ppi/vid_get_involved

High quality training is important for NESRN staff. Panel members and staff have appreciated working together on consent education. Several sessions have now been held where Panel members take on the role of prospective trial patient. These have proved to be a valuable way of assessing new staff and have also helped boost staff confidence.

In June our PCP were able to attend the first National Stroke Assembly held in Birmingham. The event was attended by stroke survivors, carers, researchers and charities. The aim of the event was to make

sure the 'voice of stroke' was heard by decision makers and those working in the field of stroke.

A variety of issues were discussed during the conference including stroke research. Opportunities to learn about the latest aids and stroke services were available as well as open sessions for reflexology, massage and art therapy. PCP members contributed a great deal to the event and thoroughly enjoyed meeting other stroke survivors from around the UK. You can view items regarding this on

<http://www.strokeassembly.org.uk/content/qa-assembly>

If you would like to know more about what we do please contact Judy Murdy on 01670 529578 or Lisa Stuart on 0191 5699809.

Neurological Patient Workshop

A neurological patient workshop was held on Wednesday 3rd August. Five patients attended and we explored ways in which we could set up a neurological patient & carer group. The group will work alongside the healthcare professionals at the request of the Tees-wide Neurological Forum.

We are in the process of setting up Terms of Reference, developing a process for engagement with the forum, and developing a flyer to promote the group.

I would like to share some of the comments from the workshop. Some of the issues highlighted on the day were:

1. Lack of information – DVLA – *'I was driving for 1 year before finding out I shouldn't have been as I wasn't insured!'*

2. Radar Key – Would be

useful to have an Info pack on diagnosis full of local information, including the Radar Key and named nurse contact details.

3. Time to talk to someone – time at the follow-up appointment. And easy access to specialist nurses.

Other comments made were:

'I have to have a relapse before I can access rehab. Something in between would be nice but I don't want to go to a leisure centre on my own – I'm quite unsteady so will feel vulnerable'

2nd Progressive MS sufferer

'I didn't get any rehab until 2 years after my diagnosis. My GP told me about the MS nurse who then got me into the rehab sessions'

1st progressive MS sufferer

'There are always issues

around re-scheduling appointments. The people answering the phone can be quite 'bolshy'. My appointment is always changed a week before hand – not good for working people!'

2nd Progressive MS sufferer

'MS patients sometimes don't see the consultant at their appointment it is usually the registrar. But you can ask to see the consultant – we need to let patients know this'

2nd Progressive MS sufferer

'The taxi firm I use are really good. I know how much it's going to cost and I get a text to let me know what car and time they will come'

2nd Progressive MS sufferer

For any more information please contact Rachel Bourne.

Stroke Patient & Carer Groups

We are currently looking to set up stroke patient & carer groups to work alongside the healthcare professionals who provide and commission stroke services.

The 1st North Tees and Hartlepool workshop and the 1st Gateshead workshop will go

ahead during September. County Durham & Darlington to follow.

We will then look at setting up groups in Sunderland and South Shields followed by South Tees.

If you would like to get involved but can't attend meetings you can always be involved via email, post or phone.

If you are interested in joining one of these groups then please contact Rachel Bourne

Contact Information

If you would like to share your story or would like more information about anything discussed in the newsletter or are interested in getting involved in any of the groups please contact Rachel Bourne, Patient & Public Involvement Lead, FREEPOST RSHH-CKJC-CJHJ, North of England Cardiovascular Network, Darlington PCT, Dr Piper House, King Street, Darlington DL3 6JL

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