

## **Secretary's Report to AGM March 2011**

**Our Monthly Newsletter** is now circulated to around 180 people, over 120 by email and the rest by post. We include as much information as we can reasonably fit on to two sides of A4, especially for local events that may be helpful to members. During the year there have been a number of requests for members to take part in surveys/questionnaires/research projects. We continue to support these in the hope that eventually the body of evidence will be so strong services may actually be provided. Any ideas for the Newsletters would be most welcome.

**Regional Headway.** I have attended meetings in Leeds and Wakefield. Headway Second Chance at Wakefield has moved from portakabin type buildings in the grounds of Pinderfields Hospital to a refurbished GP practice building in the centre of the town, next to The Ridings Shopping Centre. They employ a number of staff to run the centre that is open every week day. A large committee has the unenviable task of continually making applications for grants and raising money to cover the costs as well as being responsible as employers. Although the facilities are great and we would like to see something similar for every branch it is something we simply can't aspire to unless we gain a number of new members able and willing to take on such a time consuming responsibility.

Apart from our own Headway news and events we are also involved with other groups such as North Bank Forum, Epilepsy UK, Hull LINK, East Riding LINK and the new Neurological Alliance.

### **East Riding LINK**

During the earlier part of the year I attended numerous meetings across the county, in Bridlington, Bishop Burton College, Beverley, Driffild etc. Sub-groups covering GP Issues; Transport Action, Acute Hospitals; Care in the Community and Mental Health & Learning Disabilities all have separate meetings and report to the Lead Group meetings where members of the public may also have their say on health issues.

I was a member of the Lead Group, the Acute Hospitals and Care in the Community sub-groups. I undertook Enter and View visits to Ward 2, Castle Hill Hospital and a Residential Nursing Home in Pocklington. Alison Rowlands and Ann Burdall are members of the Mental & Learning Disabilities sub-group.

By the middle of the year I was experiencing some discomfort which led to a hip replacement operation in September. I could not continue to attend so many meetings or read and comment on so many documents. My first loyalty is to Headway so I resigned from the Lead Group and took a break from the sub-group meetings. Although I am now recovered, the change in government is resulting in LINKs being disbanded and replaced by Health Watch – what a waste of time and money spent setting up LINKs, which, in turn, replaced the Patient and Public Involvement Forums.

### **Social Policy Research Unit (SPRU) – York University**

The government funded research to assess the impact of the National Service Framework (NSF) on integrated services for people with long-term neurological conditions came to an end. The findings were not a surprise. Clearly the majority of PCTs have not made it a priority to implement the 11 Quality Requirements set out in the legislation. No fresh money available, no incentives and no penalties for failure. The Royal Neurological Alliance is enthusiastic about the Report and will use the findings as evidence when lobbying for improved services.

We have sent our congratulations to the SPRU team for winning The Queen's Anniversary Prize for Further and Higher Education 2009 and have agreed to be part of the Advisory Group for the next research project.

### **Neurological Alliance.**

I attended the first meeting of this group in November, 2010. Representatives from other neurological groups such as Motor Neurone Disease, MS, Parkinsons etc., all agreed that we need a combined voice to influence future services. We recognise that we share many similar problems and look forward to future collaboration.

## **BIRT**

On Friday 18 February I attended a seminar introducing a new service. BIRT, in partnership with North Lincs. & Goole Hospitals NHS Foundation Trust, provides high quality intensive rehabilitation in a residential setting based at Goole Hospital site. Unfortunately, only a few of our members have had the benefit of the service since the majority are discharged direct from hospital to home. BIRT are now able to offer transitional living experience. Where a patient is assessed as no longer requiring a hospital environment but is not ready to return home, this service provides continuing rehabilitation in a four-bedded house, staffed 24.7, where service users will be able to practice and develop daily living skills and increase independence in an environment similar to home. Therapeutic and clinical input will be available from the main BIRT service.

## **North Lincs. & Goole NHS Foundation Trust – NSF for people with long-term conditions.**

By co-incidence I was contacted that same week by a GP, based in Beverley, who is carrying out some research on behalf of North Lincs. & Goole Hospitals NHS Foundation Trust.

She asked if I was familiar with the NSF for people with long-term conditions as she is looking at how they can comply with the 11 Quality Requirements of this legislation. I was able to supply her with a copy of the 2006 questionnaire and answers completed by members. I also told her of our involvement with research carried out by SPRU at the University of York.

Compliance with the 11 QRs would provide us with the services we have been asking for:

- A clear care pathway with medical, therapy (especially neuro-psychology), SS and family inclusion.
- A multi-disciplinary team (MDT) for each area where all staff are trained to understand the brain and brain impairment. No matter what has caused the changes in a brain the majority of the ensuing problems are common to brain injury, Alzheimer's, MND, MS, Parkinson's, stroke etc. etc. Staff able to recognise and offer positive ways to cope with anger, memory loss, fatigue, etc., must help reduce the levels of frustration so many people experience. This ultimately improves quality of life and reduces the incidence of crisis and merry-go-round of hospital admissions.
- Access to intensive rehabilitation (such as that offered at BIRT). Discharge co-ordinated so that the patient is immediately picked up by their area MDT to continue therapies and ensure financial/housing problems are dealt with. Therapies should not be time limited. They should be available for as long as progress is being achieved.
- Access to step-down residential rehabilitation (such as the new service offered at BIRT).
- Access to respite care with staff trained in understanding brain injury.
- Access to sheltered housing with staff trained in understanding brain injury.
- Access to sheltered work facilities and social activities.

The GP said she would let us know results in due course. I continue to be optimistic, despite previous efforts coming to nothing.

A big thank you to Peter and Alison for their continuing input during the year and to our Members Committee for finding us a varied and entertaining programme of speakers and events for our monthly meetings.

Finally, tickets are selling well for the Fashion, Food & Flowers Day set for Wednesday 11 May, the middle of Action for Brain Injury Week. We are asking all the ladies to wear a "Hat for Headway" to draw attention to the Headway ongoing campaign to encourage everyone to wear the appropriate protective headgear whether skiing, riding a horse, a cycle, motor bike, skate boarding etc.