

WBNA AGM 2010 Report

The political landscape has changed with publication of the recent NHS White Paper. Strategic health authorities and primary care trusts are to be abolished by 2013 with commissioning taken over by consortia of GP practices. It is now clear that the NSF for Long-Term Neurological Conditions, launched in 2005 and still far from being implemented, has been all but abandoned. WBNA is uncertain what will take its place and we need to do all we can to ensure that the improvements outlined in this NSF are included in the proposed NHS reforms.

WBNA has held a series of Patient Consultation Events to gather the patient perspective on experiences of being diagnosed with a neurological condition, finding information, help and support, what happens when staying in hospital and gathering suggestions for improved services.

These Focus Groups have been highly informative and the findings have been passed on to the NSF Local Implementation Team. A report on 'staying in hospital' appeared in Neuro Newsletter 42. A summary of the third event, covering access to therapies, follows in this newsletter.

During 2010 WBNA collaborated with the Berkshire West Local Involvement Network (LINK) and our member organisations on a major survey of patient and carer views on the quality of neurological services provided in Berkshire West. Tony Lloyd of Berkshire West LINK will be speaking about this at the November Open Meeting and a summary report is to be published in the near future.

The committee has continued to represent patient views and taken an active part on

advisory bodies and attended PCT meetings.

Relationships with local professionals are valued and they continue to consult with us on a regular basis. WBNA is represented on the NSF Local Implementation Team and continues to engage with the national Neurological Alliance and Regional Alliances in the four surrounding counties.

Progress continues to create a Hydrotherapy Pool and Power-Assisted Gym for Newbury / Thatcham. The Alliance is a founding partner of West Berkshire Independent Living Network. www.wbiln.org.uk Its official launch is on November 4th and it will provide advice and support for all people with disabilities. It has established a new drop-in point in Newbury Library.

WBNA membership consists of 24 charities and 14 individuals covering 29 different conditions. Finances are in good shape and we have a strong Executive Committee. The Chairman thanked the President, Dr Stephen Allen, and Patrons for their support and the committee for all its hard work. He announced that WBNA is conferring Life Membership on three people who have provided great support and service over the years: Lady Anne Hallifax, Joyce Parker and Molly Davison. Our President presented certificates. There followed four presentations on the Hydrotherapy Pool project, new data on the local prevalence of neurological conditions, the ongoing joint WBNA/ LINKS survey and the patient's experience of hospitalisation. Dr Janet Maxwell, Director of Public Health, gave a presentation on recent national policy initiatives concerned with long-term conditions. She also reviewed the recent government White Paper "Equality and Excellence: Liberating the NHS" and talked about its likely consequences.

Access to Therapies

Eight different long-term neurological conditions were represented at this Focus Group held in October. There was general agreement that some useful, statutory sector therapy services are available, meeting some patient needs in some instances. However, it was felt that services tend to be time-limited and securing prompt referral and the right mix is generally a problem. Most participating in the Focus Group relied on voluntary sector or private therapy. Family, friends and the voluntary sector were very highly rated for provision of psychological support, with statutory sector services regarded as generally lacking in accessibility, helpfulness, relevance or value. The tendency for many GPs to prescribe pharmacy rather than psychological support therapy was seen as unhelpful.

Participants rated well those NHS staff who provide therapy through a multi-disciplinary team. Some individual therapists were rated for providing well-considered, holistic care. However many therapists have little or no knowledge of individual neurological conditions and there is clear evidence that sometimes staff assume the wrong things about patients' abilities and needs.

One problem identified was how to get the referral system 'switched on' as most present had found this difficult when newly diagnosed. Those with more experience of their condition tended to become increasingly expert in the range of therapies which worked for them. Also, those with longstanding conditions generally were well connected to others with the same condition and this was seen as the best way to find out what might work. For many this led to them taking combinations of therapy based on experimentation, though little of this can be obtained from the statutory sector. Most present were critical that statutory sector

therapists seem not to be well versed in the range of therapies from which neurology patients acquire benefits.

The key implication for Commissioners is to ensure that therapy services are structured around real patient needs, with a more extensive range of local services providing personalised packages of holistic care. This should draw on a very wide range of therapies, rather than the 'one size fits all' and the narrow range of services currently on offer through a poorly thought out and poorly followed care pathway.

Homecare User & Carer Forum

Those who would like the opportunity to discuss issues and concerns around the Home Care service provided by West Berkshire Council or a private agency should go to the next User and Carer Forum.

Representatives from the Adult Services Directorate will be invited to the meeting to update on what is happening. Meetings are "user friendly" and held on the ground floor of the Market Street offices of West Berks Council in Newbury. The next meeting will be 2pm - 4pm on 16th December in the Committee Room 1. Further details from West Berks Home Care, Tel. 01635 503503

Dates for your diary

Our next open meeting is on November 11th when the speaker will be Tony Lloyd of Berkshire West LINK. Dates for Open Meetings in 2011 are: January 13th, March 10th, May 12th, July 14th, September 15th (AGM) and November 17th. All meetings, except the AGM, are held at St Joseph's Church Hall, Newbury, 1.45 for 2.00 pm.

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