

10th Anniversary Celebration

WBNA, founded in 1999, held its 10th AGM on September 10th, at the Holiday Inn Padworth. The occasion was marked with a 10th Anniversary Cake, kindly baked by Molly Davison, and decorated in Alliance colours. The cake was jointly cut by our Founding President Lady Anne Hallifax and the new President, Dr Stephen Allen. WBNA chairman, David Roberts, said that the Alliance had been established by a far-sighted group of people who recognised the need for co-ordinated campaigning to improve services for people living with a neurological condition. Their vision was that better information and improved services can bring great benefits in quality of life for patients and carers, as well as reducing the need for acute stays in hospital.

By co-ordinated action as an Alliance, representing a range of neurological conditions, there is greater likelihood our voices being heard. The chairman presented Lady Anne with a bouquet of flowers and thanked her for generous support over the years. He welcomed Dr Allen, who pledged his support for the Alliance's work in future.

Postal Survey on Services

WBNA has joined forces with the West Berkshire Local Involvement Network (LINK) to carry out a postal survey to obtain the views of patient and carers on the effectiveness of the services they use. Survey forms will be distributed by local support groups in January and can also be obtained from John Holt, 01635 33582 or johnmholtbsc@aol.com. All survey forms come with a pre-paid envelope for replies. All comments will be treated anonymously and used to help inform local NHS and social care managers about how to plan and commission better services in the future.

Please let us have your comments.

Patient Consultation

WBNA hosted a meeting at Padworth on October 7th to gather from patients with different neurological conditions their experiences of: onset and diagnosis of their condition, finding out information, getting help and support and going into hospital.

Those consulted described their experiences of local service provision as varying between excellent and very poor, with most reporting inconsistent quality within the system as a whole or having to 'work the system'. Diagnosis was rarely quick or straightforward and for many spanned several years, sometimes 10 years or more.

Matters were sometimes explained well, sometimes poorly or not explained at all and occasionally answers from clinicians were 'made up' or clearly incorrect. Whilst some patients can go through a transparent and systematic process of eliminating possible other diagnoses, some were offered an interim diagnosis that turned out to be incorrect and this led to interim mismanagement. A proportion of patients faced taking their own steps to find out information or to find an expert clinician to secure a more accurate diagnosis.

The diagnosis process was greatly dependent on the knowledge and skill of the clinician(s) involved. In particular it seems that variable knowledge about neurological conditions among GPs and variable knowledge as to referral options either slowed down, stopped or brought uncertainty and inconsistency to the care pathway followed. The manner of clinicians telling patients their diagnosis was deemed important and several patients reported a poor bedside manner in the past, although few had experience of a recent diagnosis.

Most attending placed importance on ensuring prompt and direct referral access to a skilled clinical workforce and variously mentioned the importance of Consultants, GPs with Special Interest and Nurse specialists, as well as the Voluntary Sector for non-clinical support. Although the Voluntary Sector was generally well-rated for information and peer group support, it was seen as lacking in expert clinical knowledge and of not receiving appropriate support from the NHS.

This consultation event was incredibly valuable but unfortunately there was not sufficient time to explore all issues to the full, particularly experiences in acquiring information, acquiring help and ongoing support as well as harvesting ideas for improvements on all those subjects. It is proposed to hold an additional event to allow time to gather further information. A report has been prepared for the Berkshire West Local Implementation Team. WBNA is grateful to all those who participated and supported the consultation.

Pain Services in Berkshire West

Following our conference *Brains, Pains and Gains* and internet pain survey, WBNA has formulated a number of recommendations on pain services in Berkshire West. Firstly, it is clear primary care pain services need to be upgraded and made more consistent by establishing of a common care pathway for patients affected by pain. This could be achieved by the appointing a local practicing clinician to be clinical lead for pain services and a clinical champion for relief from pain. Patients experiencing pain should complete a standardised 'Pain Inventory' and keep a 'Pain Diary', to assess their needs so bringing a consistency to decision-making. Secondly, it would be valuable to conduct a one-day pain prevalence survey of all attending patients attending one of the local GP practices, as

recommended in 'A Practical Guide To The Provision Of Chronic Pain Services For Adults In Primary Care' published by The British Pain Society and the Royal College of General Practitioners (October 2004). Existing pain services in Secondary and Tertiary Care should be retained but awareness of their existence and capabilities needs to be promoted better. The results of our internet pain survey and recommendations for local pain services will shortly be published in full on our website: www.wbna.org.uk.

Racecourse Collection

We are grateful for the immense generosity of the race-goers at Newbury Racecourse. On September 18th ten volunteers from WBNA collected £1048 at the gates at the end of racing. Thanks to the management and staff of Newbury Racecourse for allowing us to collect and the collection team for all their efforts. The money will be put to good use supporting our projects

Dates for your diary

The speaker at our meeting on January 7th will be Angela Todd, who will talk about Reading's service priorities for neurological conditions. Other dates for 2010 Open Meetings are: March 11th, May 13th, July 8th, September 9th (AGM) and November 11th. Meetings (except AGM) are held at St Joseph's Church Hall, Newbury, 1.45 for 2.00 pm. All are welcome to come along.

Seasonal Greetings

At the end of a very busy and successful year, West Berkshire Neurological Alliance would like to thank all supporters, friends and colleagues and wish you all a Happy Christmas and healthy prosperous 2010.

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