

Evaluation Study on Neuro - Nurse

We are delighted that the evaluation study on the role of Specialist Neurology Nurse for Rare and Complex Conditions has concluded that she has had a very positive impact on the lives of patients and carers in West Berkshire. The impact study was carried out by staff of Reading University over several months.

Its main conclusions are:

- (1) The nurse has provided rapid and timely access to specialist knowledge and services;
- (2) Patients and carers reported greater satisfaction with health services and
- (3) Length of stay in hospital was reduced.

The post of Specialist Neurology Nurse started in October 2005 and has been funded for 2 years in the first instance. It was enabled by the work of WBNA with support and generous donations from other local charities and various donors. The Specialist Nurse post has been based within the Department of Rehabilitation Medicine at the Royal Berkshire Hospital but she has worked with those patients across the Berkshire West area who have rare and complex neurological conditions. These progressive conditions include: motor neurone disease, Huntington's disease, myasthenia gravis, multiple systems atrophy, progressive supranuclear palsy, post-polio syndrome and ataxia.

The evaluation report comments that both patients and carers were extremely positive about the post, demonstrating that the neurology nurse post has helped meet both national and local health goals. The Specialist Nurse has provided: (1) A patient-centred service providing patients with information about their condition. (2) Rehabilitation advice and support to meet continuing and changing needs. (3) Support for both family and carers.

- (4) Care during admission to hospital or other health and social care settings ensuring that neurological needs were met. (5) Appropriate speed and flexibility of service delivery within, and across, professional and agency boundaries.

We were pleased to learn that the Specialist Nurse post has been highly cost-effective. The report estimates that cost savings from the reduction in bed stay has more than covered the cost of the post. Savings in 2006 were of the order of twice the cost of the post (range 167 – 274% depending on the method of calculation). Patients and carers valued the post highly and we are reassured by the fact that the majority believe that there is little improvement to be made to the service beyond ensuring that it is continued. In the words of one carer: *“she [specialist nurse] is wonderful. She gives me so much support, which without I don't think I could cope. My wife (of over 50 years) only wish is to stay at home, and [specialist nurse] gets us all the help we need. Her job is vital, she cannot be without”*.

WBNA would like to thank all those who have supported the Specialist Nurse Project. We are indebted to Carol Allen who bravely took on the untested role of Specialist Nurse for Rare and Complex Conditions and demonstrated just what can be achieved with hard work, dedication, professional insight and caring efforts. We are also grateful to Professor Christine Collin who has provided support and clinical leadership for the project. Especially, we would like to thank the Reading and West Berkshire Branch of the Motor Neurone Disease Association, The Berkshire Branch of the British Polio Fellowship and the Reading Branch of the Huntington's Disease Society who provided funds and other input.

We are also grateful to many other grant-giving organizations and individuals who have provided funds for this pump priming pilot. We are delighted that Berkshire West PCT has committed to provide interim funding for continuation of the post, recognizing its value both to patients and NHS. We urge that the post should become permanent. If you wish to read the evaluation report you can download a copy from www.wbna.org.uk.

Race-day Collection

We are most grateful for the generosity of the race-goers at Newbury Racecourse. On May 19th several WBNA volunteers stood at the gates with collecting buckets and received donations of £1337.50. Thanks go to the management and staff at Newbury Racecourse for allowing us to collect and collection team for their efforts. We will put the money to good use to support the work of WBNA.

Hydrotherapy Pool Project

The hydrotherapy pools project received a further boost recently when the WBNA Liaison Officer, John Holt, was awarded 'The Best Volunteer within a Social Enterprise', by Social Enterprise Berkshire. At the awards ceremony held at Reading University, John paid glowing tribute to the excellent work of his many fellow volunteers, thanking them and the various, local organisations who are all supporting and pressing for hydrotherapy pools to be built at Thatcham and Tilehurst.

ME/CFS Support

A meeting is being planned to help set up a local support group for people coping with myalgic encephalitis/chronic fatigue syndrome. If you are interested in becoming involved in a local group please contact John Holt (Tel. 01635 33582 or email JohnMHoltBSc@aol.com) for information.

What you need to know about my condition

The Neurological Alliance has recently produced a helpful leaflet called 'What you need to know about my condition'. This leaflet allows people with a neurological condition to share important information on their condition with those providing them care. The leaflet can be adapted by anyone for use in any setting. It can be used in hospital wards, respite care, A&E and in the community. People may wish to carry the leaflet when they go on holiday or in case of an accident.

If you would like a copy of the leaflet please contact secretary@wbna.org.uk or admin@neural.org.uk.

Diary dates to note

The 2007 AGM will be held on Monday 3rd September at 7.30 pm. Dr James Cave, a local GP and Chair of the Local PCT Practitioners Committee will be our guest speaker. This year the AGM will be held at the Frank Hutchings Memorial Hall, Thatcham. The hall is situated near The Mill pub and restaurant at the junction of Floral Way and Harts Hill Road north of Thatcham. Please come and join us for tea/coffee and biscuits from 7.15 pm.

Our last **Open Meeting** for 2007 will be held on 8th November 2007 at 1.45 for 2.00 pm at St Joseph's Church Hall, Newbury. Speaker and subject will be announced soon. Free admission includes tea and biscuits.

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