

Focus group for the recently diagnosed

The report on our autumn focus group 'Experiences of being diagnosed recently with a neurological condition' is now published.

The combined experiences of attendees was a typical mix from very good to very poor, leading to the recommendations below. These have been submitted to the local NHS Long Term Conditions Board and Neuro Steering Group for consideration.

The recommendations included:

1. A more robust and systematic approach to assessment, integrated into a well-defined care pathway for neurological diagnosis should be established and followed consistently.
2. More GP knowledge about neurological diagnostics would be welcome.
3. Better access to good quality information throughout diagnosis would be useful.
4. Wherever possible, appropriate care management options for neurological conditions should be offered and provided as early as practicable.
5. Diagnosis is the start of a long process leading to further needs. Nurse specialists and voluntary sector peer group support should both be central to immediate post-diagnosis service design, planning and delivery.

WBNA conference 2016

Our 2016 neuro conference will be an all-day event at the Arlington Arts Centre, Newbury, on Tuesday, 3rd May, with Neuro-rehab guru Professor Derick Wade our keynote speaker. The theme will be 'Integrated pathways between of Neurological Care'. The event will carry 'CPD' training points for professionals and be of strong interest to neuro-patients and carers. The aims of the Conference are service integration and improving the patient experience. To register an interest email info@conferenceorganisers.net

WBNA focus groups 2016

We will be holding a focus group on 16th May, on 'My life as a neuro-carer', and another later in the year on 'Technology and elderly neuro-patients'. Both are intended to help inform the work of the local NHS Long Term Conditions Board, the Neuro Steering Group, and the two Thames Valley equivalents, on which we represent the local neurological voluntary sector.

Grants for carers' breaks

Grants for carers in need of up to £300 to take a break or breaks from their caring role remain available from WBNA. Applicants must live in West Berkshire, Reading or Wokingham and provide care for at least fifteen hours a week. Details are on the application form. Apply to johnmholtbsc@aol.com

West Berkshire Therapy Centre

West Berkshire Therapy Centre is strongly backed by WBNA and has now been awarded registered charity status.

It is to relocate to larger premises at Frank Hutchins Hall in Thatcham on 1st

April, when it will also install new equipment, funded by a major grant received at the recent Greenham Common Trust 'Pitch to the Panel' event. The new equipment is all motorised and will help disabled individuals to move more easily, helping with practical things such as getting out of chairs and improving balance

The NHS 'Community Neurology Project', whose aim is 'transforming the way health care in the community is commissioned for people with long term neurological conditions nationally', is considering showcasing the Centre.

Whitehall update

The Parliamentary Public Accounts Committee finally held its neurology services review, in December. Representing patient perspectives, the national Neurological Alliance accurately painted a disappointing picture of poor progress in the development of neuro-services nationally. Sadly, the leaders of NHS England and the Department of Health gave lack-lustre performances, showing a poor grasp of leadership, and a poor understanding of needs and what could be done. For more view

<http://parliamentlive.tv/Event/Index/ffe54ff2-3c91-4a4a-bfb3-aef55ce7b010>

NHS Berkshire West update

In contrast to the national scene, the NHS Berkshire West Neuro Steering Group has made strong progress in

recent months, developing pathways for local sufferers of migraine and headache that patients have seen and welcomed. This work should roll out shortly. Similar efforts have gone into reviewing the needs of local people with epilepsy, where some radical improvements to service speed and quality are under development.

Pathways for long term degenerative neurological conditions are also being worked on. The Alliance has pledged to work with Dr Richard Coates to support a migraine support group into place.

Anyone who is interested in that idea, please contact John on johnmholtbsc@aol.com

WBNA Secretary needed!

We are still looking for a Secretary, should anyone with the skills and time be available. To find out more contact John on johnmholtbsc@aol.com

Dates for your diary

Open meetings:

St Joseph's Church Hall, Newbury.
1.45 for 2 pm. Everyone welcome!

Thursday 28th January

Speaker: Catherine Sutherland,
Service Manager, Neuro-rehabilitation

Thursday 10th March

Speaker: Arlene Wilkie, *Chief Executive, The Neurological Alliance*

Thursday 12th May

Thursday 14th July

Speakers to be advised

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