

Continuity of Care

Our June focus group subject was 'Continuity of Care'. As always, there was praise for local statutory sector provision but there was much evidence of lack of continuity, with evidence of waiting times of up to a year and some assessments being repeated by 'clinician after clinician', and recurring stories of staff changes and shortages. The transition from children's to adult's services and from adult's to older people's services has been a lottery for some. Certain NHS services received more negative mentions than others, particularly the 'less glamorous' ones, but no service seems to be immune from problems of continuity of care. The focus group report will be out shortly, to be presented to Commissioners and Service Managers for consideration.

WBNA Open Meeting 10th July

At our July meeting Jackie Wilkinson, Chair of the local Mental Health User Group, led a fascinating discussion that intertwined the subjects of neurological conditions and mental health. With numerous neuro conditions represented around the table, this exposed regular and sometimes severe problems in getting prompt, holistic support, sometimes leading to an early health spiral of decline, difficult to reverse. The Alliance and the Mental Health User Group have many common interests, to inform commissioners of the need to improve the delivery and effectiveness of mental health services locally.

West Berkshire Therapy Centre

We continue to support and promote the recently opened West Berkshire Therapy Centre, many of whose clients already are reporting improved mobility and control over tasks of daily living. Opening hours have been extended to 25 hours per week. The Centre needs quickly to raise additional funds to buy a third powered cycling machine due to the clear benefits arising!

This unique community project, in Lower Way, Thatcham, offers exercise therapy for any disabling condition, using a dozen items of powered, repetitive movement equipment. Anyone with an interest in helping those with mobility problems should view www.westberkshiretherapycentre.org.uk

NHS Berkshire West

We are delighted to report that, in recent weeks, no less than three Berkshire West GPs have offered to lead together on neurological projects. We anticipate this will lead to a revitalised Neuro Implementation Team (or its modern equivalent) shortly and we are gearing up to be fully involved on behalf of the neurological patient/carer/voluntary sector. Watch this space!

Thames Valley Neuro Network

The 'map' of neurological services in Thames Valley has been published. The report contains a lot of hospital

activity statistics and some appropriate recommendations to help commissioners understand what to do to reduce neurological hospitalisations. However, a lot more effort is needed to uncover the cost, importance and value of all the health and social care services used by neuro patients. We are pressing hard for further local data to be gathered, covering the full spectrum of neurological interest and need.

One NHS Thames Valley priority arising from this 'mapping' is how to provide more effective services for those with headache and migraine. A pilot service has been established in Oxford to investigate ideas. Nationally the subject costs the NHS £1 billion pa. Many people do not get a specific diagnosis and Clinical management is variable. Our September focus group will be on 'Living with migraine and headache. Please contact us for further details.

Another priority from the 'mapping' is to improve on the statistic that neurologists see only 6% of neurological emergency cases, the other 94% being seen by generalists! Changes in the NHS commissioning structure, i.e. moving commissioning away from Specialised Commissioners to GP-lead Clinical Commissioning Groups should lead to an improvement.

Several other priorities are emerging from this 'mapping' and other work. We will continue to press that NHS priorities should align better with longstanding WBNA recommendations.

Neurology Intelligence Network

Nationally, the Neurology Intelligence Network has been launched. See <http://bit.ly/Uge8qt> Building on the dataset published recently by the

Health and Social Care Centre, the Network should make it easier for healthcare professionals and policy makers, to access data and improve public health outcomes for those with neurological conditions.

Volunteers needed!

West Berkshire Neurological Alliance is an award winning, pro-active organisation with no paid staff and an all-volunteer team. Organising our open meetings, conferences, focus groups and other research sits alongside roles representing our sector in Whitehall, Oxford and more locally, also working with neighbouring Alliances and other groups and colleagues to 'make a difference', helping to drive projects such as West Berks Therapy Centre.

We need more volunteers to keep up our role of representing people affected by neurological conditions in the way they deserve. If you have volunteering skills that match the challenge please contact John on 01635 33582 or johnmholtbsc@aol.com

Dates for your diary

Thursday 4th September 7 - 9 pm.
AGM: Holiday Inn, Padworth.

Monday 29th September 2 - 4 pm
Focus group: 'Living with migraine or headache'. Padworth. **Booking essential.**

Thursday 13th November 1.45 for 2 pm.
Open meeting: St Joseph's Church Hall, Newbury. Speaker tba.

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Registered Charity No. 1081021