

### Neuro to be a Local Priority

During 2010 The Alliance cooperated with the West Berkshire Local Involvement Network (LINK) on a major survey to ascertain the views of people with a neurological condition. Both patients and carers were consulted, with 10 neuro-conditions covered in the survey. The final report is intended to inform providers and commissioners of services about the views of patients and carers. As well as providing valuable information on the local prevalence of neurological conditions the report makes seven key recommendations:

1. The process for initial diagnosis of rarer neurological conditions needs to be standardised to avoid unnecessary and potentially harmful delays.
2. Everyone newly-diagnosed with a neurological condition should have that diagnosis confirmed at a 'Centre of Excellence' and be given a care plan.
3. Everyone diagnosed with a neurological condition should be allocated to a named healthcare professional as his or her principal contact and advocate.
4. When neuro-patients are admitted to hospital for another problem their neuro-condition needs to be taken account of and effectively treated during their stay.
5. The benefits of physiotherapy hugely outweigh its costs in helping keep people out of hospital. Physiotherapy services need to be remodelled to meet current levels of demand.
6. People with neurological conditions and their carers benefit from psychological support (Talking Therapies) and the IAPT team needs to be trained to offer services to neuro-patients and carers.
7. For patients with long-term conditions there needs to be periodic review of the

needs of their principal carers, so carers can continue effectively to carry out the role for as long as possible.

The report and its recommendations have been sent to all local health bodies and to the three local authorities in Berkshire West, for their responses, most of which were receptive and positive. Most notably The Royal Berks Hospital has decided to make neuro a Local Priority. Well done to them!

Sadly the response from the struggling, outgoing PCT, which claims, vaguely, to spend maybe £16M or maybe £33M p.a. on neurology services has clearly indicated that it does not regard neurology a priority and has no plans to action simple, cost-saving ideas. Consortium Commissioning will be taking over from the PCT in 2013 and hopefully will be more forward looking in designing effective and efficient services. For a copy of the summary and full report: [www.westberkshirelinks.com/Esurvey/ShowNews.aspx](http://www.westberkshirelinks.com/Esurvey/ShowNews.aspx).

### Your Views Are Essential

Shortly to split away from PCT control, an enlightened Public Health Department has started drafting a series of Joint Strategic Needs Assessments (JSNA), including one for MS and Parkinson's, due out for consultation in September 2011. This is intended to provide a broad understanding of current and future health needs of these groups, to allow effective planning of future services. A second module on Epilepsy and MND should follow, with others later. A summary of the drafts will be made available on the PCT website shortly and hopefully will be well publicised. Stakeholders (*I think that is you and me – ed.*) will be asked to write in or take part in workshops. We urge everyone to respond to this very welcome opportunity.



Our conference *New Opportunities for Neuro* will be held on Tuesday October 4<sup>th</sup> at Arlington Arts, Snelsmore Common, near Newbury. We are indebted to Professor Christine Collin and Dr Faraz Jeddi for helping us put together a truly exciting programme. We will be exploring the latest positive developments in neurology and neuro-rehabilitation as well as issues such as preventive medicine, self-help and the patient-therapist interface. For a copy of the full programme go to our website: [www.wbna.org.uk](http://www.wbna.org.uk) or look out for our conference brochures.

### *West Berks Carers Survey*

The Alliance has collaborated with The Princess Royal Trust for Carers, Cross Roads Care and several local groups in a survey of the needs of local carers. A special focus was on respite provision and gaps in services. The results were very revealing with some carers coping very well while others reported being close to breaking point, and all shades in between. Some reported experiencing excellent carer services while others were at the extreme opposite end of the spectrum of experiences. Only 43% of carers felt they are getting the right amount of daytime respite and 55% felt they needed additional overnight respite.

The majority of respondents reported needing respite mainly to be able to carry out simple, basic, everyday activities and get enough rest, with half also wishing to take a holiday. Cost was reported as the biggest barrier to meeting respite needs in nearly half of the responses. Care quality was an issue for 30% of respondents. Whereas respite capacity is reportedly insufficient, some respondents also indicated that other, more affordable solutions would work for them. Some

patterns emerged. The need for overnight respite packages of 'four times a year' and breaks of '1-2 nights' and '7 nights' were most frequently mentioned. However, the wider evidence suggests that each client may require an individual respite package.

From the information provided it is estimated that 2000 local carers are providing 50 + hours each week of care.

The report makes 10 recommendations covering provision, priorities and improving the quality of services. This report and its recommendations were positively received by West Berkshire Council Community Services and will be presented to its Carers Forum shortly for further consideration.

### *WBNA AGM*

The 12<sup>th</sup> WBNA Annual General Meeting will be held on Thursday 8<sup>th</sup> September at 7.00pm for 7.30pm at the Holiday Inn, Padworth. We will be reviewing what we have achieved during the year and what we plan to do in 2012. Refreshments will be provided and there will be an opportunity to meet and talk to each other. New members for the committee are always welcome.

RSVP using the accompanying form or email: [secretary@wbna.org.uk](mailto:secretary@wbna.org.uk).

### *Dates for your diary*

The next open meeting after the AGM will be on November 17<sup>th</sup> at St Joseph's Church Hall, Newbury at 1.45 for 2.00 pm. The speaker will be Jan Evans, Head of Adult Social Care at West Berkshire Council and she will update us following the recent Carers Survey Report and be consulting with those present on assistive telecare.

### *West Berkshire Neurological Alliance*

2, Clayhill Crescent, Newbury,  
Berkshire RG14 2NP  
Tel: 01635 33582 Fax: 01635 569177  
Email: [secretary@wbna.org.uk](mailto:secretary@wbna.org.uk)  
[www.wbna.org.uk](http://www.wbna.org.uk)  
Registered Charity No. 1081021