

Destabilise, destabilise, destabilise

As we welcome into post Helen Singles, the new commissioner for Long Term Conditions for Berkshire West PCT, the NHS structure is on the move again and the future holds many more questions than answers. The expected demise of the Strategic Health Authorities is unlikely to cause many tears to be shed. However, the announcement that PCTs will disappear in 2013 is another matter. There are many improvements that observers, such as ourselves, might wish to see happen to reduce the overly administrative approach of PCTs. Some PCTs have made a useful difference, although few have done much specifically to address the unmet needs of neurology patients. (Please let us know if you know of one.)

In 2013 the commissioning of NHS services will be picked up by GPs, working in consortia. We are informed that probably three GP consortia will cover Berkshire West; presumably one each for Wokingham, Reading and West Berkshire. At present most GPs are fully committed to 'hands-on' medicine and we suspect that few will see themselves as 'coalition commissioners'. These GP consortia will need considerable administrative support (best kept to a real minimum in our view) and setting this up seems bound to be time consuming and not cheap. A new NHS National Commissioning Service will look at the more specialised and regional services only, leaving the bulk of commissioning to GP consortia. So will anyone be looking at services that are best commissioned at intermediate or county levels? We see a nasty gap looming unless some new, extra

layers of NHS administration have to be put in place. No thank you!

The national Neurological Alliance is seeking answers right now in Whitehall. More locally, our role will be, as always, to be available to inform commissioners in PCTs or GP consortia, (be they configured as single-, duo-, trio-, super-, multi-, mega-, pan-clusters or whatever), seeking to ensure that care pathways for neurology patients are clear and accessible and that each patient may receive timely, holistic care, with expert and specialised neuro-trained clinicians available as needed. That could all have been in place before now if the old Berkshire Health Authority had been left to get on with it.

Staying in Hospital

In May WBNA hosted a Focus Group to learn about the experiences of people affected by an existing long-term neurological condition when they stayed in hospital. Seven different long-term neurological conditions were represented. There was wide agreement that excellent acute services are regularly provided in hospitals across the region. At the same time those present reported recurring and very clear evidence of the general need for hospitals to employ better trained ward staff who would be more able to provide holistic care relating to pre-existing neurological conditions. Loss of dignity (and worse) can and sometimes does arise, particularly when hospital staff are busy or perhaps assume the wrong things about patients' ability as regards their mobility, strength, exhaustion level, continence

control, ability to swallow, ability to feed themselves, speaking ability or if they mistakenly appear unable to think for themselves.

When someone with a long-term condition is in hospital their care-givers' (family or friend's) input, as well as prompt access to specialist neurology staff, can make a very positive difference. Some in the Focus Group mentioned that not being allowed to take important long-term medications is a real problem.

The problems identified by the Focus Group participants seemed to arise almost regardless of which hospital or type of ward people had experienced. The exception seemed to be neuro-rehabilitation wards, which generally received consistent praise, perhaps because these staff have specialist training and a better understanding of neurology and its impacts.

One important implication for Commissioners is to ensure that contracts with secondary and tertiary care should cover not only the need to provide expert and specialised services of suitable quality but that those services should also meet the needs of patients with existing conditions or co-morbidity. Secondary and tertiary care providers must therefore gear-up to meet these co-morbidity needs and the audit and improvement programme should be configured accordingly.

West Berks Independent Living Network

WBILN is a new organisation set up by a number of local support groups including WBNA. This user-led organisation will be controlled by local service users and carers and aims to promote independence and community involvement for those with disabilities and to help people lead fulfilled lives and meet their aspirations.

WBILN will be based in the newly-refurbished Broadway House, just off The Broadway in Newbury where there will Drop-In facilities and advice services. This will also be the base for a number of other local charities such as CAB and the Princess Royal Trust.

As well as providing support and advice, WBILN is looking into providing services such as advocacy and brokerage for those with personalised budgets. It aims to provide advice for those falling below conventional eligibility criteria and help identify hidden demand for services. WBILN should provide a meaningful voice at decision making levels. Further information from Sharon Jones (Sharon@wbiln.com) or from the website www.WBILN.com

WBNA AGM

The 11th WBNA Annual General Meeting will be held on Thursday 9th September at 7.00pm for 7.30pm at the Holiday Inn, Padworth. Our Guest Speaker will be Janet Maxwell, Director of Public Health at Berkshire West PCT. We will review what we have achieved and hope to achieve, also to enjoy refreshments. New members for the committee are always welcome. RSVP using the accompanying form or email: secretary@wbna.org.uk.

Dates for your diary

Our last Open meeting for 2010 is planned for November 11th at St Joseph's Church Hall, Newbury, 1.45 for 2.00 pm. The speaker will be announced shortly, all are welcome to come along.

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