

### Message from The Alliance

By the time this newsletter is distributed, hopefully, we will have a new and stable government. With huge debts burdening the country, most health and social care authorities will be carefully reviewing their budgets and looking for savings. Now is the time to remind them that over 8 million people in England are living with a neurological condition, from epilepsy to motor neurone disease, from stroke to acquired brain injury. Also, population ageing and its association with a number of neurological conditions means that this number will grow steadily over the coming decades. Remember too, most neurological conditions are chronic or progressive and few have cures. Almost all people with a neurological condition rely on services provided by the NHS, Local Authorities (LAs), family and friends and, sometimes, independent care providers over a number of years, until the end of their lives.

So far this huge need has not translated into routinely good services. The Alliance needs to get across the message that neurological conditions are more prevalent than cancers or diabetes and yet neurological conditions have not received the same focus or funding. This shortfall was recognised in National Service Framework (NSF) for Long-Term Neurological Conditions in 2005. This NSF provides a remarkable common vision of the services that people with a neurological condition should be able to expect: a vision of quality and equality. Service users, carers, health and social care professionals and civil servants all agree that achieving the 11 Quality Requirements in the NSF should radically improve well-being and health outcomes for people with a

neurological condition.

However, despite the personal and economic cost, evidence indicates that, over the last five years, neurological care has rarely been prioritised by commissioners at a local level. Researchers at York University carried out a survey for the Department of Health to support implementation of the NSF, which revealed widespread concern amongst the neurological community that the NSF is not having the desired impact on services. Patients, carers, staff and volunteers have all said:

**“Despite the NSF being well-received when launched, there was a common perception that there was no clear thinking about how to deal with it, and generally no one taking responsibility for action strategically.”**

### Need for a Neurology Review

The last Government commissioned a mid-point review of NSF implementation, to be conducted by the Long-Term Conditions (LTC) Delivery Support Team. The Alliance has concerns that this work may not be prioritised by the new Government. At all costs we must make it happen.

The mid-point review will largely question PCT commissioners to establish the extent to which they have commissioned against the NSF Quality Requirements. This will help add to the picture of NSF implementation but, sadly, will not examine the quality of commissioning arrangements and outcomes for patients.

There are many examples of good, innovative practice – and even some areas where a picture of change is emerging. Successful implementation over the next 5 years will very much depend on our ability

to identify and disseminate good practice; provide evidence of need and of the cost-effectiveness of interventions. We also need to identify NSF champions who can support weaker services. Therefore the Alliance is urging the Care Quality Commission to carry out a special review to identify what works and why. This should lead to the adoption of good practice elsewhere.

Members of the Alliance need to point out inequalities in services have economic consequences. Delays in diagnosis not only lead to social isolation but also to missed educational and employment opportunities. Lack of access to early, preventative care has serious cost implications for service-users if their condition is allowed to deteriorate. Lack of joined-up community care can lead to costly acute admissions to hospital. Without tailored care and support, people with neurological conditions can find themselves unable to remain in work or to maintain a good attendance at work. For instance, an estimated 25 million days are lost from work or school each year because of migraine alone.

The Alliance needs to get across the message that expenditure on good quality services will not only lead to benefits for patients but lead to greater savings to the public purse in the long run.

### *Meeting Local Health Needs*

It has been proposed to conduct a Health Needs Assessment covering neurological conditions in Berkshire West. This is a good idea but first we need:

- full PCT commitment to meeting the specific needs of neurology patients
- better justifications for current NHS activity and spending
  - more commitment to prevention
- prompt action to implement existing ideas for service improvements
- services that 'meet patients needs', not 'this is what we can do for you'
  - Better use of local data

Other Neurology Health Needs Assessments around the country have tended to measure only existing NHS and Social Care activity, not to look at whether real needs are being met properly. They have been poor value and have made almost no specific recommendation that will lead quickly or directly to a single patient or carer receiving a better service.

Locally there remains unfilled the need to agree an integrated vision that will deliver services in line with the NSF for long-term conditions, to ensure equitable, easier and timelier access to appropriate health and social care services. Locally we need to:

- establish a Workforce Strategy for neurology patients, linked to easy-to-access care pathways.
- ensure services are appropriate and better value-for-money
- meet the NSF for Long Term Neurological Conditions

Berkshire West PCT allegedly spends over £26 million p.a. on neurology patients. We know this could be better spent and continue to press for improvements.

### *Dates for your diary*

At our Open Meeting on May 13<sup>th</sup> James Hamilton and David Tait will talk about 'West Berkshire Council - Services to people with long-term conditions'. Other dates for 2010 Open Meetings are: July 8<sup>th</sup>, September 9<sup>th</sup> (AGM) and November 11<sup>th</sup>. All meetings, except the AGM, are held at St Joseph's Church Hall, Newbury, 1.45 for 2.00 pm. All are welcome to come along.

### *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)

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