

Future service planning and delivery

In revamping the NHS, two key National Directors have been appointed, one for Long Term Conditions and another for 'Recovery and Rehabilitation'. It is planned that they will work together and 'look after' neurology. This lack of focus at the top has got Parliament's Public Accounts Committee very concerned. Patients should be concerned too!

Recommendations are out as to which services will be commissioned by the National Commissioning Board rather than locally. These include:

- Equipment for complex disability
- Specialised spinal services
- Specialised rehab for brain injury
- Specialised Neurosciences
- Neurosurgery
- Interventional neuroradiology
- In-patient neurology
- Neurophysiology & neuroradiology
- Neurorehabilitation
- Neuro Critical Care
- Neurology Out-patients
- Specialised Learning Disability
- Asperger's & Autism Spectrum Disorder Specialised Services
- Neuropsychiatry
- Specialised Pain Management

The accessibility of these services and how they will integrate with those commissioned by local CCGs (Clinical Commissioning groups) will be critical to overall outcomes of quality of care.

The Alliance's early discussions with CCG (Clinical Commissioning Group) leads are encouraging. Our local doctors identify with many of the same opportunities that we air. However, the hapless prioritisation system currently used by the outgoing PCT looks set to be adopted by the CCGs too, and that needs to change if neuro patients are to see any actual service developments.

The NHS regional project intended to ensure minimum standards for neuro rehab recently hit new administrative snags, but we continue to press that these important standards are meaningful and introduced equitably across the region as soon as possible.

The announcement that each region will have a neuro network from 2013 is most welcome. Over the years we have accumulated much evidence and many great ideas from our members, to feed into that Network when it gets going!

Report on our 13th AGM

In his final report before retiring from the Alliance, Chairman David Roberts described how budget constraints in our local Councils and the NHS are causing a severe impact on those with a neurological condition. Major restructuring of the NHS is unlikely to solve much. Poor neuro care means that too many are admitted to hospital as emergencies, suffer delay in diagnosis and receive little information.

We remain astonished that local commissioners have not acted on any of our money-saving and quality improvement ideas. The draft 'Needs Assessment' for neurology is unlikely to be complete before the PCT is wound up. Few will be sad to see our struggling PCT disappear, with so little commissioned for neuro patients.

Our membership remains strong, comprising 27 local charities and 17 individuals, covering some 28 neurological conditions.

We have funded all our activities and reserves are strong. We were delighted that South Central Health Authority awarded us £10k to develop the post of a GP with Special Interest in the Management of Pain. We worked with Drs Deepak Ravindran and Faraz Jeddi of the Royal Berkshire Hospital on this, although GP interest has been thin.

We hosted a Focus Group on 'Minimum Standards for Community Neuro-Rehab Teams', feeding volumes of patient/carer information to the NHS team developing a regional standard.

We hosted a Focus Group on 'Living with Incontinence' and from that we have initiated a survey jointly with West Berkshire LINK, with no less than 44 organisations assisting, a remarkable project with remarkable interest! Statutory sector commissioners await the findings eagerly.

We supported a focus group on epilepsy nurse specialists, to ensure commissioners build around the patient/carer perspective in that area of need.

Our focus group for wheelchair users led to space being made available in the West Berks Community Hospital, so

wheelchairs are now being used during assessments there, a real improvement.

Despite setbacks in finding a site for a Hydrotherapy Pool and Power-assisted Gym for Newbury/Thatcham, we remain confident the project will succeed.

We continue to work with, and support, partner organisations such as West Berkshire Disability Alliance, LINK and Independent Living Network.

At the end of the AGM thanks were given to our retiring President, Patrons and committee for their tireless support. A strong executive committee of 8 was elected, with Irene Waters taking over the Chair. Dr Deepak Ravindran gave an inspiring talk on pain management. Lifetime membership was awarded to David Roberts to thundering applause!

Dates for your diary

Open Meeting: Thursday November 8th at St Joseph's Church Hall, Newbury at 1.45 for 2.00 pm. Guest speaker **Dr Elizabeth Johnson**, South Reading Clinical Commissioning Group.

Open meeting dates for 2013:

- January 17th Dr Daphne Banat, Head of Scheduled Care, RBHFT
- March 14th
- May 9th
- July 11th
- November 14th

All 1.45 for 2 pm, St Joseph's, Newbury

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