

Local Neurology Services Report

A new hard-hitting report from the Royal College of Physicians and the Association of British Neurologists concludes that, overall, services for patients with neurological conditions are poorly organised and do not meet patients' needs.

Neurological disorders are very common and account for about one in ten GP consultations, 10% of emergency medical admissions (excluding stroke) and disability for one in 50 of the population. The report emphasizes that there are many neurological conditions which vary in severity, some being very common, such as headache, migraine, epilepsy, Parkinson's and MS, and some rare such as motor neurone disease, myasthenia and muscular dystrophies. Patients need a range of neurology services at different stages of their illness - acute admission, outpatient care and long-term care. However, these are currently poorly organised and badly integrated, leaving many unable to access the right specialist at the right time and often far from home.

Neurology services in the UK have mainly developed around large regional neurosciences centres with an emphasis on research and academic excellence. Whilst they have produced world class research and new treatments for patients, general hospital services have suffered particularly due to a lack of local neurologists, in contrast to the USA and Europe where there are far more neurologists per head of the population (1:40k *versus* 1:125k in the UK). This lack of neurologists in general hospitals has resulted in poor local services exacerbated by an unplanned increase in outpatient demand driven by waiting time targets, with

inadequate resources and poorly structured services, particularly for patients with chronic neurological conditions.

This new report outlines three proposals:

- An expansion and improvement of local services with a shift in emphasis from scheduled to emergency care
- Organised care for patients with long-term neurological conditions, managed in part through an enhanced role for specialist nurses and general practitioners with a special interest (GPwSIs) in neurology
- Better local planning of services with increased clinical involvement within a commissioner/provider context, creating a neurological network to improve clinical outcomes and better value for money.

Many of the report's 29 practical recommendations are cost-neutral, and can simply be achieved through more efficient working and better use of existing resources. A significant increase in the number of neurologists will be needed over the next decade to meet increased patient expectations.

The Alliance contributed evidence to the RCP Working Party and we endorse their recommendations. A copy of the full report: *Local Adult Neurology Services for the Next*

Decade is available at

www.rcplondon.ac.uk/details.aspx?e=354.

Focus on Equipment

The Alliance held its 5th Patient Focus Group on 18th April at the Holiday Inn, Padworth. Nine people took part and these were selected by local charities because they were intelligent, good communicators,

positive in outlook and interested in the way that services are provided. Four staff from local social services also attended.

Although those present were grateful for the improvements in service, there is still a minefield of problems that patients face when seeking suitably-adapted equipment to allow them to lead as normal and independent lives as they are able. At this Focus Group eight different long-term neurological conditions were represented and a number of key issues came to light.

1. Large expensive equipment is costly to maintain. Some patients felt pressured by company sales staff promoting expensive maintenance agreements. Local authorities, who fund the initial purchase of such equipment, should investigate leasing-out arrangements to limit the ongoing costs.
2. Patients also were concerned at the long lead-in time in provision of specialist equipment and lack of urgency in carrying out repairs. In addition, those carrying out specialist measurements and individual assessments for equipment need proper training. Provision of ill-fitting equipment leads to much unnecessary pain and suffering and still further delays in rectifying the problem. A patient needs to be forceful, determined and an expert in obtaining the most suitable equipment.
3. Unnecessary red-tape with the Disabled Facilities Grant can mean expensive additional adaptations being required to meet the requirements of the scheme.
4. Assistive technology needs to be given greater prominence for it offers new opportunities to improve memory, communication and sensory awareness, as well as improved responsiveness. It allows people suffering invisible impairments, such as mild dementia, to maintain better control and live more independent lives.

5. Disabled access in some public buildings - Reading Library being a prime example - is still a major problem for wheelchair users, who need to go and ask for a key and then find the facilities too small to accommodate themselves with their wheelchair.

Joyce Parker 1922 -2011

It was with great sadness that we learned of the death of Joyce Parker. Joyce was a leading member of Newbury Stroke Care and one of the founding members of West Berkshire Neurological Alliance. She saw the value of the various neurological support groups working together to help all people affected by a neurological condition in West Berkshire. She set the ball rolling and was instrumental in writing our constitution to make sure that the Alliance was founded on a firm basis. For many years Joyce served as Vice Chairwoman and for a time she was Acting Chairwoman. We shall miss her.

Dates for your diary

Our next open meeting is on July 14th, the speaker will be Christine Eeley, Princess Royal Trust for Carers. Dates for further Meetings in 2011 are: September 15th (AGM) and November 17th. All meetings, except the AGM, will be held at St Joseph's Church Hall, Newbury, 1.45 for 2.00 pm.

WBNA 2011 Conference

Our next conference will be: *New Opportunities for Neurology: Prevention, Rehabilitation and Self-help* to be held on Tuesday October 4th at Arlington Arts, Mary Hare School, Snelsmore Common, near Newbury. Mark the date in your diary. We will be mailing the programme very soon.

West Berkshire Neurological Alliance

2, Clayhill Crescent, Newbury,
Berkshire RG14 2NP

Tel: 01635 33582 Fax: 01635 569177

Email: secretary@wbna.org.uk

www.wbna.org.uk

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