

# Neurology on the move?

Richard Langton Hewer

**ABSTRACT – This paper describes the unsatisfactory situation that currently affects the provision of neurological services in parts of England, as identified in three recent reports, and contains a number of suggested ways in which the situation might be improved, while highlighting the good work being done by specialist nurses and therapists and by the Neurological Alliance on behalf of patients and their families.**

**KEY WORDS: Neurological services, neurological service research, standards of care in neurology, Association of British Neurologists, neurological alliance**

The specialty of neurology has advanced considerably in the last few years. There has been an improvement in stroke services and advances in the understanding and treatment of neurological disorders (such as multiple sclerosis and Parkinson's disease, although not yet major clinical breakthroughs) and an improvement in important educational initiatives. Despite these significant developments, there remain deficiencies in service provision.

The indifferent quality of neurological services in parts of England has been recognised for many years,<sup>1–4</sup> particularly by the Services and Standards subcommittee of the Association of British Neurologists (ABN). The use of outpatient clinics for new patients was discussed in three documents.<sup>5–7</sup> An enhanced role for general practitioners (GPs) and geriatricians was proposed both years ago and more recently.<sup>7</sup> The interface between palliative care and neurology was the subject of a report by the Royal College of Physicians (RCP).<sup>8</sup> Finally, the suggestion was made that there should be a neurologist based in each district general hospital (DGH).<sup>9</sup>

There have been a number of significant documents which have been published during the past year from the National Audit Office,<sup>10</sup> the House of Commons Committee of Public Accounts<sup>11</sup> and the Neurological Alliance.<sup>12</sup> (The latter document contains a particularly useful analysis of the issues.) The newly formed NHS Commissioning Board published its proposals in July 2012<sup>13</sup> and the Neurological Alliance responded shortly afterwards in August 2012.<sup>14</sup>

Despite a plethora of reports produced over a long period, there has, so far, been little change in the provision of neurological services over the last 20 years. However, the number of neurologists has increased, apparently largely in response to public pressure on the government to reduce outpatient waiting times for new patients.

The government responded positively to the report by the House of Commons Committee of Public Accounts, except that

they did not agree that there should be a national czar for neurology. In July 2012 the NHS Commissioning Board agreed with the Neurological Alliance that there should be a strategic clinical network for neurology.<sup>13</sup> A network covering mental health, dementia and other neurological conditions is to be established and supported from 2013. However, it is not clear what this will mean in practice. At the time of writing, the RCP and the ABN have not issued any public response to the government's documents, although it is understood that the ABN is preparing a report. The positive conclusion, however, is that neurological services are clearly now on the government's radar.

## What problems exist?

A number of particular problem areas have been identified. These include:

- a shortage of neurologists
- an uneven distribution of neurologists, with a greater number situated in London and fewer in the rest of England; the result is that many patients with acute neurological problems are not being seen by a neurologist, particularly in DGHs
- a shortage of neurological rehabilitation services
- a lack of national and local leadership
- a lack of outcome measures, making it impossible to assess the cost-effectiveness of neurological services. This has particular importance because of the rising cost of neurological problems.<sup>10</sup>

Most of these problems have been recognised for years but little has been done to resolve them. Recently, further problems have arisen in relation to the financial cap being imposed by commissioners on costs, particularly those related to inpatients.

## Research into service provision

There are gaps in research and audit information relevant to service organisation and delivery. This deficiency has important practical implications for the planning of neurological services. There are a number of areas where additional information could be helpful.

The first concerns epidemiology and the course of diseases. There have been no recent comprehensive epidemiological studies. Neurology is characterised by a few common disorders, such as stroke, and a vast number of uncommon disorders which together constitute a substantial burden of disability and workload. There is also a dearth of information related to the course of neurological diseases. This creates difficulties when planning services. For instance, in Parkinson's disease the disorder usually progresses through a number of stages extending over 12 years or so. These range from initial symptoms, which can often be controlled with medication, to total dependency with incontinence and intellectual

Richard Langton Hewer, honorary professor of neurology,<sup>1</sup> emeritus consultant neurologist<sup>2</sup> and chairman of the Association of British Neurologists Services Committee 1984–91

<sup>1</sup>Bristol University, UK; <sup>2</sup>North Bristol NHS Trust, UK

deterioration, although not all cases follow this course. Neurologically disabled children (with conditions such as cerebral palsy, muscular dystrophy, hereditary ataxia, brain injury, spina bifida and epilepsy), as they pass into adulthood and leave the paediatric service, present particular problems in the absence of fully comprehensive disease course information.

The second area concerns service delivery. Here there are two elements that appear to account for most of the expenditure on neurological services. The use of hospital beds has not been defined. We do not know whether beds are being used appropriately or whether a particular admission to hospital was necessary. There also appears a lack of information regarding the problems and needs of inpatients.

The use of outpatient clinics in different parts of the country and of specialist nurses (especially those with generic rather than single disease responsibilities) and GPs working outside the hospital has not been comprehensively investigated. This is particularly surprising considering the priority given to the topic by the government. The use of self-help management, with computer programs to support them, is a possible positive development. Again, evaluation will be essential. To summarise, outcome measures are needed in a number of areas and their absence makes the cost-effectiveness of interventions difficult to assess.

Finally, there has been little research into different models of care. There is a good case for expanding research into the ways in which neurological services are currently arranged and how improvements in the quality of services might be achieved. Funding might well be obtainable from one or more of the major health charities. Journal editors could play an important role by encouraging the publication of relevant material.

### A recent initiative

The Neurological Alliance have recently published a document which includes the following objectives:<sup>14</sup>

- A public health observatory for neurology is to be set up to lead the way for gathering information about the outcomes that matter in neurology.
- Key indicators and quality metrics relating to neurological services are to be developed.
- A national survey of people with neurological conditions is to be undertaken to gather insights into the care experienced by patients.

These are a welcome and laudable set of objectives. They fit in well with the suggestion that there should be an expansion of service research. However, they are ambitious and will require academic input. As things stand at the moment it is not clear whether or not the stated objectives are achievable.

### The future

The commissioners of neurological services have a daunting task ahead of them. They are being asked to propose a way in which improvements might be achieved at a time of financial stringency. They will be taking advice from organisations representing

patients and from professional bodies, and they will also be influenced by the reports from the National Audit Office, the Parliamentary Committee of Public Accounts and the Strategic Clinical Network document. What should their priorities be? Three initial questions are suggested:

- 1 How can services for patients with acute neurological problems (eg uncontrolled epilepsy, Guillain Barré Syndrome, head injury, meningitis and the many instances where the diagnosis is unclear) presenting to 'non-centre' hospitals be improved?
- 2 How should services for patients with progressive and/or disabling neurological disorders be organised?
- 3 Should the policy of giving priority to the outpatient waiting list be revised, bearing in mind that many patients appear to fall into the category of the 'worried well' and little significant disease is identified in clinics? Unless action is taken here there will be little chance of releasing neurological time for other, potentially more useful, activities.

### Acute problems in 'peripheral' hospitals

Full use should be made of telephone and telemedicine contact with the relevant centre. Each acute hospital must have access to computed tomography (CT) scanning (the results can be reported by a radiologist at the centre). However, these measures are insufficient and there cannot be any substitute for onsite neurological input. Ideally, there should be a neurological consultant based in each acute-care hospital. This will be difficult to achieve in all areas of the country, even if there is some redistribution of consultants from neurological centres to peripheral hospitals, as there is now little likelihood of a significant number of new consultant appointments.

The stroke networks set up to deliver effective thrombolysis therapy have demonstrated that non-neurologists (eg casualty doctors, emergency physicians and paramedics) can be usefully recruited and trained to provide a comprehensive service in a defined clinical area. However, the scope for expanding this policy into other domains is limited. Education and training of non-neurologists is an important element in the provision of both acute and long-term care.

Eventually there may be a reduction in the number of hospitals providing acute care. This, however, is highly controversial. In the long term it could result in more involvement of neurologists in acute care.

### The management of progressive and non-progressive disorders

The objective is to provide a seamless support service dealing with both medical issues (eg medication) and other factors producing disability. It is here that neurologists can have a crucial role.

Collaboration, coordination and leadership are the key components and are central to the strategic clinical networks that are

planned. There needs to be close collaboration with other disciplines, including general practice, emergency medicine, general medicine, palliative care, rehabilitation medicine, geriatrics, neuropsychiatry and general psychiatry.

There is also much scope for involving non-doctors, including specialist nurses and therapists as well as public health physicians, social workers and organisations representing patients.

With so many groups potentially involved, the result could be chaos unless there is a high level of coordination. This will not occur without effective leadership and management. Leadership could be provided by doctors, although there are other possibilities.

At the time of writing there do not appear to be any published examples of how neurological clinical networks might function in practice. This presents important research opportunities. It would be helpful if one or more experimental networks could be set up before any plan is rolled out nationally.

A further problem is that the strategic clinical networks document links neurology with mental health. The difficulty here is that the two topics are not closely linked historically or organisationally in the UK and there is currently little collaborative working, although the situation is different in much of Europe.

## The role of the professions

High-quality medical leadership at both national and local level is essential. If doctors are to assume this role, sessional time will need to be allocated for the work. The first task of the local lead would be to review current arrangements and to produce a report on the present situation and what will be needed in the future. This exercise could perhaps be usefully repeated every 2 years or so. Each department or unit should have a website that is regularly updated.

The role of non-specialist doctors who have neurological responsibilities could be usefully recognised, for example by the ABN inviting them to become associate members. The role of specialist nurses and other medical staff from a range of disciplines could also be encouraged by similar increased professionalisation and the enhanced status that this could confer. A forum for the presentation of papers on service matters could be valuable. Alternatively, if the ABN does not wish to expand its membership as suggested above, a new organisation could be created, or possibly hosted by the Neurological Alliance.

The changes have training and educational implications. This will be important both for 'non-neurological' doctors and also for ancillary professionals. Again, this will require time – and imagination.

## Conclusion

Some of the matters discussed here are controversial. However, hopefully they could form the basis for debate. The objective is to establish an agreed basis for a revamped neurological service which is attuned to the needs of patients. The next task will be to test the proposals in a number of geographical areas and then to implement the arrangements nationwide. A once-in-a-lifetime opportunity exists and it is important that our profession acts in a positive way.

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**Address for correspondence: Prof R Langton Hewer, Three Gables, Valley Road, Leigh Woods, Bristol BS8 3PZ.  
Email: rlangtonhewer@doctors.org.uk**