



**2003**

# **UK Neurology – The next ten years**

*Putting the patient first*

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# Executive summary

- 1.** UK neurologists are committed to improving the care of adults with neurological conditions, and solving the current shortfalls in service provision.
- 2.** Easy and timely access to outpatient neurological services is vital for all patients regardless of geography. This requires close working with primary care providers to change the way in which these services are delivered.
- 3.** All acutely ill inpatients with neurological problems should be looked after by consultant neurologists with teams of appropriately trained staff.
- 4.** Waiting times for non-urgent neurological investigations should be reduced significantly to no more than 4 weeks for brain imaging and 8 weeks for clinical neurophysiology.
- 5.** The neurologist should work as part of a multidisciplinary team, crossing traditional boundaries of primary, secondary, tertiary and social care, and be focused on the needs of those with neurological conditions.
- 6.** Interdisciplinary working is essential with elderly care physicians in stroke, rehabilitation consultants in chronic disability and psycho-geriatricians in dementia. This will also involve closer working with nurse specialists and professions allied to medicine.
- 7.** The interfaces between primary, secondary and tertiary care need particular attention. A quality service should be available as close to home as feasible, but still allow easy access to appropriate specialist expertise and equipment in a responsive and flexible fashion.
- 8.** Tertiary centres should be available to provide sub-specialist services, to plan regional services, and to facilitate continuing professional development, education and research.
- 9.** The achievement of the goals and standards set out in this document will require significant increases in staffing, not only neurologists and neuroscience-related specialists, but also nurse specialists and the professions allied to medicine.

# I

## Introduction

- 1.1.1 In the past seven years the Association of British Neurologists (ABN) has produced three documents on the provision of services for adult neurological patients. In 1996<sup>1</sup> and 1997<sup>2</sup> the Association concluded that comprehensive care at regional centres and more focused care in local hospitals would require at least one consultant neurologist per 100,000 population.
- 1.1.2 The third document, in 2002<sup>3</sup>, addressed the care of inpatients with acute neurological illnesses in local hospitals. It stressed the importance and clinical benefits of all such patients being under the care of a consultant neurologist. This comprehensive care would need one consultant neurologist per 40,000 population.
- 1.1.3 This document looks at every aspect of neurological care. It emphasises the importance of an expanded and extended role of the neurologist as an integral part of a team that provides care for all adults with neurological disorders. It sets realistic standards which can be achieved over the next ten years and which are vital for improved patient care. The present document is intended to link closely with *Levelling up standards of care for people with a neurological condition*<sup>4</sup>, produced in May 2002, by the patient-based charity umbrella organisation, the Neurological Alliance.
- 1.1.4 This comprehensive vision of the development of neurological services over the next decade will be of assistance to clinicians, managers and Trusts planning services locally, regionally and nationally, including the National Service Framework for Longterm Conditions, as well as to those with neurological disorders, their carers and the charities.

# 2

## Neurological conditions – an overview

### 2.1 What is neurology?

Neurology is the branch of medicine that deals with disorders of the nervous system, including the brain, spinal cord, peripheral nerves and muscles. These can be conditions which are managed almost entirely in the community (such as epilepsy and migraine), acute neurological emergencies (such as stroke and meningitis) and chronic disabling conditions (such as dementia, multiple sclerosis and Parkinson's disease).

### 2.2 How common are neurological conditions? <sup>2,5</sup>

2.2.1 Most patients with neurological symptoms present initially to primary care services.

2.2.2 About one in eight of all general practitioner (GP) consultations is for neurological symptoms, commonly headaches, blackouts and other alterations of consciousness, dizziness, tingling, numbness and weakness.

2.2.3 A large number of people attending hospital outpatient clinics have neurological disorders.

2.2.4 Twenty per cent of all acute emergency admissions to medical wards have a significant neurological problem, half of them with stroke.

2.2.5 About 20,000 people in every million of the population have a disability, often severe and progressive, as a result of neurological conditions.

2.2.6 Changes in the age structure of the UK population will lead to increasing numbers of people with degenerative conditions of the brain such as dementia and Parkinson's disease, requiring diagnosis and management.

### 2.3 What are the main neurological investigations?

2.3.1 The first and foremost diagnostic tool in neurology is the detailed history and examination undertaken by a skilled clinician with a wide experience of the varying presentations of neurological conditions.

2.3.2 Imaging the brain and spinal cord with computerised tomography (CT) and magnetic resonance imaging (MRI) is essential to investigate many people with neurological diseases.

2.3.3 Electroencephalography (EEG) may be useful in patients with loss of consciousness and epilepsy, and nerve conduction studies and electromyography (EMG) in the assessment of patients with weakness or numbness.

2.3.4 Lumbar puncture with analysis of the cerebrospinal fluid is important in selected patients, especially those with suspected brain infection or inflammation.

2.3.5 Nerve, muscle and brain biopsy and the use of DNA testing and other specialised tests are sometimes of great diagnostic value.

# 3

## Current service provision

### **3.1 Current service provision.**

- 3.1.1 Early and much of the continuing care are provided through primary care or community teams with little direct support from specialist neurologically trained staff.
- 3.1.2 Most people referred to a neurologist are seen in general neurology clinics held at local hospitals, with most referrals coming from GPs.
- 3.1.3 Most acutely sick neurological patients are admitted to a local hospital Trust through accident and emergency departments and admission units under the care of admitting general physicians or specialists in non-neurological conditions.
- 3.1.4 Many with complex neurological problems (both outpatients and inpatients) are seen at regional neurology and neurosurgery centres (regional neuroscience centres), where a full range of investigations, neurosurgery and subspecialist neurological services are available, or at neurology centres which have similar facilities, though lacking in neurosurgery, neuropathology, and sometimes other subspeciality services.
- 3.1.5 Neurologists work closely with neurosurgeons, in particular in the management of brain haemorrhage, tumours and a variety of spinal conditions.

### **3.2 Limitations in current service provision.**

- 3.2.1 There is a considerable geographical variation in the ease of access to neurological services, due in part to variations in the number of neurologists and the way in which the service is provided. Currently there are only 352 whole time equivalent consultant neurologists, with a ratio of 1:170,000 in the UK population, which compares very unfavourably with most other European countries.<sup>3</sup>
- 3.2.2 People with neurological conditions often suffer from a lack of coordination between healthcare professionals in the provision of continuity of comprehensive care.
- 3.2.3 There are few standards for neurological services that could be used as audit tools to evaluate and improve services.
- 3.2.4 Waiting times for outpatient appointments remain unacceptably long (over 20 weeks) in many areas of the UK.
- 3.2.5 Secondary waiting times for investigations such as brain imaging and clinical neurophysiology are often even longer (in some areas over 52 weeks).
- 3.2.6 In some areas pressure to see new outpatients to meet NHS targets has reduced the capacity to follow up many patients with chronic neurological disorders, who require long term specialist care if secondary complications are to be avoided.

- 3.2.7 Most acutely ill neurological patients in local hospitals are not under the care of a consultant neurologist and wait unacceptably long before a neurologist sees them to provide expert advice, if they see one at all.
  - 3.2.8 The number of beds at many regional neuroscience and neurology centres are insufficient to allow the rapid transfer of acutely sick neurological and neurosurgical patients from local hospitals.
  - 3.2.9 Critical care facilities at district hospitals, neurology and regional neuroscience centres are not sufficient for patients with acute neurological diseases.
  - 3.2.10 Patients often travel long distances to neurology and regional neuroscience centres for tests and treatment because of a lack of adequate neurological facilities at local hospitals.
  - 3.1.11 Many neurologists are insufficiently involved with important common brain disorders such as stroke, dementia, disability, head injury and brain tumour:
  - 3.1.12 Facilities are insufficient to provide continuing, long-term care of chronic neurological conditions.
- 

## 4

# Goal

*Neurologists want to ensure that people with neurological conditions have timely access to a high quality, comprehensive and coordinated, patient-centred and expert service, with equity of provision regardless of geography, age, race and gender.*

# 5

## The way forward – a quality service

### 5.1 Emergencies

- 5.1.1 The ABN document *Acute neurological emergencies in adults*, published in 2002<sup>3</sup> summarises some urgent needs. All emergency admissions to a local hospital with acute neurological problems should be under the care of consultant neurologists and their teams. These standards cannot be achieved without a significant increase in the number of neurologists and a change in the way neurologists work. An increase in neurological beds to approximately 15 beds per 100,000 of the population would be needed. Until these facilities are introduced all patients admitted to a local hospital with a major neurological problem should at least have immediate access to an expert neurological opinion and be assessed by a neurologist within 24 hours, or possibly via a telemedicine link.
- 5.1.2 Rapid access is needed to the designated regional neuroscience centre for certain neurological emergencies and neurosurgery. Adequate neurological and neurosurgical bed numbers must be available to accommodate this standard.
- 5.1.3 Access to emergency CT brain scanning in all local hospitals is needed 24 hours, 7 days a week. Access to MRI scanning for emergencies at all times should be immediately available now for patients with acute cord syndromes. Emergency scans should be reported by a neuroradiologist in person or by imaging link.
- 5.1.4 Access to urgent EEG and EMG facilities is needed in local hospitals that admit patients from A & E departments.

### 5.2 Onset and diagnosis – working with GPs and the primary health care system

- 5.2.1 All people with significant neurological symptoms need a diagnosis, and appropriate treatment should be started quickly. This can be achieved by the provision of rapid access to a local high quality neurological service, which is part of a clinical neuroscience network. Such a network should include a group of local neurological services functioning in local hospitals and the community which link with neurology and neuroscience centres, share common protocols and guidelines, and share specialist services that may be based in only some parts of the network.
- 5.2.2 At every stage patients should be informed and involved in the planning of their care.
- 5.2.3 The key to improving neurology services locally is a closer working partnership between neurologists and primary care and social services, to offer a coordinated comprehensive care package incorporating all relevant aspects of the local health system. This should include care and support in the interval between referral to, and the appointment with, a neurologist.

- 5.2.4 Neurologists need to explore with commissioners, including GPs, the optimal sites for general neurology outpatient clinics. These may include community-based clinics, in addition to local hospital outpatient departments.
- 5.2.5 Short out-patient waiting times must be achieved. The NHS Plan requires that patients referred by general practitioners wait no longer than 17 weeks by 31 March 2004. We believe these waiting times must become significantly shorter with routine patients being seen within four weeks or less. Outpatients considered urgent by the referring clinician or neurologist should not wait more than a week.
- 5.2.6 These goals may be achieved by having a neurology outpatient clinic in each district every weekday.
- 5.2.7 A designated consultant neurologist should be available in each district and easily accessible daily (including weekends) to speak to GPs directly about urgent clinical concerns.
- 5.2.8 Neurologists need to work closely with GPs, GPs with a special interest, nurse specialists and other health care professionals to explore the most effective way to meet these outpatient standards and to consider new ways of delivering services.
- 5.2.9 GPs' confidence and competence in handling common outpatient neurological problems should increase if they work more closely with neurologists. Shared care protocols and guidelines should be developed and include wider access to appropriate key investigations, including CT.
- 5.2.10 The aim should be to break down traditional divisions between primary, secondary and tertiary-based practice, in order to provide a seamless high quality neurological service based around local needs as part of the broader neurosciences network.
- 5.2.11 People with neurological conditions, carers and local branches of neurological charities should all be involved, along with a wide range of healthcare workers, in discussions on how neurological services can best be delivered in each district.

#### **Clinical vignette – part A**

*A 48 year old man, complaining of problems with his writing and using his right hand, is referred by his GP to the general neurology outpatient clinic at the local hospital. He is diagnosed within four weeks as having early Parkinson's disease and started on medication. He improves and after one or two more visits is discharged to the local Parkinson's disease nurse specialist and his GP for ongoing care in the community, with clear indications for referral back to the neurologist.*

### **5.3 Diagnostic services**

- 5.3.1 People with neurological conditions should not wait an inappropriately long time for investigation after seeing a neurologist. Where possible, and where the patient desires it, a one-stop service should enable consultation and all investigations on the same day.
- 5.3.2 Adequate access to brain imaging is essential. Routine waiting times for CT or MRI should not exceed four weeks. Patients requiring more urgent imaging must be accommodated. Appointments for investigations should be at a time convenient to the patient.
- 5.3.3 Each local neurological service will require access to a clinical neurophysiology service for EEG and EMG investigations, providing urgent appointments immediately and routine appointments within four weeks for an EEG and eight weeks for an EMG. However, the current levels of staffing in this speciality are a major obstacle to achieving this standard. Alternative safe, effective and innovative methods of delivering the service need to be examined in conjunction with consultant clinical neurophysiologists.
- 5.3.4 An adequate neuropsychology service is necessary, based locally wherever possible. An outreach service from the regional neuroscience centre may be an alternative.

### **5.4 Intermediate management**

- 5.4.1 After the initial outpatient consultation and investigation, a diagnosis can usually be made and treatment advice given to the patient, their family and the GP.
- 5.4.2 A minority will require ongoing care, in which case a detailed plan should be made jointly with the patient, the GP and, where relevant, with rehabilitation and other local community services to ensure continuity of care.
- 5.4.3 Neurologically trained nurses and GPs with special interest should play an increasing role in the interface between community, primary, secondary and tertiary care in order to improve clinical care, communication, information and access to services.
- 5.4.4 More nurses are needed with a special interest in the major common neurological diseases (such as epilepsy, stroke, dementia, multiple sclerosis, Parkinson's disease and motor neurone disease). More nurses with broader expertise for patients with neurological conditions are also needed. If such nurses are well integrated in the regional neuroscience network, they can play a major role in improving and hastening appropriate care and in liaison and communication.

- 5.4.5 In addition to general follow-up neurology clinics, specialist clinics should be established at local hospitals for the common neurological conditions (such as multiple sclerosis, epilepsy, Parkinson's disease, stroke and dementia). These clinics should be supported by doctors, professionals allied to medicine, specialist nurses and other professionals. They will foster team-based working in order to provide patients with a full range of facilities.
- 5.4.6 People with neurological conditions should have access to the most appropriate part of the service at all times. Where indicated clinically they should have easy access to services at the regional neuroscience or neurology centre.

#### **Clinical vignette – continuation, part B**

*After two and a half years he develops further problems with his right leg affecting his walking and his work as a plumber. He is referred back to the local multidisciplinary Parkinson's disease clinic where his medication is changed and he is seen in the community by an occupational therapist and physiotherapist. He improves and his ongoing care remains with the nurse specialist and GP, with an annual review in the local hospital Parkinson's disease clinic.*

### **5.5 Long-term management**

- 5.5.1 Long-term management and care is required for the major common chronic disabling neurological conditions such as stroke, dementia, epilepsy, Parkinson's disease, and multiple sclerosis, as well as for many rarer conditions, including motor neurone disease and muscular dystrophy.
- 5.5.2 People with chronic neurological conditions need to be under the direct care of a designated specialist who is skilled, available and able to access the appropriate resources. This may be a neurologist or an elderly care physician, psycho-geriatrician, clinical geneticist or consultant in rehabilitation medicine. Joint care may be appropriate so long as clinical responsibility is defined clearly. Alternatively it may be a neurological nurse specialist or other paramedical specialist with the appropriate competencies, so long as they have direct access to an appropriate neurological specialist.
- 5.5.3 Neurologists should be part of the multidisciplinary teams providing care for all patients with chronic neurological diseases. These teams include specialist and general nursing, physiotherapy, speech and language therapy, occupational therapy, dietetics and social care. Within each district a neurologist should work with the multidisciplinary team for patient care in each major chronic neurological condition. Rapid access to these therapy services in the community is essential.
- 5.5.4 Care should be provided by these teams in a community setting wherever possible.

- 5.5.5 Closer links between the community rehabilitation teams, the local hospital and the regional neuroscience or neurology centre should provide seamless care so that rigid boundaries are removed from every level of the service.
- 5.5.6 Patients with specific and usually complex conditions should be reviewed in specialist multidisciplinary clinics, where time is available to address their needs and those of their carers. Neurologists need to know how to access such clinics.
- 5.5.7 At all times patients should have access to high quality information about their neurological condition, investigations and treatment.
- 5.5.8 Where relevant a key worker should be appointed to assist in the patient's management, especially at the interfaces between health and social services, vocational re-entry, and education.
- 5.5.9 Neurologists sometimes have been part of the team providing palliative care for their patients, and recognise that particular skills are required to provide care in the final phase of chronic, deteriorating conditions. In some, such as motor neurone disease, input is appropriate from the point of diagnosis. Patients, carers and family need to be kept informed fully about the prognosis and the range of services available, whether a hospice, nursing home or their own home. It is essential to co-ordinate pain control, and emotional and psychological care. Neurological teams should also be involved in supporting carers and family with practical issues after death, including bereavement counselling. All of this will require a new approach to provide neurological, palliative care staff and trained volunteers, and to support the emotional well being of these staff.

## 6

# The evolving role of Regional Neuroscience Centres and Neurology Centres

- 6.1.1 The major expansion of local neurology services as proposed will have significant effects on regional neuroscience centres and neurology centres.
- 6.1.2 Regional neuroscience and neurology centres should promote and be part of the development of neurological networks in association with a variety of partners to improve the whole service for a population of between one and four million.
- 6.1.3 Patients will sometimes need to be admitted to these Centres for specialist investigations such as catheter angiography and video-telemetry when they are not available in the local hospital.
- 6.1.4 Patients will also need to be admitted to these Centres for specialised procedures and treatments including interventional neuroradiology, the insertion of indwelling pumps and stimulators, and routine and specialised neurosurgery.
- 6.1.5 Some selected inpatients with complex problems will need to be transferred for fuller assessment.
- 6.1.6 Individual Centres already have, and should develop further, regional, supraregional and national expertise in particular fields with cross-referral for investigation and treatment.
- 6.1.7 Patients should only have to travel long distances to Centres when it is either not appropriate or not possible to make the service available closer to their home.
- 6.1.8 Teaching, audit, medical education, continuing professional development, protocol development, and monitoring services and standards will be an expanding part of the role of neuroscience networks and are likely to be coordinated from the Centres.

### **Clinical vignette – continuation, part C**

*Twenty months later the patient contacts the nurse specialist and asks for an earlier review in the Parkinson's disease clinic because he is now having long periods each day of immobility when the tablets do not seem to work. After re-assessment and full discussion he is admitted to the regional neuroscience centre to see whether a continuous infusion pump of apomorphine will help. After a week he is improved and discharged back to the care of the multidisciplinary team at the local hospital. The nurse specialist supervises the infusion pump in the patient's home. Eventually he requires neurosurgical insertion of a deep brain stimulator performed at the regional neuroscience centre. Apart from regular reviews there, he is managed by the local team in the community.*

- 6.1.9 The Centres will be a shared resource as part of the network, enabling all those involved in the provision of care for people with neurological conditions to develop their professional skills.
- 6.1.10 These proposals are likely to have major implications for the training of neurologists, as will the European Working Time Directive. The need for neurological trainees to obtain a broad training by spending more time at local hospitals has to be balanced with the requirement to maintain adequate staffing at the Centres.

# 7

## Academic neurology, research and development

- 7.1.1 The future of academic neurology will shortly be discussed in a new ABN document *Academic neurology in the United Kingdom: threats, opportunities and recommendations for the future*.<sup>6</sup>
- 7.1.2 Academic departments of neurology, based mainly at university medical schools, remain vital for the development of quality neurological services and for the training of undergraduates and postgraduates.
- 7.1.3 Academic departments are usually linked closely to the Centres.
- 7.1.4 Such departments should be well integrated with local clinical services, and support research and educational activities undertaken by NHS staff at all levels in the neuroscience network.
- 7.1.5 Effective clinical networks increase the opportunity for many forms of research, including randomised trials and observational epidemiology.
- 7.1.6 Academic departments of clinical neurology should play a major role in the coordination and teaching of undergraduate basic neuroscience and clinical neurology.
- 7.1.7 The future development of neurological services should benefit from health services research.

# 8

## Key priorities

The ABN has set out standards of care that should be met within the next decade and ideally considerably sooner. The key priorities are:

- 8.1.1 To ensure that people with acute neurological emergencies, looked after currently by general and other non-neurological physicians, are managed by neurologists.
- 8.1.2 To provide appropriate and speedy access to local neurological outpatient services, with rapid diagnosis and investigation for new patients and timely re-assessment of patients with chronic problems.
- 8.1.3 Greater integration of neurology with other disciplines, both medical and non-medical, to develop team-based working and deliver care most appropriate to the patient's needs.
- 8.1.4 Involvement in the provision of co-ordinated, multi-disciplinary management over time for patients with chronic disability conditions.

# 9

## Turning the vision into reality

- 9.1.1 This document sets out the direction in which the ABN considers neurological services should develop over the next ten years to transform the quality of patient care throughout the UK.
- 9.1.2 Implementation will be gradual, phased, and different in each Strategic Health Authority and groups of Primary Care Trusts, but it should reflect genuine integration and joint planning aimed at developing neurological networks to achieve the ABN standards. Some of these are described in this document and a full set of standards for neurological services is currently under development by the Association.<sup>5</sup>
- 9.1.3 Individual Centres and groups of neurologists will need to engage with commissioners, Primary Care Trusts and local health communities to implement these changes by drawing up a five to ten year strategic plan for the development of neurological services.
- 9.1.4 Neurologists need to enter into discussions with their medical colleagues, medical directors and chief executives on ways to start implementing all these plans.
- 9.1.5 Neurologists will need to improve working relationships with other medical and healthcare professionals in order to provide comprehensive expertise for the long-term management of neurological disability.
- 9.1.6 The ABN will need to engage with the Workforce Development Confederations, Royal Colleges of Physicians and the Neurology Specialty Advisory Committee in trying to achieve a realistic expansion in the number of consultants, specialist registrars and senior house officers.
- 9.1.7 The necessary expansion of related speciality services, particularly clinical neurophysiology, neuroradiology, neuropsychology and neuropathology needs to be addressed nationally by the ABN, the Royal Colleges and other professional associations.
- 9.1.8 The changing role of the consultant neurologist that is needed to ensure this vision of the future is achieved should be embraced by the whole speciality.
- 9.1.9 Progress in achieving the desired improvement in the level of neurological care will need to be monitored carefully and such audit should be used to inform future planning by the local community.
- 9.1.10 Consultant neurologists will have varying roles and tasks which may change at different stages of their careers.
- 9.1.11 Consideration must be given to the changing needs of consultant neurologists, over a lifetime of clinical practice, in respect of their ongoing professional development and ability to deliver service, and their commitment to education, research and administration.

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