



# The Neurological Alliance

The Neurological Alliance, a collaborative forum of 50 organisations, represents the needs and views of people in the UK with a neurological condition. The Neurological Alliance comprises organisations concerned with several hundred conditions ranging from the relatively common to the very rare. Together the member organisations of the Neurological Alliance have over 220,000 individual members.

## **Our aims are to:**

- ✓ Raise awareness of neurological conditions and their impact on individuals and society
- ✓ Inform and influence policy makers about the needs of people with neurological conditions
- ✓ Secure the highest standards of service and improved care for people with neurological conditions.
- ✓ Promote research and the dissemination of information about neurological conditions.

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### **Working group members**

Maggie Alexander, Brain and Spine Foundation

Ruth Berry, Alzheimer's Society

Tricia Holmes, Motor Neurone Disease Association

Graham Nickson, Headway, The Brain Injury Association

Julie Tickle, Joint Epilepsy Council

Nikki Joule, Policy Officer, Neurological Alliance

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Neurological Alliance, PO Box 36731, London, SW9 6WY  
Telephone: 020 7793 5907 Fax 020 7793 5939

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# Executive summary

## Introduction

This document outlines the standards of care that people with neurological conditions should expect. The overall aim of these standards is to ensure the availability of high quality neurological, rehabilitation and community services to those who require them. The document focuses on generic standards covering all stages of a neurological condition from onset and diagnosis; through intermediate care and long term management; to the end of life.

The Neurological Alliance has produced this document in consultation with people who live with neurological conditions, their carers and the organisations that represent them.

## Key principles

The Neurological Alliance standards of care are based on the following key principles which underpin the provision of quality services for people with neurological conditions.

### **Independence and quality of life**

Promotion of maximum independence and optimum quality of life for people with neurological conditions.

### **Speedy access**

Speedy access to specialist diagnosis, investigation and treatment by knowledgeable professionals sensitive to the needs of people with particular neurological conditions.

### **Comprehensive assessment**

Expert and sensitive assessment of need supported by timely referral for appropriate treatment and services, including medical, surgical and rehabilitative treatment and care, aids and equipment, domiciliary services, counselling, respite and day care.

### **High quality information**

Access to high quality, easily accessible information about specific neurological conditions, appropriate services and relevant voluntary organisations. This should be provided verbally and in written (or other portable) form for the person affected as well as their family and carers. Information should promote and support informed choice.

### **Well trained interdisciplinary professionals**

Care provided by professionals who have access to high quality information and training about particular neurological conditions, who are knowledgeable about management and treatment, and who work in an interdisciplinary fashion with other professionals and services, including appropriate voluntary organisations.

### **Prevention**

Prevention of avoidable death and disability and secondary complications.

**On-going access**

Easy, on-going access to services through one point of contact.

**Equity of service provision**

Equity of service provision for all people with neurological conditions regardless of geography, age, gender or race.

**Co-ordinated care across sectors**

Continuity of care and co-ordinated services between health, social and education, housing, employment and benefits services.

**Access to voluntary organisations**

Access to appropriate voluntary organisations.

**User involvement**

Involvement of people with neurological conditions, and their carers, in treatment options and decisions, and in the management of their condition.

**Holistic rehabilitation**

The provision of holistic and ongoing rehabilitation, which addresses all aspects of a person's life and involves their carers.

**Established care pathways**

Established care pathways to facilitate appropriate and timely movement from acute care to rehabilitation and through other transitional periods.

**Good record keeping**

Up to date patient records accessible to all professionals involved with the care of someone with a neurological condition, and the person with the condition.

**Addressing the needs of carers**

Attention to the needs of carers including assessment of their needs.

This report provides details of the main stages that need to be considered when planning services for people with neurological conditions and provides recommendations on key areas for change and improvement.

**Levelling up** page 4

The main stages are:

- ✓ Prevention
- ✓ Emergencies
- ✓ Onset and diagnosis
- ✓ Intermediate management
- ✓ Long term management
- ✓ Palliative care

## Making improvements

The document outlines action for commissioners and providers of services to facilitate the achievement of continuous improvement in service provision and outcomes.

### Joint planning/commissioning

Improved arrangements for joint working between health and social care and other agencies need to be developed. The development of care trusts and the inclusion of neurological services in Health Improvement Programmes are recommended.

### Monitoring of standards

Local clinical governance arrangements should oversee the process of monitoring local services against agreed standards, including monitoring tools derived from the Neurological Alliance standards of care and other published standards.

### Research

Areas where further research is required include:

- ✓ Epidemiology
- ✓ Costs, both national and personal
- ✓ Use and appropriateness of health services
- ✓ Use and appropriateness of social services
- ✓ Prevention
- ✓ Acute / emergency neuro-services
- ✓ Symptoms
- ✓ Treatment and cure

### Education and training

People with neurological conditions should be able to expect that health and social care professionals have an understanding of the issues which are common to many neurological conditions. Interdisciplinary training should be undertaken by those professionals specialising in neurological conditions. Voluntary organisations can very effectively be involved in training alongside professionals.

People with a neurological condition and their families/carers should also have access to education and training so that they can be involved in their own management and make informed choices about personal lifestyles.

### **Working with voluntary organisations**

Voluntary organisations have an important part to play in the care of people with neurological conditions. The Neurological Alliance and its members are able to help in the implementation of these standards and are committed to working together with central and local government and health and social care professionals in service planning, delivery and review.

### **Taking forward the standards**

The Neurological Alliance urges providers of services for people with neurological conditions, and those who commission services, to adopt these standards of care and to work towards them becoming a reality for all those across the UK with a neurological condition. The Alliance will be working with professional associations and our member organisations to develop audit tools and to identify models of good practice.

## **Introduction - standards of care for people with neurological conditions**

### **Developing the standards of care**

This document is a revision of previous standards of care published by the Neurological Alliance in 1992 and 1996. A small working group, drawn from the Neurological Alliance Policy Forum, has produced this document in consultation with members of the Neurological Alliance and others.

A draft of the document was issued in June 2001 for consultation. We received over 60 sets of comments on the draft from a range of respondents including individuals with neurological conditions and some carers, local branches of our member organisations and some professionals; (see Appendix 1 - Respondents to the consultation draft). We considered all the comments received and this final version of the document has taken them into account.

### **The need for patient-centred standards of care**

A recent survey by the Neurological Alliance found that there are still large variations across the UK in the standards of care experienced by people with neurological conditions and in their ability to access quality services. The report of this survey recommended a levelling up of all neurological services to meet the standards set by the best services.<sup>1</sup>

The Neurological Alliance welcomed the Government announcement, in February 2001, of the plan to develop a National Service Framework (NSF) for long term health conditions focusing on neurological conditions and brain and spinal injury.<sup>2</sup> The Alliance hopes that the standards set out here will inform the development of the NSF in England, and the Scottish, Welsh and Northern Ireland Executives, in order that the needs of people living with a neurological condition throughout the UK might be addressed.

The NHS Plan outlined an aspiration that patients should have more say in their own care and more influence over the way the NHS works.<sup>3</sup> The standards in this document from the Neurological Alliance are patient-centred and aim to be complementary to the clinical guidelines currently being prepared on various neurological conditions, for example the National Institute of Clinical Excellence (NICE) guidelines for multiple sclerosis, head injury and epilepsy, the Scottish Intercollegiate Guideline Network (SIGN) Guideline for Epilepsy, and the standards for people of all ages with stroke published in the NSF for older people. Our standards are generic and are derived from the experiences of patients and carers. The focus on quality of life reflects patient and carer aspirations that improvements in quality of life in future will be valued more highly in the measurements of clinical outcomes made by providers of services.

### **Taking forward the standards of care**

This standards of care document is the subject of an ongoing Neurological Alliance project. The aim is to develop the standards into an audit tool to enable voluntary organisations, providers and commissioners of neurological services to measure and audit the care being provided for people with neurological conditions.

The Neurological Alliance standards of care are intended to complement documents being produced by various professional associations, including the Association of British Neurologists (ABN)<sup>4</sup>, the Society of British Neurological Surgeons (SBNS)<sup>5</sup> and the British Society of Rehabilitation Medicine (BSRM).<sup>6</sup>

In addition, a number of member organisations of the Neurological Alliance have produced standards of care for various specific neurological conditions; (see Appendix 2). We commend and promote the development and use of these standards.

The Neurological Alliance recommends that commissioners and providers of health and social services for people with neurological conditions use our standards as a benchmark against which to audit their services. This document, and the Neurological Alliance standards of care project, can assist them in developing higher quality and more easily accessible services that meet the needs of their service users and carers.

## **Neurological conditions – an overview**

Neurological conditions result from abnormal function or damage (caused by illness or injury) to the brain, spinal column or nerves. They have various causes, many of which are not yet known. Neurological conditions affect young and old, rich and poor, men and women and people from all cultures and ethnicities.

People can experience the onset of a neurological condition at any time in their lives. Some conditions, such as cerebral palsy, are present from birth, and some, such as Duchenne muscular dystrophy, commonly appear in childhood. Other conditions, such as Alzheimer's disease and

Parkinson's disease affect mainly older people. There are also conditions which have a sudden onset due to injury or illness, such as a head injury, stroke, viral infection affecting the brain or cancers of the brain and spine. While some conditions may stabilise or improve, the neurodegenerative conditions, such as multiple sclerosis, motor neurone disease and progressive supranuclear palsy, can cause a rapid or prolonged deterioration of a person's quality of life and their ability to live independently.

## Numbers of people with neurological conditions

### Lack of data

There is little systematic collection of data on the numbers of people with neurological conditions in the UK. There is an urgent need for more hospital and community based data collection and research and assessment of needs in relation to people with neurological conditions<sup>7</sup>.

Appendix 3 shows the numbers of people in the UK with various neurological conditions. These figures are not comprehensive, but provide an illustration of the range of neurological conditions with which the Neurological Alliance is concerned. The table demonstrates some of the gaps in knowledge and the need for further work to establish better data on the numbers of people living with various neurological conditions.

### Impact on health and social services

Acute neurological cases have been shown to account for 20% of admissions to medical wards<sup>8</sup> and a typical primary care trust (PCT) of 250,000 people will have around 1,500 adults who are so physically disabled as to require help for most of their day-to-day activities<sup>9</sup>. OPCS studies<sup>10</sup> found neurological conditions reported in 13% of home-dwelling disabled people and in 40% of those with the two severest grades of disability.

### Projected increase in numbers

The numbers of people with neurological conditions will grow sharply in the next two decades. Improved survival rates at birth mean that more children affected by conditions such as cerebral palsy will reach adolescence and adulthood. Improved general health care and infection control will ensure longer lives for people with degenerative neurological conditions such as some of the muscular dystrophy conditions. Increased longevity means that more people will develop conditions which often occur later in life, such as dementia, Parkinson's disease and stroke. One study found neurological disability was reported by 1% of people aged over 40 years and 10% of people aged over 80 years<sup>11</sup>.

Improved diagnostic techniques are helping to identify increasing numbers of people with neurological conditions and ever improving treatments, therapies and technologies can be expected to extend the lives of this increasing population.

## Needs of people with neurological conditions

### Complexity of needs

People with neurological conditions often have complex needs as neurological disorders can affect many parts of the body and manifest themselves in a multitude of symptoms, affecting many aspects of person's ability to function. People may have more than one disorder. Symptoms can be confused and misdiagnosis is common. Physical health needs are only part of the picture. People with neurological conditions need access to education, training, employment, housing and an adequate income.

### Socio-economic impact

Socio-economic deprivation is associated with increasing prevalence and severity of stroke, head injury, cerebral palsy<sup>12</sup>, and MS<sup>13</sup> and of disability in general<sup>14</sup>. As most neurological disorders are long-term conditions, the condition impacts on people's economic independence and their ability to participate fully in society.

Many neurological conditions severely affect people's quality of life and some cause life-long disability. Some conditions are fluctuating and unpredictable making day-to-day management and planning difficult. The impact goes beyond the person with the condition, and will often have a significant effect on their family and others, including impacting on the economy of the whole family. This is compounded by the fact that people will often have to find money to pay for long-term medication, childcare, expensive aids and adaptations. There may be poor access to benefits as medical assessors often lack knowledge and understanding of neurological conditions. Not receiving sufficient financial support for care or mobility needs can put additional strain on a person with a neurological condition and their family.

### The needs of carers

Though most people with a neurological condition wish to remain independent for as long as possible, many people will require the support of a carer for all or part of their daily functioning. This is a role frequently carried out by family members, partners or close friends.

Carers often have to give up paid employment or reduce their hours of work in order to care. This has an immediate effect on both their individual and household incomes. They also lose out on pension rights and opportunities to build up savings. If the person they care for is a partner, this will mean that neither partner is able to ensure the economic independence of the family in the future. This impacts hardest on those caring for someone with a long-term condition or disability. Research by the Age Concern Institute of Gerontology found that people who had cared for more than 10 years were more likely to be receiving means-tested social security benefits and had spent less time as members of occupational pension schemes than those caring for shorter periods<sup>15</sup>.

In addition to the economic problems, carers' own health is affected by their caring role. A recent study<sup>16</sup> found that 51% of carers had suffered a physical injury such as a strained back since they began to care and 52% had been treated for stress related illness.

**Impact on the family**

Some neurological conditions are hereditary or there is a genetic component to the causation. The impact on the whole family of an individual being diagnosed can be immense. This can strain relationships and has implications for the life choices of the whole family.

**The need for understanding**

Neurological conditions are very poorly understood by the general public and there is a need to address this problem. Levels of awareness are low even about relatively common conditions, such as epilepsy and head injury. There is also a large number of rare conditions, such as Guillain Barré syndrome and ataxia-telangiectasia which are largely unheard of and poorly understood by health and social care professionals. This has an impact on access to appropriate health services.

Poor awareness of neurological conditions, and of the needs of people affected by them, amongst educational policy makers and teachers impedes access to sensitive and appropriate education services.

There is a generally a need for greater understanding and acceptance of people with speech, movement or behaviour difficulties. The attitudes of others compound the difficulties people with neurological conditions experience. They are often stigmatised and misunderstood which can lead to further social, emotional and economic problems.



## Quality services for people with neurological conditions

**Speedy access to co-ordinated specialist care**

As most neurological conditions have a long lasting or life-long impact there is a need for coordinated, patient-centred services which ensure continuity of comprehensive care to meet people's on-going needs. People with neurological conditions will need access to health services at different times and for various reasons: emergency care in the case of sudden onset or later deterioration, extra support during crises or changes in life circumstances, ongoing review and information at other times. People with neurological conditions are not necessarily heavy users of health services; many people will manage their own condition, with appropriate support from health and social services, for long periods of time. When they do use health services, however, they require speedy access to appropriate, often specialist, services and health professionals who fully understand their condition.

**Information on accessing services**

Most importantly, people with neurological conditions need to know how to access the services they require. In order to achieve this there is a need for appropriate and comprehensive information that is updated regularly and disseminated widely.

**Equitable access to services**

People also need equitable access to quality services. Access to quality services should not depend on the area of the country in which someone happens to live, or on their ethnicity or social class. Neurological Alliance members report a postcode lottery for neurological services and there is some evidence that Black and minority ethnic people, and those from socially deprived areas, have lower than average usage rates of neurological services and receive a lower quality of service when they do access these services<sup>17</sup>.

**Patient-centred care**

People with neurological conditions, and their carers, will often become experts in the condition, and in assessing how the condition affects their lives. Health and social care professionals should recognise and use this expertise. Assessment of needs should be genuinely patient and carer centred and holistic. In particular, there is a need for seamless links between and within health and social services, education services, housing, employment and benefit services.

**Access to all health services**

Though access to specialist neurological expertise is often the focus of services for people with neurological conditions, they also require access to all general health services. These include gynaecological and maternity services, urological services and dentistry. There is a need to ensure that these services are sensitive to the needs of people with a range of neurological conditions and disabilities, and that professionals understand the impact of the neurological condition and any medication.

**Appropriate and on-going rehabilitation**

People with neurological conditions need appropriate support to enable them to maximise the quality of their lives at every stage of illness or disability. The provision of rehabilitation services for people with neurological conditions is often overlooked. There needs to be recognition that rehabilitation is an ongoing process which necessitates the regular reassessment of people's needs. Particular attention should be paid to ensuring the availability of vocational rehabilitation. Research suggests that approximately only 19 – 29% of people who had a job prior to severe head injury are back at work, either full or part-time, five years after their injury if they do not receive any vocational rehabilitation<sup>18</sup>. However, the return to work figure can be doubled where the person with the head injury has followed a vocational rehabilitation programme.

**Information about voluntary organisations**

Many people with neurological conditions benefit from the information and support provided by voluntary organisations, which enables them to manage their condition and use health and social services appropriately. Health and social care professionals should ensure that they provide contact details of appropriate organisations.

**Involvement in research**

Service users can benefit from being involved in research in a number of ways. Involvement may provide access to a higher standard of care, and is likely to improve the quality of care for

current service users and others in the future. People should be fully informed about relevant research and given the opportunity to participate where appropriate. People with neurological conditions, their carers and the organisations that represent them should be involved in setting priorities for research, and in determining research questions.

### **Patient-centred outcomes**

The experiences of people using services and their assessments of quality of life should be integral in measuring the effectiveness of health and social services.

## Prevention

Many neurological conditions cannot be foreseen or prevented. There is a need for more research on the causes of neurological illness. Where prevention is possible, it is obviously in the interests of all service commissioners and providers to ensure that the means are available. This involves all levels of service planning and developments from central Government, through health authorities and boards, PCTs and all departments within local authorities.

### **General prevention**

#### **Accident prevention**

There should be national and local strategies in place to reduce accidents and injury on roads, in workplaces, in the home and in public places. These will require considerable inter-agency working.

#### **Health promotion**

Training for health and social care professionals should include the promotion of personal health care, including education about the areas of risk that can result in neurological damage. Alcohol and drug use, smoking, obesity and lack of exercise can produce problems in themselves, but are also risk factors in relation to particular conditions such as stroke. Hypertension is a major risk factor for stroke, and adequate means of detection and treatment should be provided.

#### **Antenatal screening**

A full screening programme should be available to all pregnant women, and their partners, with full information and counselling available.

#### **Prevention of secondary harm**

Strategies should be developed to ensure that secondary damage is minimised following a brain injury or onset of a neurological condition. Care and treatment should maximise opportunities for recovery and reduce further preventable damage. Medical and surgical interventions, whether they be to prevent recurrent onset, improve functioning or slow down progression, should be readily available. In addition, measures should be taken to prevent further

consequences of the condition, for instance pressure sores and soft tissue damage, reduced lung function and contractures. Attention should also be given to the prevention of life-threatening infections.

## Genetic testing

### Education

Developments are rapid in this field, and there should be an ongoing education programme for health and social care professionals and the general public.

### Referral to genetic services

Referral to a geneticist should be offered as a matter of course where there is any suggestion of a genetic implication. People need specialised counselling and information about the genetic implications of neurological conditions in order that they may make informed and considered choices.

### Access to tests

Where technically possible, tests should be offered to people at risk of having a genetic disorder or being a gene carrier. Timing is particularly important for people who are considering a pregnancy - adequate time for counselling, decision-making and technological preparation is essential.

### Access to counselling and treatment

Those found to be at risk of developing a neurological condition, through a genetic test or through the testing of a family member, should be offered access to counselling and any treatment that may prevent or delay onset of the condition.

## Emergencies

The aim of emergency care is to prevent death and disability through immediate access to expert interventions. There are an increasing number of interventions that can be made in the hours immediately following an injury or infection when it may be possible to arrest or limit major brain damage. This is particularly true for head injuries, but can also apply in some cases to stroke, epilepsy and other conditions.

### Speedy access to appropriate facilities

Response to emergency calls should be immediate. Ideally, people should be at Accident and Emergency (A & E) centres within one hour of the incident. They should be taken to A & E departments which provide a full range of services including intensive care and scanning equipment. Staff who are trained and competent in the management of neurological emergencies should be available at all times.

**Fast and expert diagnosis and support**

Quick and accurate diagnosis is essential, and needs to be carried out by experienced and well qualified staff. There should be expertise in managing the effects of trauma, both for the patient and their family, as part of the emergency service provision.

**Support for carers**

Staff should be readily available for supporting families, with early referral made for further information, counselling and other services required.

**Appropriate referral**

Where an ongoing neurological condition is suspected, referral should be made to specialist neurological or neurosurgical services for diagnosis and further treatment.

**Information**

Patients, and their carers, should be given written information to take away from the A & E department outlining any precautions they should take and with contact details of any relevant neurological services and patient support organisations.

 **Onset and diagnosis****Effective diagnosis**

Everyone has a right to expect that any medical condition will be investigated and diagnosed efficiently. At the onset of symptoms most people will initiate the process of establishing a diagnosis through their GP. Not infrequently, problems arise because it may take some time before the GP recognises the symptoms as neurological and/or the GP is uncertain whether an individual's symptoms warrant a specialist referral - for example slight tremors, clumsiness or persistent headaches. This can be a very anxious and frustrating time for the person and their family. Ensuring speedy access to an accurate diagnosis should be a priority.

**GP referral**

GPs would find it helpful to have guidelines for specialist referrals, both in terms of criteria for referral and what kind of specialist service to refer to. Local guidance could specify which consultants or units specialise in particular conditions. Information about professionals with particular expertise and specialist centres should be widely disseminated. As a general rule people should be referred for a specialist opinion if there is uncertainty about diagnosis or management of a condition.

**Interim support**

When a person is referred, there may still be a period before a definitive diagnosis can be made. Sometimes this is because the situation is not clear-cut and sometimes because the initial referral proved to be inappropriate. Delay of a diagnosis should not involve delay in

implementing community care services and patients should be informed about sources of support and advice. This might be provided by a general neurological centre or resource, where they exist, or by a specialist nurse.

### **Waiting times**

The waiting time from the initial referral by the GP to being seen by the consultant should be related to the severity and type of condition. In some cases, such as a transient ischaemic attack and stroke, people need to be seen immediately. Any case thought to be urgent should be seen within two weeks. If the initial referral is inappropriate, a re-referral to another consultant should be made with the person being seen as soon as possible - time could be saved if one consultant referred directly to another rather than using the GP as an intermediary. The GP should, of course, be kept informed of this action.

### **Sharing the diagnosis**

The consultant should explain to the patient the process of diagnosis, including the range of tests to be carried out and the time it is expected to take. At this stage it would be helpful to ascertain the patient's perspective of the problem and, when possible and appropriate, the potential diagnosis should be discussed. The diagnosis should be shared as soon as possible with the patient and, with the patient's consent, their partner, family and other carers.

### **Information**

People often have difficulty absorbing much information at this stage, and the opportunity for a timely follow-up appointment for further discussion should be made available. Everything possible should be done to meet information needs, including oral and written information. Information should address social issues such as implications for education and employment, in addition to information about the medical aspects of the condition. Voluntary organisations often produce the most comprehensive literature on particular conditions and can offer support, advice and guidance to both families and professionals involved in the care of people with neurological conditions. Health professionals should provide information about relevant voluntary organisations.

### **Care plan**

A clear established protocol should enable the patient to be referred back to the GP with written confirmation of the diagnosis and/or the consultant's conclusions as soon as possible. A care plan should be included outlining the responsibilities of the consultant, the GP and the community services already involved. This should suggest how the continued surveillance and management of the patient should be undertaken. The patient and carer should be given a copy of the care plan.

### **Care pathways**

Defined pathways should be established for collaboration between and within health and social services, thus ensuring that support is available to individuals and their families from the onset of symptoms, through diagnosis and thereafter. For in-patients a discharge protocol is a statutory requirement - planning should start at the time of admission. A similar principle should be

established for outpatients so that counselling on the social implications of the condition is readily available and any necessary services and equipment offered, and if agreed by the patient, put in place.

### **Continuity of care**

Consistency of service and continuity of care are vital. Specialists, primary health care professionals, rehabilitation and social services need to work as partners in a co-ordinated team. The Neurological Alliance supports a case management model where an identified professional ensures that all the care and clinical input a person requires is accessed at the appropriate time.

### **Patient records**

Patient records should be kept up to date and be accessible to all the professionals involved in the care and treatment of a person with a neurological condition. Patients should also have access to their own records.

### **Training**

All health and social care professionals involved should attend training sessions in recognising, understanding and managing neurological problems and disability.

### **Diagnostic equipment**

The technology and equipment that should be utilised to ensure efficiency and effectiveness throughout the diagnostic process should be identified. Health commissioners and providers should ensure that this equipment is available.

## **Intermediate management**

### **Standards for intermediate management**

This phase refers to the post-diagnostic period, though it should be noted that some people may not be given a definitive diagnosis, but may still require management of their symptoms. The implementation of appropriate medication, therapy and social support lays down the foundation on which long-term management and service input will be built. This phase of care is needed during any acute or unstable period. Continuity of care is important – when someone has a long-term condition their case should not be "closed", rather they should be able to speedily access this phase of care should they need it.

Some people with neurological conditions will want to have complete control over their care and full knowledge about the services and treatment options available to them. It is acknowledged, however, that some people are not able, or do not want, to be fully involved in, and informed about, their care. The following standards may therefore need some flexibility in their implementation.

**Levelling up** ✂ page 16**Patient-centred services**

It is essential to establish plans for the individual's best quality of life both immediately and for the future. It is impossible to do this unless the local disability services are available, involved, adequate and flexible. Services need to be integrated between key providers, and good communication and liaison are essential.

**Interdisciplinary working**

All those involved need to take responsibility not only for their own particular input, but also for ensuring that the range of potential needs and treatment/services has been considered and implemented where appropriate.

The following professionals and agencies may be involved in the care of someone with a neurological condition:

- ✂ Neurologist
- ✂ Neurosurgeon
- ✂ Neurophysiologist
- ✂ Neuroradiologist
- ✂ Neuropsychiatrist
- ✂ Specialist nurse (neurological or condition specific e.g. MS specialist nurse, Parkinson's disease nurse, epilepsy nurse specialist)
- ✂ Consultant in rehabilitation medicine
- ✂ Genetic services
- ✂ Neuropsychologist
- ✂ Paediatrician
- ✂ Counsellor
- ✂ Speech and language therapist
- ✂ Physiotherapist (with neurological expertise)
- ✂ Dietician
- ✂ Ophthalmologist
- ✂ Social worker
- ✂ Occupational therapist
- ✂ Art therapist
- ✂ Music therapist
- ✂ Voluntary organisation (as advocate or provider of service or information)
- ✂ Education services
- ✂ Leisure services
- ✂ Housing services
- ✂ Benefits agencies
- ✂ GP
- ✂ Community nurse
- ✂ Orthotist
- ✂ Prosthetist
- ✂ Equipment providers

**Involvement of GPs**

Immediately following an out-patient consultation, or in-patient episode, the consultant should pass written confirmation of the diagnosis and care plan, including reference to community services already involved, to the GP. The patient should have a copy of this plan. The GP should make a consultation appointment with the patient, and preferably the carer, soon after the hospital discharge or out-patient consultation.

**Rehabilitation**

Ongoing rehabilitative treatment for sudden onset conditions, such as stroke and brain injury, has been shown to significantly reduce disability and to improve long-term outcome for patients. Immediate and continuing rehabilitation should be made available to patients and should include access to multi-disciplinary teams. Patients should be actively involved in goal setting. Secondary prevention advice on conditions such as stroke should form an integral part of rehabilitation.

**Emotional support**

Immediate and continuing emotional and psychological support should be made available to the person and their family/carer from an appropriate professional and/or a voluntary organisation.

**Information and advice**

Patients and carers should be given one point of contact through which they can access appropriate information and advice tailored to their need. This is a role best fulfilled by a specialist nurse or care adviser. Everyone with a neurological condition should have access to someone fulfilling this role.

Information and advice should cover:

- ✓ Brief explanation of the condition
- ✓ Options for the treatment and management of the condition
- ✓ Implications of the condition for life choices (e.g. advice on pregnancy or becoming a parent)
- ✓ drug contraindications
- ✓ Secondary prevention
- ✓ Sexual health
- ✓ All services available from health and social service care providers - statutory and non statutory
- ✓ Information about what to do in a crisis
- ✓ Emotional support (counselling services and self help/support groups)
- ✓ Equipment available – sources and who should pay for this
- ✓ Financial and social security benefits
- ✓ Respite care
- ✓ Housing
- ✓ Education
- ✓ Employment
- ✓ Recreation/leisure
- ✓ Transport/mobility
- ✓ How to make suggestions for improvements or complaints about services
- ✓ Contacts for further support

### Care plans

Care plans should be based on the principles of full involvement of the person affected, and their carers and family, emphasising real choice and optimising quality of life.

Care plans should include:

- ✓ Agreements between the GP and the consultant about their particular responsibilities
- ✓ Arrangements for ongoing monitoring and referral
- ✓ Ready access to appropriate rehabilitation services
- ✓ Early response to referral
- ✓ Implementation to an agreed timetable
- ✓ Adequate levels of care and support services (or the provision of direct payments for them) including day care and flexible respite/relief services
- ✓ Equipment loan services
- ✓ Information about available services and treatment options

### Co-ordination of care

A mutually agreed case manager or key worker should be identified for disabled people. In the majority of cases this is likely to be the social services care manager, but it could be the GP or any one of the range of professionals who plays a significant role in the care of the person.

It is essential that the individual concerned, their carer and family and all those involved, mutually agree on the person identified as the key worker, and that they understand the role and work in collaboration and partnership. This involves communicating regularly and implementing agreed plans. Good co-ordination, particularly between the different agencies and departments providing community care, can bring major benefits to service users.

### Equipment

Assessment for equipment by a trained professional should be comprehensive and swiftly followed by the provision of the equipment required. Reassessments of need should always include a reassessment of equipment that the person could benefit from.

### Care pathways

Clear and simple service guidelines or care pathways should be developed to allow people easy access to the services they require. These should be disseminated widely.

## Long term management

Long term management should be concerned with ensuring the highest quality of life, whatever the cause or severity of disability. In the intermediate phase, plans for treatment and services should have been initiated and put into practice, and in the majority of cases these will provide the basis for ongoing management. However, some conditions are unpredictable and can fluctuate, and the process of a number of neurological conditions is degeneration. During a medical crisis or during a period of change in their lives, people may need to access the kind of care described at the onset or intermediate management phase.

### **Expert patients**

It should be recognised that people with long-term neurological conditions often become experts in their condition. They should be offered the opportunity to be fully involved in assessments of their needs and in decisions about how to meet these.

### **Access to general health services**

People with long-term neurological conditions also have particular needs in relation to general medical care. There is a need to ensure that general health services, such as dentistry, are accessible and appropriate for people with neurological disabilities. People may need access to a good incontinence service, including advice and provision of laundry facilities. Finally, people with some neurological conditions will require specialist care when using mainstream services, such as maternity services.

### **Emotional support**

A range of services providing emotional and psychological support should be available to people affected by neurological conditions, and their carers and family members. This will range from support groups and counselling through to psychological services and therapy. Such services should be publicised widely, in order that people can access these when needed.

### **Access to regular reassessment**

Assessment and reassessment should be carried out according to individual need, though people should be offered an assessment at least once a year. Particular attention should be paid to those conditions which fluctuate or cause relatively rapid deterioration - speed and flexibility are essential.

Service user-centred care plans should be discussed and agreed at each assessment - this would include plans for medical treatment, therapy, social services, emotional support and equipment.

Unmet needs should be identified so that commissioners can plan to meet needs as resources become available.

### **Annual review**

Patients should have an annual review. According to the condition and the individual situation, this could be undertaken by the consultant or the GP in communication with the consultant. Many people feel that they benefit from being monitored by a specialist, and an annual appointment should be on offer. The annual reassessment should include:

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- ✓ A review of the medical management,
- ✓ Assessment for a range of interventions that might benefit the patient, including surgical intervention
- ✓ The potential for the patient to benefit from intermittent (time limited) community rehabilitation programmes
- ✓ A comprehensive assessment of needs in relation to equipment and assistive devices
- ✓ A reassessment of needs and abilities of the principal carer

**Transition**

A major review of the care plan, both medical and social, should be carried out before young adults are transferred from paediatric and child care services. Particular attention should be paid to the transition between children's and adults' specialist health services and from adult disability services to elderly care services. In addition, education, housing and employment needs should be carefully assessed and planned for at these life stages.

**Rehabilitation**

Rehabilitation programmes should be offered to all who could benefit from them. Individually tailored vocational rehabilitation should be available to assist people in getting back into work, provide a therapeutic earnings placement or provide purposeful activity.

**Carers' needs**

The needs of the carer and family should be attended to with a separate assessment if necessary. Enhanced day and respite care facilities are likely to benefit both carer and the individual concerned, allowing care to be maintained at home for as long as possible. It is essential that the quality of respite care is carefully monitored in order that carers, and the person with the neurological condition, can have confidence in the care provided.

**Appropriate residential care**

Where permanent residential or nursing home care is necessary, appropriate and adequate facilities should be available as locally as possible. Younger people should not be placed in establishments generally intended for elderly people. Therapies and activities should be available as required. Priorities for people will vary - for some individuals and families the ability to visit will be more important than the facilities a home provides. Cost should not prevent appropriate accommodation being offered.

**Training**

Professionals and care workers in residential and nursing homes and those in general and elderly care hospital wards should have training about the needs of people with particular neurological conditions.

## Palliative care

Some neurological conditions are life threatening. This section relates specifically to people who are in the last phase of a chronic and deteriorating condition. It is recognised, however, that for some neurological conditions, for example motor neurone disease, a palliative care approach should be initiated from the point of diagnosis. In many cases death is caused by an infection which the person is too weak to withstand.

### **Information about prognosis and options**

At the appropriate time the person affected and the carer and family should be as fully informed as possible as to the prognosis and the range of services available whether within a hospice, nursing home or for care in their own home.

### **Care plan**

A care plan should be agreed and frequently reviewed by the person affected, carer and family, GP and co-ordinator to include symptom and pain control, emotional and psychological care. The aim of such a plan should be to optimise the person's quality of life.

### **Involvement of carers and family**

In most instances, social care support should focus as much on the family as on the person concerned. The work of Macmillan nurses, for example, could be used as a model.

### **Hospice and nursing home care**

When care at home becomes impossible, a hospice or nursing home specialising in terminal care should be considered as they are expert in meeting the needs of both patients and families. Those working in hospices and nursing homes should have an awareness of the needs of people with neurological conditions. Service providers should review the numbers of these facilities in order to ensure access for all those who might need it.

Planning ahead should ensure that the person affected and their family are able to establish links with the hospice or nursing home to build up relationships with the staff whilst communication is still possible. This could be done through a day unit or staff who visit at home where these services are available.

### **Support for carers**

Advice and support should be readily available about how to cope with practical issues after death. Bereavement counselling should be available.

### **Training and support for staff**

Professional staff and volunteers should participate in on-going training programmes and have access to support for their own emotional well-being.

## Making improvements – issues for commissioners and providers

In the preceding sections the Neurological Alliance has set out standards of care that it believes should be met. The immediate targets for the Alliance are the dissemination and acceptance of these standards. We hope to involve key personnel within health and social services in working towards the implementation of the standards. We will be developing audit tools based on these standards.

In this section some steps are outlined which should facilitate the achievement of continuous improvement in service provision and outcomes.

### **Joint planning/commissioning**

People with neurological conditions require a range of services and, if their needs are to be met comprehensively, joint planning and working is required at all levels. Neurological conditions should feature specifically in Health Improvement Programmes (HIMPs), and Local Health Plans in Scotland, in order that local health, social care and voluntary sector agencies collaborate to commission appropriate services for their population.

The development of care trusts should ensure closer working between health and social service agencies in commissioning and provision of services. There will be a need to ensure that services for people with neurological conditions are given an appropriate share of available resources. People with neurological conditions, their carers and the organisations that represent them, should be involved in the commissioning of services by and from care trusts. Managed clinical networks could be an effective model to ensure integrated services.

### **Monitoring of standards**

Services for people with neurological conditions should be audited using these standards from the Neurological Alliance; the various relevant clinical guidelines developed by National Institute for Clinical Excellence (NICE), the SIGN Guidelines and against the standards set by the Department of Health National Service Frameworks. In addition there are various standards produced by professional bodies, including the Royal College of Physician's clinical guidelines for stroke<sup>19</sup> and the Society of British Neurological Surgeons standards for neurosurgery<sup>20</sup>. Local clinical governance arrangements should oversee the process of monitoring the local services against these standards. In addition the Commission for Health Improvement (CHI) will monitor services regularly to ensure that they are meeting NSF standards and targets.

### **Research**

Research is essential in all areas of health and social care to determine the needs of people who have a neurological condition, and how best these may be met. It is important that results of research studies are rapidly incorporated to enhance management and quality of care. Research is also required into the various ways of ensuring that professionals acquire both knowledge and understanding of the effects of neurological conditions. This applies at the expert and the generalist level and to medical and social care students as well as practitioners.

In addition to ongoing research into treatment and cure, key areas include:

### **Epidemiology**

There are still major deficiencies in knowledge about incidence and prevalence of many neurological conditions, and crucially a lack of information about the disabilities and on-going needs of people with neurological conditions. This lack of information makes the planning of services difficult.

### **Costs, both national and personal**

It is known that the costs of neurological conditions are considerable, but identification and monitoring of the costs and their secondary effects is an essential prerequisite for realistic cost-benefit analysis. Investment in prevention, community care, rehabilitation, specialist expertise training and education can then be set against savings in incidence, complications, prolonged hospital and residential care and welfare benefits.

### **Health services**

Data should be collated and presented on provision of health services for neurological patients. This would include numbers of neurologists, neurosurgeons, rehabilitation physicians, therapists, neuro-psychologists, specialist nurses and other specialist personnel. It would also include the provision of equipment, such as scanners, and the appropriate staff to operate these. In addition, there should be research into the effective organisation and delivery of services. The problems experienced in caring for and managing people with neurological conditions are common, and evidence-based data needs to be disseminated so that efficient, effective and high quality services can be replicated.

### **Social services**

Few social services departments regard people affected by neurological conditions as a separate group. However, although there is overlap with the needs of people with other disabilities and elderly people, there are also specific issues involved. Data on needs, provision and outcomes need to be collated so that gaps can be identified and people with neurological conditions given equitable priority.

### **Prevention**

Research on preventative strategies needs to be collated and analysed. This should lead to a renewed programme of research into all aspects of prevention. This should also include research into prevention of morbidity and secondary complications e.g. contractures, pressure sores, infections, falls and the incidence and treatment of depression within the context of neurological illness.

### **Acute / emergency neuro-services**

Information about mortality and morbidity rates in different parts of the country following acute neurological damage (e.g. head injury and stroke) should be collected, collated and analysed.

### **Symptoms**

Many neurological conditions have a number of variable symptoms which cause distress and discomfort and deserve research in their own right e.g. spasticity, dysphagia, ataxia and thalamic pain.

## Education and training

### Awareness of neurological conditions

Many neurological conditions are relatively rare and anyone other than a specialist is unlikely to have detailed knowledge of a specific condition. However, people with neurological conditions, and their families/carers, should be able to expect that health and social care professionals have a background education and understanding of the issues which are common to many of these conditions. They also have a right to expect that professionals will attempt to find out about their particular condition - text books have a limited part to play, but more importantly the voluntary agencies are able to provide comprehensive literature. An outward looking neurology and rehabilitation medicine service should also be able to provide information and guidance on management of neurological conditions.

### Interdisciplinary training

Disability awareness and management should be included in the training for all who come into contact with people living with neurological conditions, including nurses, medical students, therapists and support workers such as care attendants. The training should be undertaken on a joint basis between health and social care professionals where appropriate. Academic units for medicine, therapies and social care should be identified in the UK which would have some responsibility for the co-ordinated production of teaching materials relating to a neurological condition and its effects. Voluntary organisations can very effectively be involved in training alongside professionals. As representatives of people with neurological conditions their knowledge can be extensive and a highly relevant supplement to that held by professionals.

### Training for self management

People with a neurological condition and their families and carers should also have access to education and training so that they can be involved in their own management and make informed choices about personal lifestyles.<sup>21</sup>

## Working with voluntary organisations

Voluntary organisations have an important part to play in the care of people with neurological conditions. The Neurological Alliance and its members are committed to working together with central and local government and health and social care professionals in service planning, delivery and review. Where they exist, regional neurological alliances are ideally placed to work with local service commissioners and providers.

Voluntary organisations have often developed to meet the increased expectations and needs of people with neurological conditions and to fill gaps in service provision. They actively contribute in many areas to the support of people with neurological conditions, their families and carers. In some cases they directly provide care and support, working alongside the statutory services. Voluntary organisations are experts in representing service users, and are able to advise on the most appropriate ways of involving service users and carers in service developments.

The Neurological Alliance and its members are able to help in the implementation of these standards. They can offer the following.

**Information**

Provision of comprehensive information in a variety of formats for people with neurological conditions, their families and carers, and for health and social care professionals at all levels.

**Support**

All the voluntary organisations concerned with specific neurological conditions offer support and guidance by telephone, some with organised helplines. Several of the larger organisations employ a national network of professional staff, working closely with volunteers. Some organisations provide advocacy and counselling. Many organisations facilitate the development self-help groups.

**Training and education**

A combination of professional expertise and the ability to represent the views of affected people and carers, ensures that voluntary organisations can both organise and participate in training programmes. These events build on the range of materials available, informing and supporting those involved in commissioning and providing neurological services.

**Volunteers**

Most voluntary organisations have a network of local groups whose members share personal experience and provide much practical support, advice and comfort. In some cases, such support is more formally organised (for example, befriending services).

**Provision of equipment and financial support**

Some of the larger charities have flexible equipment loan services and the availability of limited finance to provide support, complementing statutory provision.

**Direct service provision**

A number of voluntary organisations provide residential care, including respite care facilities. Some also provide medical assessment facilities. A few provide and manage educational facilities, including schools.

**Research and policy analysis**

Many of the voluntary organisations in membership of the Neurological Alliance support and promote research to meet the needs of people with neurological conditions. A number of organisations are funders of biomedical and social research. Some organisations have developed expertise in engaging people with neurological conditions and their carers in the research process.

Many organisations frequently seek the views of their members on a range of health and social policy issues, and can access the day-to-day experiences of people living with neurological conditions and using health and social care services.

**Condition-specific standards of care**

A number of organisations have developed standards of care for particular neurological conditions. These are listed in Appendix 2.



## Conclusion

The gulf between the best standards of care for people with neurological conditions and the worst is unacceptably wide. Although a National Service Framework is promised for the future, people with neurological conditions cannot and should not have to wait any longer to see significant improvements in the services they receive. This report provides a framework, influenced extensively by patients' views of what constitutes acceptable standards, against which commissioners and providers can plan meaningful improvements in the services they deliver.

# Appendix 1 - Respondents to the consultation draft

## **Voluntary organisations**

Ataxia Group  
 Alzheimers Society  
 Bury / Bolton ME Support Group  
 Charcot-Marie-Tooth (CMT) International UK  
 Dystonia Society  
 Encephalitis Support Group  
 Epilepsy Scotland  
 Greater Manchester Neurological Alliance  
 Headway – The brain injury organisation  
 Headway – Cardiff Branch  
 Headway – Leicester Branch  
 Headway – Shropshire Branch  
 Huntingtons Disease Association  
 Joint Epilepsy Council  
 Lincolnshire Post-Polio Network  
 Migraine Trust  
 Motor Neurone Disease (MND) Association  
 MS Society - Cheshire and Mersey Region  
 The Progressive Supranuclear Palsy (PSP Europe) Association  
 Parkinson's Disease Society  
 Parkinson's Disease Society – Aberystwyth Branch  
 Parkinson's Disease Society – Burnley Branch  
 Parkinson's Disease Society – Cleveland Branch  
 Parkinson's Disease Society – Cromer Branch  
 Parkinson's Disease Society – Eastbourne Branch  
 Parkinson's Disease Society – Slough Branch  
 Parkinson's Disease Society – Norwich Branch  
 Parkinson's Disease Society – Shrewsbury Branch  
 Parkinson's Disease Society – Worcester and District Branch  
 Rett Syndrome Association UK  
 Stroke Association  
 UK Acquired Brain Injury Forum (UKABIF)  
 West Berkshire Neurological Alliance

## **Professional groups and individuals**

British Society of Rehabilitation Medicine  
 Society of British Neurological Surgeons  
 Dr Anthony Paxton, Gloucestershire  
 Sue Hillan, Occupational Therapist, Wirral.

## **People with neurological conditions and carers**

In addition 18 individuals with various neurological conditions and 7 carers commented on the draft document.

## Appendix 2 – Guidelines and standards from Neurological Alliance member organisations

### Cerebral Palsy

*Recommendations for minimum standards of healthcare in children with cerebral palsy*  
Hemihelp, IPSEN Ltd 01753 627777

### Dementia

*Dementia in the community – Management strategies for general practice*  
Alzheimer's Society. Tel: 020 7306 0606. Website: [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

### Epilepsy

*Epilepsy Care: Making it happen – A tool kit for today*  
British Epilepsy Association. Tel: 0113 210 8800. Website: [www.epilepsy.org.uk](http://www.epilepsy.org.uk)

### Headache

*Migraine – A professional resource file*  
Migraine Trust. Tel: 020 7831 4818. Website: [www.migrainetrust.org](http://www.migrainetrust.org)

### Motor neurone disease

*Standards of Care – to achieve quality of life for people affected by MND (1998) Model of Care, and An Audit Tool*  
*MND Resource File - A patient centred approach for health & social care professionals.*  
MND Association. Tel: 01604 250505. Website: [www.mndassociation.org](http://www.mndassociation.org)

### Multiple sclerosis

*The basics of best practice in the management of Multiple Sclerosis (1999)*  
Multiple Sclerosis Trust. Tel: 01462 476700. Website: [www.mstrust.org.uk](http://www.mstrust.org.uk)

*Standards of healthcare for people with MS*  
MS Society of Great Britain and Northern Ireland. Tel: 020 8438 0700. Website: [www.mssociety.org.uk](http://www.mssociety.org.uk)

### Parkinson's disease

*Moving and shaping - the future. Commissioning services for people with Parkinson's Disease*  
*Parkinson's Aware in Primary care - a guide for primary care teams*  
Parkinson's Disease Society. Tel: 020 7931 8080. Website: [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

### Progressive supranuclear palsy

*Health care for patients with Progressive Supranuclear Palsy*  
Progressive Supranuclear Palsy (Europe) Association. Tel: 01327 860299. Website: [www.PSPeur.org.uk](http://www.PSPeur.org.uk)

### Stroke

*Stroke - Good practice in primary care (2002)(ref PGO) and Stroke - Good practice resource pack (2001) (ref R1)*  
Stroke Association. Tel: 01604 231000. Website: [www.stroke.org.uk](http://www.stroke.org.uk)

### Tuberous sclerosis

*Clinical Guidelines for the care of patients with Tuberous Sclerosis Complex*  
Tuberous Sclerosis Association. Tel: 01527 871898. Website: [www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org)

## Appendix 3 - Incidence and prevalence of some neurological conditions

Condition	Incidence: number of new cases per 100,000 that develop each year (and total number of new cases in the uk)	Prevalence: total number of people per 100,000 (and number with the condition in UK)	Source
Alzheimer's disease / dementia	25,000 per 100,000 in over 65 year olds	1,000 (700,000)	Alzheimer's Society based on ONS population estimate 1996
Ataxia (including Friedrich's ataxia)		5,000 (at least)	Estimate from Ataxia Group of Great Britain and Northern Ireland
Ataxia-Telangiectasia		0.3 (200 approx.)	Ataxia-Telangiectasia Society Headway and Society of British
Brain injury: Problems can occur following any head injury and are experienced by most people who survive after a severe injury.	Severe injury 10 -15 Moderate injury 15 - 20 Mild injury 250 - 300 New and sustained disability amongst adults resulting from head injury 100 - 150	228 (with long term problems) (135,000)	Neurological Surgeons. Incidence figures from <i>Head Injury - A practical guide</i> Trevor Powell, 1994, Winslow Press Ltd. Also Thornhill, S and Teasdale, GM et al <i>Disability in young people and adults one year after head injury: prospective cohort study</i> BMJ 2000; 320: 1631-1635. Prevalence estimate using data from study by McMillan and Greenwood (1991)
Brain tumour	20 per 100,000 (12,000)		Hopkins, <i>Clinical Neurology, a modern approach</i> , OUP 1993
Cerebral Palsy		186 (110,000)	Scope - based on population studies
Charcot-Marie-Tooth Disease		40 (23,600)	Estimate from Charcot Marie Tooth UK
CJD	0.1 per 100,000 (50 - 70 approx.)		Alzheimer's Society
vcJD	27 new cases in year 2000 (Presently increasing year on year)	101 cases since 1995	Alzheimer's Society
Dystonia (primary idiopathic i.e. not associated with another condition)		65 per 1000,000 (38,000)	Dystonia Society - estimate
Encephalitis	7.4 per 100,000		Beghi et al (1984) "Encephalitis and aseptic meningitis", Olstead County, Minnesota 1950 -1981, <i>Annals of Neurology</i> 283-394.
Epilepsy	80 per 100,000	500 (300,000 approx.)	Clinical Standards Advisory Group <i>Services for people with epilepsy</i> 2000 and <i>Lancet</i> 336 1267-1271
Essential tremor		850 (500,000)	Estimate from National Tremor Foundation - Professor Leslie Finley

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Condition	Incidence: number of new cases per 100,000 that develop each year (and total number of new cases in the uk)	Prevalence: total number of people per 100,000 (and number with the condition in UK)	Source
Guillain Barré syndrome	2.5 per 100,000 (1,500)		Estimate from Guillain Barré Syndrome Support Group
Headache	Migraine 400 per 100,000 <sup>1</sup>	15,000 (8,000,000)	1. Steiner TJ <i>et al</i> , Epidemiology of migraine in England. <i>Cephalalgia</i> 1999; 19:305-6. 2. Olesen J, Goadsby PJ, Cluster Headache and related conditions in Olesen J(Ed) Frontiers in Headache Research Vol 9 OUP 1999 3. Goadsby PJ, Lipton RB, A review of paroxysmal hemicranias <i>Brain</i> 1997; 120:193-209 4. Silberstein SD <i>et al</i> , Headaches in Primary Care Oxford/Isis Medical Media 1999
	Cluster Headache 4 per 100,000 <sup>2</sup>	100	
	Paroxysmal Hemicrania <sup>3</sup>	10	
	Chronic Migraine <sup>4</sup>	3,000	
	Chronic tension-type headache <sup>4</sup>	2,000	
Huntington's disease	2 per 100,000	13.5 (approx.) (6 - 10,000)	Huntington's Disease Association
Motor neurone disease	4 per 100,000 (2,500)	7 per 100,000 (4,000 approx.)	Motor Neurone Disease Association
Multiple sclerosis		144 (85,000)	MS Society and MS Research Trust - estimates based on UK area studies and international data
Multiple system atrophy		1 (600)	Estimate from Sarah Matheson Trust
Muscular dystrophy		50 (30,000)	Muscular Dystrophy Campaign - estimate
Myalgic Encephalomyelitis (ME)		300 - 500 240,000 approx.	Dowsett E G, Richardson J The <i>Epidemiology of Myalgic Encephalomyelitis (ME) in the UK 1919 - 1999</i> Evidence submitted to the All Party Parliamentary Group of MPs on ME 23.11.99
Myasthenia gravis		30 approx. (10,000 - 30,000)	Myasthenia Gravis Association - estimate based on their database
Narcolepsy		50 (30,000)	Narcolepsy Association - estimate based on patient counts in Europe and America
Neurofibromatosis	17 per 100,000 (10,000 approx.)	40 (24,000)	Neurofibromatosis Association
Parkinson's disease		200 (120,000)	Parkinson's Disease Society - advice from medical adviser
Progressive supranuclear palsy		6 per 100,000 3,600	Nath, A <i>Brain</i> 2001 no. 24 "The prevalence of PSP in the UK" pages 1438-1449.

Condition	Incidence: number of new cases per 100,000 that develop each year (and total number of new cases in the uk)	Prevalence: total number of people per 100,000 (and number with the condition in UK)	Source
Post-polio syndrome		Estimates range from 100 - 300 (120,000 approx)	Lincolnshire post polio Network
Rett syndrome		0.1 per 100,000 females at age 14 years 2,500 females in UK	Rett Syndrome Association UK - figures from Dr Alison Kerr, medical adviser to RSAUK.
Spina Bifida and Hydrocephalus	(500 - 700)	24 per 100,000 (14,000 approx.)	Estimate from Association for Spina Bifida and Hydrocephalus - from their database of contacts
Spinal cord injury	53 per 100,000		<i>The First 48 Hours</i> (2000), Spinal Injuries Association
Spinal cord problems leading to surgery	1.25 per 100,000		Society of British Neurological Surgeons
Spinal tumour	Primary spinal tumours (750 approx) 240 per 100,000		<i>Spinal tumours - A guide for patients and carers</i> Brain and Spine Foundation 2002
Stroke	(100,000)	500 (300,000)	Oxford Community Stroke Project. <i>Incidence of stroke in Oxfordshire: first years experience of a community stroke register</i> BMJ 1983;287:713-7 Geddes, 1996 (disability prevalence)
Tourette syndrome	0.5 per 100,000	40 (20,000 - 30,000)	Tourette Syndrome (UK) Association - Brian Robertson, Pub. 2000
Transverse myelitis	(300 approx.)		<i>Transverse myelitis - A guide for patients and carers</i> Brain and Spine Foundation 2000
Tuberous Sclerosis		14 (8,000)	Tuberous Sclerosis Association - based on various published studies

## References

1. Joule N, June 2001, *In search of a service – the experiences of people with neurological conditions*, Neurological Alliance.
2. Department of Health press release, 28 February 2001, *Health secretary announces new plans to improve health in poorest areas*, Department of Health reference 2001/0108.
3. Department of Health, July 2000, *The NHS Plan. A plan for investment. A plan for reform*, page 88, The Stationery Office.
4. ABN, Acute Neurological Emergencies in Adults, 2002.
5. Standards for patients requiring neurological care are being developed jointly by SBNS and regional specialist services commissioners.
6. British Society of Rehabilitation Medicine *Proposed clinical standards for specialist community rehabilitation services*; British Society of Rehabilitation Medicine *Proposed clinical standards for in-patient specialist rehabilitation services*.
7. See Appendix 3.
8. Morrow and Patterson The neurological practice of a District General Hospital, *J Neurology, Neurosurgery and Psychiatry* 1987 50, 1397-1401.
9. Figures from *Neurological rehabilitation in the UK* 1992.
10. Office of Population Censuses and Surveys. OPCS Surveys of Disability in Great Britain, HMSO 1988.
11. Haerer AF, Anderson DW, Schoenberg BS, Functional disability associated with major neurological disorders, *Arch Neurol* 1986; 43: 1000-1003.
12. Dowding VM, Barry C. Cerebral palsy: social class differences in prevalence in relation to birthweight and severity of disability, *J Epid Comm Health* 1990; 44: 191-195.
13. Phadke JG. Clinical aspects of multiple sclerosis in North Eastern Scotland with particular relevance to its course and prognosis, *Brain*, 1990, 113: 1597-1628.
14. Prescott-Clarke P, Primatesta P, *Health Survey for England*, 1995. London, The Stationery Office.
15. Hancock R, Jarvis C, Tinker A, Askham J, *The long term effects of being a carer*. Age Concern Institute of Gerontology, London, 1994.
16. Henwood M, *Ignored and Invisible? Carers Experience of the NHS*, Carers National Association, 1998.
17. Joule, N. *In search of a service*, 2001 The Neurological Alliance. Icarus, April 2000, *The use of neurological services by Black and ethnic minority communities*, Glaxo Neurological Centre. Macleod, M, Effect of deprivation and gender on the incidence and management of acute brain disorders, *Intensive Care Medicine*, Manuscript submitted for publication.
18. Powell, T. *Head Injury – A practical guide*, 1994, Winslow Press Ltd. Dr Andy Tyerman – personal communication.
19. Royal College of Physicians *The National Clinical Guidelines for Stroke* (2000).
20. Standards for patients requiring neurological care are being developed jointly by SBNS and regional specialist services commissioners.
21. Department of Health, *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century*, 2001.

# Neurological Alliance member organisations 2001-2002

Alzheimer's Society  
Association for Spina Bifida and Hydrocephalus (ASBAH)  
Ataxia Group  
Ataxia-Telangiectasia Society  
BASIC (Brain & Spinal Injury Charity)  
Brain and Spine Foundation  
British Acoustic Neuroma Association  
British Epilepsy Association  
Child Brain Injury Trust  
Charcot Marie Tooth UK  
Dementia Relief Trust  
Different Strokes  
Encephalitis Support Group  
Mersey Neurological Trust  
Greater Manchester Regional Neuro Alliance  
Guillain Barré Syndrome Support Group  
Headway National Head Injuries Association  
HemiHelp  
Huntingtons Disease Society  
Joint Epilepsy Council  
Lincolnshire Post Polio Network  
ME Association  
Migraine Trust  
Motor Neurone Disease Association  
Multiple Sclerosis Society of Great Britain  
Multiple Sclerosis Society - Northern Ireland  
Multiple Sclerosis Trust  
Muscular Dystrophy Campaign  
Narcolepsy Association (UK)  
National ME Centre  
National Meningitis Trust  
National Society for Epilepsy  
National Tremor Foundation  
Rett Syndrome Association  
Sandwell Neurological Alliance  
Sarah Matheson Trust (group for people with Multiple System Atrophy)  
Scope  
Speakability  
The Dystonia Society  
The Myasthenia Gravis Association  
The Neurofibromatosis Association  
The Parkinson's Disease Society  
The Progressive Supranuclear Palsy (PSP Europe) Association  
The Stroke Association  
Tourette Syndrome (UK) Association  
Tuberous Sclerosis Association  
UK Acquired Brain Injury Forum (UKABIF)  
West Berkshire Neurological Alliance

**Levelling up** sets out the standards of care that people with neurological conditions should expect. Recent research has shown that for people in the UK living with a neurological condition the quality of the services that they receive is extremely variable.

Produced in consultation with people who live with neurological conditions, their carers and the organisations that represent them, *Levelling up* provides a benchmark of standards for all stages of a neurological condition from diagnosis to long-term management.

*Levelling up* also outlines action for commissioners and providers of services to facilitate the achievement of continuous improvement in service provision and outcomes for people with neurological conditions.

*"An excellent document – thank you to all involved in the update and reworking"*. Dystonia Society

*"I hope this report will be recognised and taken on board by statutory authorities"*. Parkinson's Disease Society Branch

*"A good clear document which the BSRM wholeheartedly endorses"*. British Society of Rehabilitation Medicine



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Neurological Alliance, PO Box 36731, London, SW9 6WY

Telephone: 020 7793 5907 Fax 020 7793 5939

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