Nottinghamshire County Council

Report to Health and Wellbeing Board

2nd May 2012

Agenda Item:4

REPORT OF DIRECTOR FOR PUBLIC HEALTH

STROKE AND PHYSICAL DISABILITY, INCLUDING LONG TERM NEUROLOGICAL CONDITIONS – MAY 2012

Purpose of the Report

1. The paper outlines the current provision in health and social care for both stroke and other long-term neurological conditions, especially those causing physical disability. It also highlights the key areas where further developments are needed in Nottinghamshire to improve support for people with these conditions and to ensure equitable services across the county.

Information and Advice

Stroke

2. A stroke occurs when blood flow to part of the brain is interrupted, causing damage to the brain tissue. The two main causes of stroke are blood clots blocking arteries (*Ischaemic*, 85 per cent of all strokes) and arteries bursting (*Haemorrhagic*, 15 per cent).

3. Strokes where the symptoms resolve within 24 hours are known as *transient ischaemic attacks* (TIAs).

4. Around 1 in 4 people who have a stroke die as a result, approximately 1 in 5 within 30 days of the stroke. Around half of stroke survivors are left dependent on others for everyday activities; among people who survive a stroke, long-term health problems can include:

   - Paralysis down one side of the body
   - Inability to speak
   - Loss of cognitive abilities
   - Incontinence.

5. Stroke survivors often need care for some time after their stroke, and potentially for the rest of their lives, which can put emotional and financial strain on those around them. Emotional and behavioural disorders also occur following a stroke. Depression is the most common, occurring in up to 20% of stroke survivors. Behavioural disorders have implications for stroke rehabilitation, because patients who have post-stroke depression have less ability to participate in their rehabilitation, and some studies suggest that post-stroke depression leads to poorer long-term functional outcome. Post-stroke anxiety is

also associated with decreased functional recovery, which can persist for years after the stroke.

Who is at risk of a Stroke?

6. Stroke, like a heart attack, is a vascular disease, and its risk factors include:

   - Increasing age
   - Male gender
   - High blood pressure
   - High cholesterol
   - Atrial fibrillation (a type of irregular heart rhythm)
   - Diabetes
   - Smoking
   - Unhealthy diet or high alcohol intake
   - Previous stroke or TIA, or family history of stroke.

7. These issues are all addressed as part of the NHS Health Check programme for people aged 40 to 74, which is now running in general practices across the county.

8. Stroke is often viewed as a disease of older people, but one quarter of strokes occur in people under the age of 65, and it can strike people of any age, including children. People of African or Caribbean origin and men of South Asian origin are more likely to have a stroke than people from other ethnic groups. Although men are more at risk of stroke than women, the number of women having strokes is higher than the number of men, reflecting the higher proportion of older women in the population.

Long Term Neurological Conditions

9. Long-term Neurological Conditions (LTNC) have been defined as:

   ‘Conditions that result from any disease or injury to central/peripheral nervous system and will affect the individual and their family for the rest of their lives[1]’

10. Long-term neurological conditions can be broadly categorised as follows:

    - **sudden-onset conditions**, for example acquired brain injury or spinal cord injury, followed by a partial recovery.

    - **intermittent and unpredictable conditions**, for example epilepsy, certain types of headache or early multiple sclerosis, where relapses and remissions lead to marked variation in the care needed;

    - **progressive conditions**, for example motor neurone disease, Parkinson's disease or later stages of multiple sclerosis, where progressive deterioration in neurological function leads to increasing dependence on help and care from others. For some conditions (e.g. motor neurone disease) deterioration can be rapid.

- **stable neurological conditions, but with changing needs due to development or ageing**, for example post-polio syndrome or cerebral palsy in adults.

11. The number of people with neurological long-term conditions has also been estimated from existing research[1]**.** [See **Appendix 1**]

Why are Stroke and Physical Disability Public Health issues?

12. Stroke is the third biggest cause of death in the UK and the largest single cause of severe disability. There are approximately 110,000 strokes and 20,000 TIAs per year in England alone. Around 300,000 people are living with moderate to severe disabilities as a result of stroke. It is estimated that, in 2008-09, the direct care cost of stroke was at least £3 billion annually, within a wider economic cost of about £8 billion. As the population ages, there will be an increase in the number of people having strokes despite improvements in the detection and management of key risk factors such has high blood pressure and atrial fibrillation.

Physical Disability

13. Physical disability covers a wide range of conditions. People with physical disability are one of the main service user groups for adult social care services. Physical disability is also implicated in many referrals to adult safeguarding services. The national picture indicates that more children and young people with profound disabilities and long-term conditions are living longer and surviving into adulthood. Therefore, the longer term needs of this group are growing and require attention.

14. Long term neurological conditions are one group of diseases that can cause physical disability. There are currently an estimated 10 million people in the UK (around 1 in 6 people) with neurological conditions, with an estimated 24,421 to 32,595 people living in Nottinghamshire.

Key Facts

- ‘Approximately 350,000 people require help for most of their daily activities.
- Over one million people are disabled by their neurological condition.
- Each year 600,000 people (1% of the UK population) are newly diagnosed with a neurological condition.
- 10% of visits to A&E are for a neurological problem.
- 17% of GP consultations are for neurological symptoms.

[1] Neuro Numbers a brief review of the numbers of people in the UK with a neurological condition. Published by the Neurological Alliance April 2003

- 19% of hospital admissions are for a neurological problem requiring treatment from a neurologist or neurosurgeon (mostly stroke, epilepsy, dementia, headache, head injury and MS)

- 25%, or about one quarter of people aged between 16 and 64 with chronic disability have a neurological condition.

- 33%, approximately one third of disabled people living in residential care have a neurological condition.

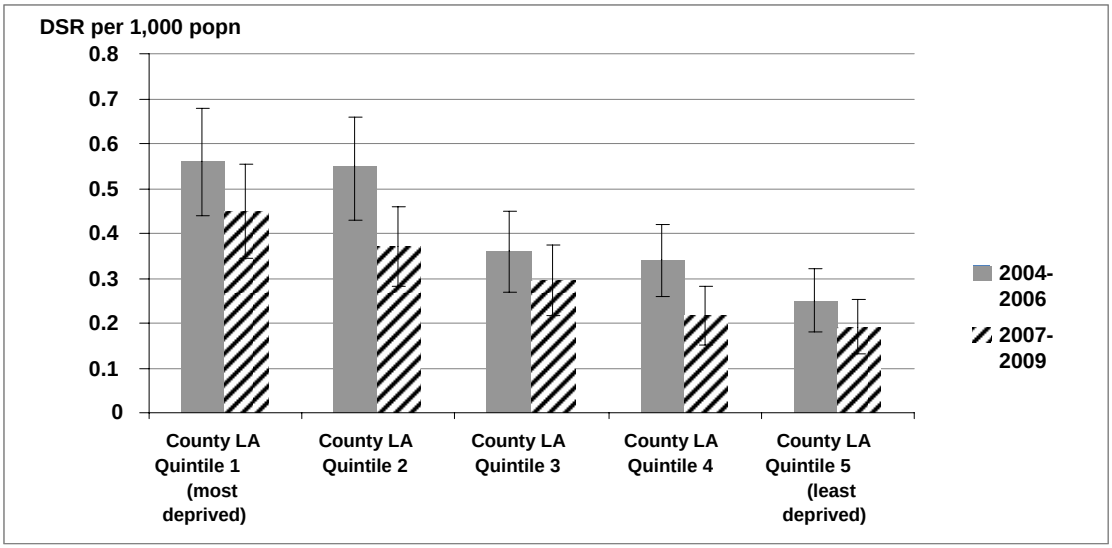
- Approximately 850,000 people in the UK care for someone with a neurological condition'[2].

15. There are currently a range of services being provided for people with LTNCs in the county, but these services are often fragmented and not equitable. The development and implementation of a coordinated programme of action will ensure that there are services across the area to meet the needs of patients, families and carers.

Impact of Deprivation

16. Individuals in the most deprived groups are more likely to experience a stroke and to die from one. Figure 2.1 shows the change in stroke mortality in those aged under 75 by deprivation quintile between 2004/06 and 2007/09.

Figure 2.1 Change in stroke mortality in those aged less than 75 years by deprivation quintile in Nottinghamshire, including Bassetlaw: 2004/06 to 2007/09



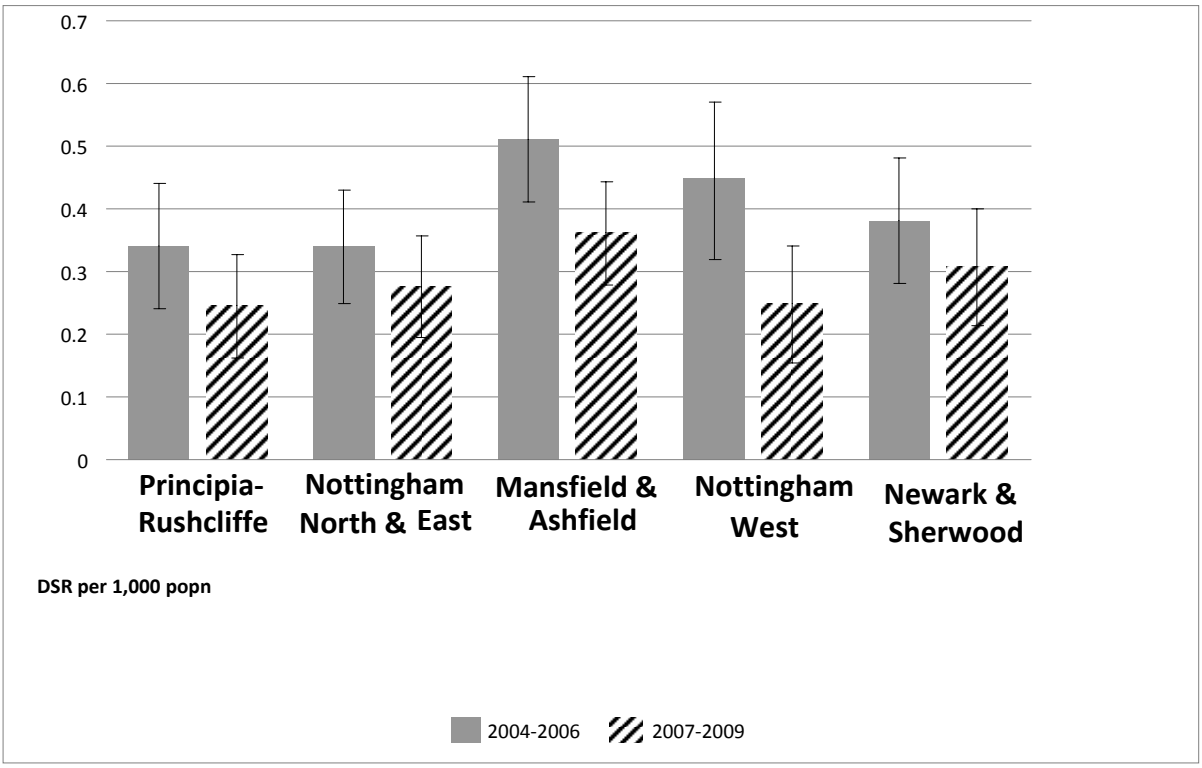
Source: eHealthscope

17. The figure illustrates clearly that although stroke mortality has fallen in all deprivation categories in the two periods, there still remains a significant difference between those living in the most deprived areas and those in the two least deprived areas. However, the gap between mortality in the least and most deprived areas has narrowed over the period

[2] The Neurological Alliance. April 2003. Neuro Numbers: a brief review of the numbers of people in the UK with a neurological condition.

by 16%. The largest reductions have occurred in quintiles 2 and 4 and the least in quintile 3.

Figure 2.2 Change in stroke mortality in those aged less than 75 years by Clinical Commissioning Group: 2004/06 – 2007/09



18. The impact of deprivation is reflected in the mortality rates across the Clinical Commissioning Groups (CCGs) in Figure 2.2. Five CCGs demonstrated an improvement in mortality rates, with Nottingham West showing the largest change with a 45% reduction. Mansfield and Ashfield had the next biggest reduction at 29%. However, within the 2 time periods, none of the differences between the CCGs are statistically significant. Data is not available for 2004-06 for comparisons in Bassetlaw.

19. The relationship between common LTNC and deprivation is summarised in Table 2.

Table 2 Social deprivation and common neurological long term conditions

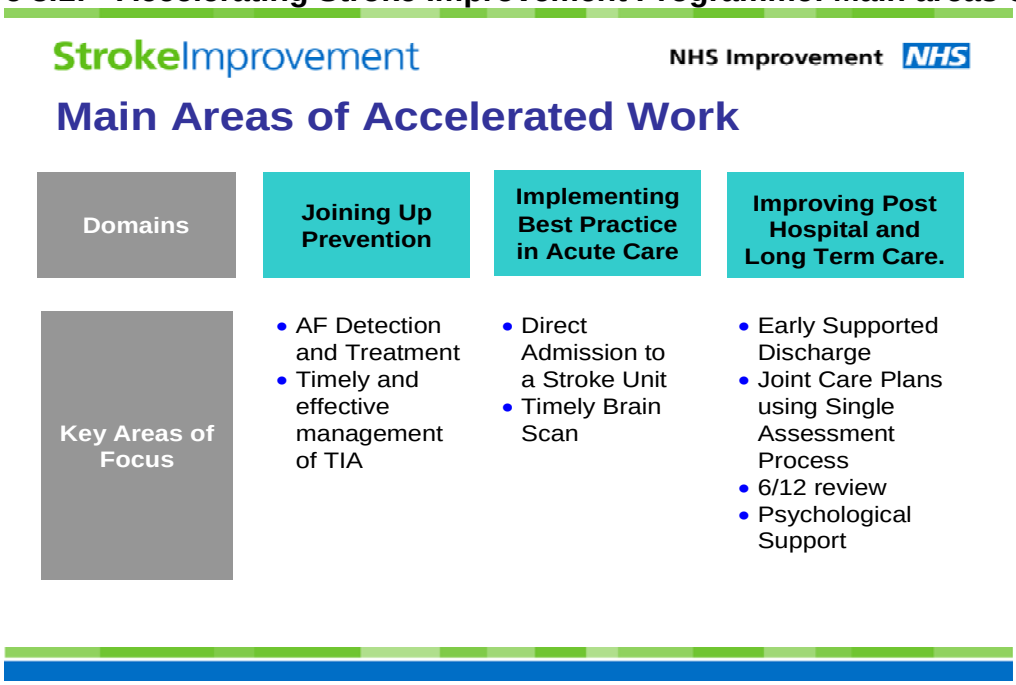
Condition	Association with deprivation
Stroke	Higher in deprived populations
Epilepsy	Higher in deprived populations
Parkinsonism including Parkinson's disease	Not found
Spinal cord injury	Not found
Multiple sclerosis	Not found
Motor neuron disease	Not found
Cerebral palsy	Higher in deprived populations
Muscular dystrophies	Higher prevalence of Duchenne in deprived populations
Huntington disease	Not found
Traumatic Brain Injury	Higher in deprived populations
Acquired (non traumatic) Brain Injury	-

National and Local Policy Drivers

National Policy for Stroke

20. The Department of Health (DH) published the National Stroke Strategy in December 2007. Subsequently, the DH launched the Accelerating Stroke Improvement (ASI) Programme in 2010. This was based on the knowledge that, while there had been good progress so far on awareness raising and acute care, more effort was needed on prevention, especially in the detection and management of atrial fibrillation (an irregular heart rhythm that increases the risk of stroke), long-term care and rehabilitation. The main areas of ASI work are shown in Figure 3.1 below. The Royal College of Physicians also coordinates a national Sentinel Audit of stroke care every other year, which provides a measure of progress against key indicators.

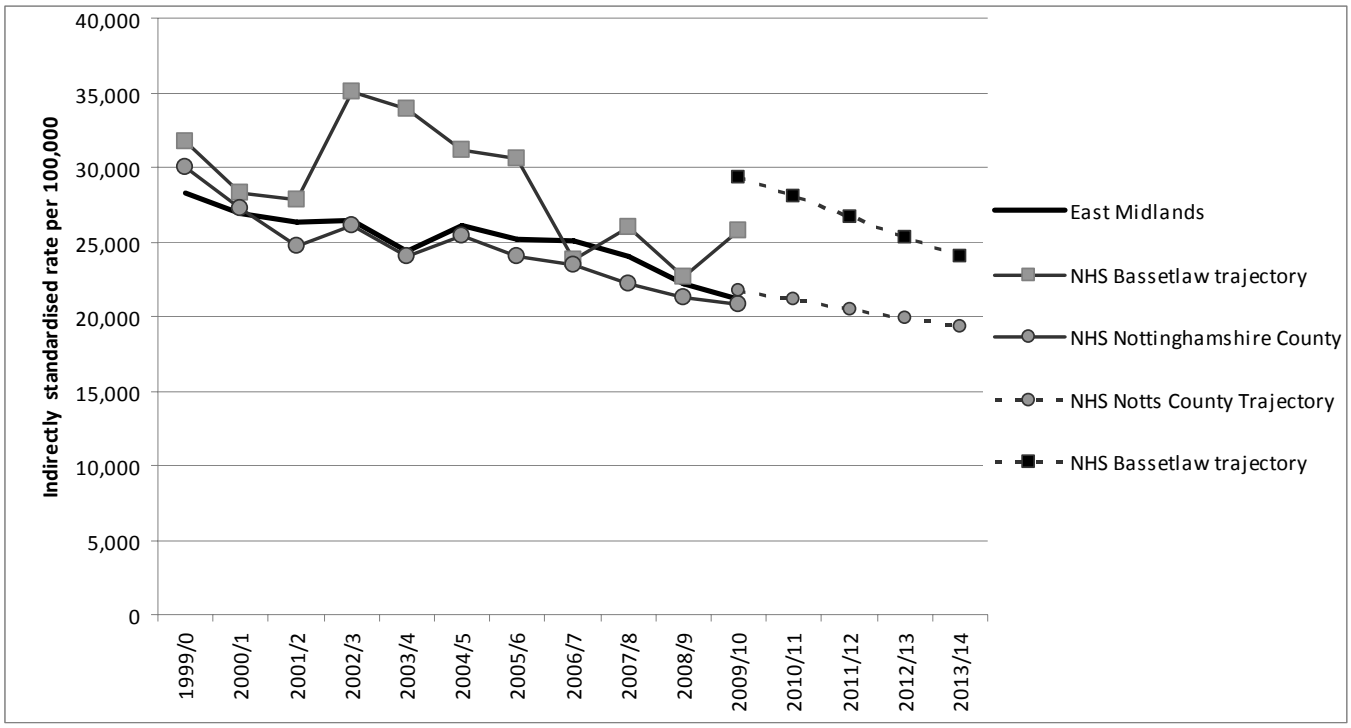
Figure 3.1: Accelerating Stroke Improvement Programme: Main areas of work



Local Policy for Stroke

21. Stroke is one of the health priorities for NHS Nottinghamshire County and NHS Bassetlaw. Their aim is to reduce stroke-related deaths by 27% by 2014, through better care for people at high risk of stroke and improvements in acute stroke care. Current progress on this target is shown in Figure 3.2 below. It can be seen that NHS Bassetlaw, which had a 30 day mortality rate higher than the East Midlands average from 2002/03 to 2005/06, has now reduced the mortality rate to well below the agreed trajectory. The mortality rate for NHS Nottinghamshire County is also decreasing slightly ahead of the trajectory and remains below the East Midlands average.

Figure 3.2 Trends in deaths within 30 days of emergency admission to hospital due to stroke



Source: Hospital Episodes Statistics NCHOD FY Nov 2010 and National Statistics

22. NHS Nottinghamshire County has also been implementing the East Midlands strategy for 'Better Stroke Care'. This has resulted in Nottingham University Hospitals NHS Trust (NUH) being designated the 'Comprehensive Stroke Centre' for the East Midlands, with access to the widest range of facilities including neurosurgery. NUH and Sherwood Forest Hospitals NHS Foundation Trust (SFHT) are working together to provide specialist stroke services on both City Hospital and Kings Mill Hospital sites.

23. From December 2010, NHS Bassetlaw commissioned a reconfigured pathway for acute stroke patients that are compliant with the National Stroke Strategy. Patients are taken to the Acute Stroke Unit at Doncaster Royal Infirmary and after a few days either go home or are transferred to Bassetlaw Hospital for rehabilitation.

National Policy for Long Term Neurological Conditions

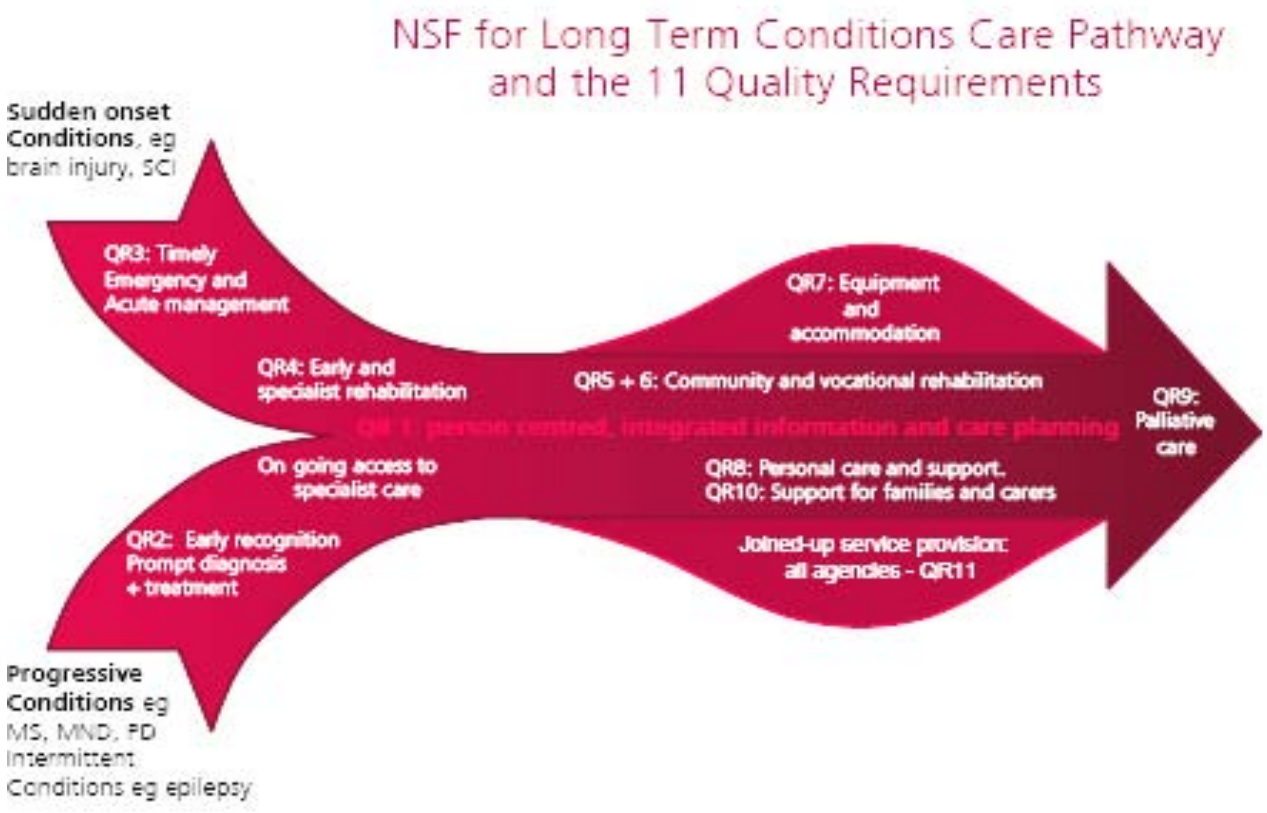
24. The National Service Framework (NSF) for Long Term Conditions developed in 2005; is a 10 year programme for change. It sets 11 quality requirements to transform the way health and social care services support people with long-term neurological conditions to live as independently as possible. The 11 quality requirements cover:

1) A person centred service
2) Early recognition, prompt diagnosis and treatment
3) Emergency and acute management
4) Early and specialist rehabilitation
5) Community rehabilitation and support
6) Vocational rehabilitation
7) Providing equipment and accommodation

8) Providing personal care and support
9) Palliative care
10) Supporting family and carers
11) Caring for people with neurological conditions in hospital or other health and social care settings[3].

Figure 3.3 below summarises how these quality requirements fit into the pathway[4].

Fig 3.3 Quality requirements and the LTNC Pathway



25. It is recognised that people with long-term neurological conditions have improved health outcomes and a better quality of life if they can access prompt advice and support from relevant practitioners with dedicated neurological expertise.

26. Additional documents which support this approach are:

- Supporting people with long term conditions: an NHS and social care model to support local innovation and integration (2005).

[3] The National Service Framework (NSF) For Long Term Conditions Department of Health 2005
[4] Department of Health (April 2010) Long Term conditions: A good practice guide to the development of a multidisciplinary team and the value of the specialist nurse. Skills for Health-Workforce Projects Team.

- NICE clinical guidelines for the diagnosis, treatment and management of Multiple Sclerosis, epilepsy and Parkinson's Disease. These guidelines outline the range of care that should be available.

- The National Audit of Services for People with Multiple Sclerosis (Royal College of Physicians and the Multiple Sclerosis Trust). The most recent Audit report was published in 2011.

- The white paper 'Equity and Excellence – Liberating the NHS emphasises the principles of 'no decision about me without me'.

- The Operating Framework for the NHS in England 2012/13 emphasises the need to prepare for the roll out of Personal Health Budgets. All people with NHS continuing care needs should be offered a personal health budget for relevant aspects of their care by April 2014 at the latest.

Local Policy for Long Term Neurological Conditions

27. NHS Nottinghamshire County PCT have been working across key partnerships such as social care, voluntary sector patient and community representatives to ensure that national policy guidance is used to guide implementation locally, based on local need. The aim is to ensure that services for people with a range of LTNC's are accessible and coordinated from diagnosis until end of life and that patients, families and carers are involved within their care process at all stages of the journey. This tiered work programme is being driven forward by the multi-agency Nottinghamshire County Managed Clinical Network and the NHS Bassetlaw Long Term Neurological Conditions Committee. Both groups have an active action plan that details the priorities that require being driven forward.

28. The focus for these work programmes is on early referral and diagnosis, specialist support and rehabilitation, improved health outcomes for patients and population and management of long term neurological conditions in most appropriate setting.

Table 3.1 Tiers of Care for Long Term Neurological Conditions

Prevention, awareness & lifestyle improvement	**Tier one:** **Point of access, diagnosis & self-management**	**Tier two:** **Condition management & support**	**Tier three:** **Complex management, rehabilitation, crisis management**	**Tier four:** **Highly specialised intervention, treatment**
-Identification of high risk groups and localities and targeted social marketing for TBI. -Education programmes for health professionals on identification of individuals with ltnc and their health and social care needs	-Local assessment/ diagnosis of patients with ltnc's: Identified on ltnc register. -Referral to multi-disciplinary locally based teams. -Direct access to investigations where appropriate including psychological assessment. -referral to multi disciplinary locally	-Monitoring and management of patients by multi-disciplinary locally based teams: -regular assessment and proactive management -lead case manager and single point of access -access to information/ advice-telephone/telehealth	stabilisation -rehabilitation -discharge planning -near to patient as appropriate -Specialist Complex management and rehabilitation: -rapid/direct access/crisis intervention	Access to highly specialist intervention: -assessment -specialist treatment -neurosurgery -Access to planned specialist palliative care services: -home care/ care package/ preferred place of care -hospice/ specialist

Prevention, awareness & lifestyle improvement	Tier one: Point of access, diagnosis & self-management	Tier two: Condition management & support	Tier three: Complex management, rehabilitation, crisis management	Tier four: Highly specialised intervention, treatment
	based teams. -Delivery of an educational/self management programme for people newly diagnosed with a ltnc located in an appropriate setting for patients. -Availability of support groups in locally appropriate environments.	-medicines management -access to psychological therapies -rapid response and treatment of patients with exacerbations -Individualised self management plans.		palliative day/ inpatient care -advance care planning -psychological support for patients and carers -carer education and support

Health Need

Predicted Trends in Incidence of Stroke

29. Despite advances in preventing stroke occurring, the increase in the number of elderly people across the county will result in an increase in the number of people having strokes. Over the next 20 years, this is likely to result in an increase of between 22% and 54% in the number of NHS Nottinghamshire County residents having a stroke. The equivalent increase for NHS Bassetlaw is very slightly less at between 16% and 48%, as Bassetlaw has proportionately fewer very elderly residents.

Long Term Neurological Conditions

30. Neurological conditions affect all ages and people may experience the onset of a neurological condition at any time in their lives. The table below depicts the estimated number of people newly diagnosed each year for the top five LTNC's.

Table 4.1 Incidence of 5 commonest Long Term Neurological Conditions

'Condition	Incidence: number of new cases that develop each year	Prevalence: total number per 1000,000 (& number with the condition in the UK)	Source
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)	Headway, the brain injury Association and society of British Neurological Surgeons. Incidence figures from Powel T….1994. (Winslow Press LTD)
Epilepsy	80 per 100,000	500 (300,000 approximately)	Kilson A, Shavron S. clinical Standards Advisory Group. London: DoH, 2000. Sander JWAS, Hart YM, Johnson A, Shavron SD, National General Practice Study of epilepsy: newly diagnosed

'Condition	Incidence: number of new cases that develop each year	Prevalence: total number per 1000,000 (& number with the condition in the UK)	Source
			epileptic seizures in a general population. 1990; 336:1267-1271
Essential tremor		850 (500,000)	Estimate from the National Tremor Foundation-Professor Leslie Finley
Migraine	400 per 100,000	15,000 (8,000,000)	Steiner TJ et al, Epidemiology of migraine in England. 1999; 19:305-6
Parkinson's disease	17 per 100,000 (10,000 approximately)	200 (120,000)	Parkinson's Disease society-based on advice from medical advisor.'[5]

31. Prevalence estimates for a range of LTNCs are currently being developed to help identify future trends and un-met need more accurately. However, the number of people with a neurological condition is estimated to grow sharply in the next two decades. This is due to factors such as the increasing elderly population, improved survival rates and general health care, improved diagnosis and raised awareness.[6]

Current Provision

Prevention of Stroke

32. Research demonstrates that appropriate clinical and lifestyle interventions can greatly reduce the prevalence of stroke and increase positive health outcomes. Locally, key risk factors are identified via the NHS Health Check programme and the Quality and Outcomes Framework (QOF) of the GP contract, as well as services like New Leaf for specific interventions such as smoking cessation. The East Midlands Cardiovascular Network (EMCVN) is now starting a major piece of work across the East Midlands to emphasise the importance of the identification and treatment of people who have atrial fibrillation (an irregular heart rhythm which often leads to blood clots forming in the upper chamber of the heart).

33. A key aspect of the QOF is the ability to record all those who have had a stroke accurately, in order to ensure that they can be followed up and offered the best care to prevent a further stroke.

[5] ibid
[6] The Neurological Alliance. April 2003. Neuro Numbers: a brief review of the numbers of people in the UK with a neurological condition.

Table 5.1 Estimated and observed prevalence for stroke by Clinical Commissioning Group[7] - 2010/11

Clinical Commissioning Group	Numbers on GP Registers (2010/11)	QOF register as % of expected numbers
Bassetlaw	**2,136**	**86%**
Mansfield & Ashfield	3,348	81%
Newark & Sherwood	2,406	86%
Nottingham North & East	2,881	94%
Nottingham West	1,916	96%
Principia - Rushcliffe	2,323	101%
NHS Notts County	**12,874**	**90%**

34. Table 5.1 above shows the total number of patients who are 'stroke survivors' and the total numbers expected to be on the individual practice registers. Possible explanations for the difference between the expected and observed numbers include practices that care for many people in nursing homes, who may have a much higher than expected prevalence for stroke. However, inaccurate recording is also likely to be a factor.

Acute Care for Stroke

35. All patients should be admitted to hospital following a stroke, as early assessment and initiation of rehabilitation have been shown to improve outcomes. Locally, patients will be admitted to Doncaster Royal Infirmary, Kings Mill Hospital or City Hospital campus of NUH in the first instance. Following initial tests including a brain scan (usually by CT), acute management and initial rehabilitation, patients may then either be discharged onto an Early Supported Discharge (ESD) scheme, to the Community Stroke Team in Bassetlaw or to Bassetlaw Hospital or a Community Hospital for a period of rehabilitation

36. The cost of admissions in the financial year 2009/10 are summarised in table 5.3.

Table 5.3 Cost of hospital admissions for stroke: 2010/11

PCT	Stroke		TIA	
	Spells	**Cost**	**Spells**	**Cost**
NHS Bassetlaw	96	£444,401	67	£80,021
NHS Nottinghamshire County	1194	£5,292,580	259	£362,295

Source: Data warehouse

Acute Care for Long Term Neurological Conditions

37. Following a referral from primary care, patients needing further investigation and diagnosis or inpatient care will usually be seen by staff in the Neurology departments of the Acute Trusts, at Doncaster Royal Infirmary, Kings Mill Hospital or NUH. For longer term rehabilitation requirements, there are specialist rehabilitation units at Linden Lodge, on the City Hospital campus of NUH and the Chatsworth Unit at Mansfield Community Hospital.

[7] Estimated data based on APHO stroke prevalence model, 2009 version.

Community Services

Community Stroke Services

38. There are a range of community services across the county for stroke survivors. In addition, people can also access the generic community rehabilitation services.

39. In the south of the county, there is a multi-professional Community Stroke Team, now commissioned through NUH, who provide rehabilitation to selected people on discharge from hospital until their rehabilitation goals are met, typically after 6 to 12 weeks.

40. NUH is now providing a basic Early Supported Discharge (ESD) scheme, which provides a range of staff who support people at home within 3 to 7 days of having a stroke. Agreement for a full ESD, with nursing as well as rehabilitation staff, has been reached for implementation in 2012/13. ESD is a key feature of the Accelerating Stroke Improvement Programme and is associated with reduced mortality and improved outcomes for stroke survivors.

41. There is also an ESD in the north of the county, commissioned from SFHT, which has proved very effective in enabling the Stroke Unit at SFHT to run with relatively few beds and is also very popular with patients.

Community Rehabilitation Services for Long Term Neurological Conditions

42. A multi-agency specialist rehabilitation and support service would promote faster recovery, reduce avoidable deterioration, and reduce the number of hospital admissions for people with LTNCs. It would also provide a point of contact for patients, families and carers. Plans for this service are being developed in conjunction with existing health and social care providers and the relevant voluntary agencies. Progress so far has resulted in successful bids to both the Multiple Sclerosis Society and Parkinson's UK. This has resulted in over £150,000 being granted to fund two full-time specialist nurses who will form the start of a community rehabilitation service, together with the reorganisation of existing services. A key remit for both posts will be to demonstrate the cost effectiveness associated with their work resulting in reductions of GP visits, hospital admissions, length of stay and increased patient satisfaction, to support future investment into the service.

Rehabilitation and Reablement

Stroke

43. Following publication of the National Stroke Strategy, local authorities received a ring-fenced allocation to develop a range of services for people who have had a stroke and their families, and to raise awareness around stroke. For Nottinghamshire County Council, the total amount of funding received was £130,000 per year for three years from April 1st 2008 until March 31st 2011.

44. The County Council, in partnership with both PCTs, has developed a number of initiatives to address the needs of stroke survivors and their carers across Nottinghamshire. The overall strategy has been to improve access to a range of services that benefit stroke survivors and their carers. Stroke remains a priority within the Joint Commissioning Unit in

the Adult Social Care, Health and Public Protection department. Examples of initiatives to date include:

a. Family and Carer Support

A support service for carers of stroke survivors living in the south of the County was established in March 2009, to match that already provided in Mansfield and Ashfield. NHS Nottinghamshire County and Nottinghamshire County Council are continuing to support this scheme in 2012/13. A service jointly funded with NHS Bassetlaw has also now been commissioned and began in February 2011.

Funding from the Stroke Grant has also provided an additional worker at SFHT providing specific input for stroke survivors around work, training and volunteering opportunities for an initial twelve month period during 2011/12.

b. Grants to small groups

Grants to a maximum of £2,000 have been provided to support local groups and reduce social isolation, particularly for those in rural and hard to reach areas. Examples include supporting Radio Faza (a community radio station targeting Asian communities) to deliver a stroke awareness programme; a confidence course for people with aphasia; and a self management programme for people living with stroke in the north of the county.

c. Social Work support for stroke survivors

Social work support with a specific remit for stroke has been funded to assess the social care needs of stroke survivors leaving NUH. The main focus is on supporting stroke survivors who will be returning home.

d. Strokeability

Strokeability is a 12 week programme offering gentle exercise, relaxation, information and advice to stroke survivors and their carers. It is jointly supported by NHS Nottinghamshire County and Nottinghamshire County Council. To date, courses have been delivered in Sutton-in-Ashfield, West Bridgford, Hucknall, Ollerton, Newark, Gedling (Carlton & Arnold), Kirkby-in-Ashfield and Southwell. Further courses across the county are planned for 2012 including development of a course in Broxtowe. Stroke exercise groups are now running in Newark, Ollerton and Kirkby-in-Ashfield. Evaluations show that the courses are well received and reduce social isolation, although the impact on physical ability is minimal in the timescales involved.

e. Training and Development

A specific stroke training programme was developed in conjunction with the Stroke Association and delivered from February to April 2011 to all reablement staff employed by Nottinghamshire County Council. In addition, an e-learning package on stroke core competencies remains available on the County Council's intranet.

Sensory Impairment

45. Nottinghamshire County Council's Adult Deaf and Visual Impairment Service provide services across the county. They have developed a reablement service for adults aged 18+ with a focus on maximising people's independence.

46. The provision of equipment for visually impaired people is free where there are clear risks connected with the health and safety of service users. In other instances, advice and information is given on suitable self purchases.

47. Specialist Technical Officers for the Deaf also have a reablement function in relation to environmental aids for Deaf/deafened and hard of hearing people across Nottinghamshire. The provision of equipment is based on eligibility criteria in line with the Chronically Sick and Disabled Persons Act. Specialist Social Workers for the Deaf also have an assessment function and each has adequate British Sign Language skills in order to communicate directly with the Deaf community. Social Workers for visually impaired adults contribute to the community care assessment process offering a specialist insight into the needs of adults with a visual or dual sensory impairment.

Generic Services Supporting People with Long-term Conditions

48. Most services provided by community-based health services and those commissioned or provided by Adult Social Care, Health and Public Protection staff are not dependent on individual diagnosis, but are part of the range of services available to all those eligible between the ages of 18 and 65. Key services are described briefly below.

a. <u>Self Management Programmes</u>

In 2011-12 NHS Nottinghamshire County has so far delivered 12 Expert Patient courses across the county (including two ten week 'regaining confidence after stroke' courses), incorporating 100 patients with various long-term conditions. A further 3 courses are planned before the end of March. National evaluation of the programme states that on average every patient who attends a course results in a potential saving to the NHS of £1,800:00

A Health Peer Mentor Programme is also being piloted to support people with a stroke, fibromyalgia, diabetes or brain haemorrhage on a one-to-one basis.

b. <u>Supporting People</u>

Supporting People services are those that are commissioned to provide housing-related support to vulnerable people, to help people to live independently. This includes short term accommodation-based support for those also in housing need, short term support to help set up a new home, or longer term support to enable someone to sustain a home.

Support includes:

- assistance with housing and welfare benefits
- advice, advocacy and liaison with other agencies
- monitoring health and wellbeing

- safety and security
- developing social and life skills
- emotional support and confidence building
- resettlement when setting up and managing a new tenancy
- provision of community alarms
- advice about home improvements.

Housing-related support does not include social or personal care and it is not intended to replace any statutory duty. However, since the inclusion of the funding within the Area Based Grant, there has been greater opportunity to be more flexible in the specification of services, allowing greater opportunity to deliver against a broader agenda.

c. START Reablement Service

Nottinghamshire County Council has a generic START reablement service, (Short Term Assessment and Reablement Team), which is available for people who have had an accident or illness that has caused them to lose the ability to undertake some or all daily activities. Reablement support can last for up to six weeks. Reablement aims to support people to regain skills and confidence to reach and maintain independence at home. The START service provides short term homecare and Occupational Therapy.

d. Assistive Technology

Assistive Technology is available for certain vulnerable and/or disabled people for use in the home; sensors can detect when things have gone wrong and send an alert either to a support centre or to someone else in the home. This can help people to live independently in their own home with the reassurance that help is available if problems occur. For carers, the equipment can help to reduce stress and provide reassurance.

e. Electronic Information services including Information Prescriptions

Electronic Information services are available for all people with long-term health and social care needs and their carers. They offer service users and patients and their carers timely and relevant information at the point that they need it most, to help them manage their own condition.

NottsInfoScript

49. NottsInfoScript is an information portal for people with long-term health and social care needs. It provides information on the different conditions as well as other relevant areas, such as benefits, support groups, leisure, work etc. It is intended to be used by health and social care staff, patients and carers. Information prescriptions have been shown to increase self-care and involvement in care planning. In turn this can reduce hospital admissions and GP visits. NottsInfoScript is a web-based information site that also offers a postal service for people who are unable to access the internet.

Notts50Plus

50. Notts50Plus is an information and advice website for people over 50. It is designed to be easy to use and to provide people with the information and advice they need to keep them

safe, well and active. Information includes leisure activities, lunch clubs, meeting people, crime prevention, money and benefits, shopping and gardening services. The website was designed in conjunction with older people.

NottsInfo4You

51. NottsInfo4You is a website for vulnerable adults, which works similarly to Notts50plus. It is designed to provide information on services and groups for people who may not otherwise be eligible for services. Information includes parenting, support groups, benefits and financial advice, carers etc.

Central Database

52. The central database is designed to hold information for all sites in one place. This means that only one area needs to be updated and this information then supports the other sites. The database can also link to additional existing council sites e.g. pinpoint, sport directory, brokerage site etc. The information items are assigned to the person responsible for updating. The database sends information requests to the responsible person every 6 months and the responsible officer then updates the information item. The database administrator moderates the information item before it shows on the live sites. This means that all sites can be updated from one information update.

Support for Carers

53. The families and carers of stroke survivors and people with other long term conditions are able to access a range of services provided by Nottinghamshire County Council and NHS Nottinghamshire County.

54. These include:

- **Breaks for carers**: For example, short term residential or day care for the person they care for, home-based 'sitting' services or buying in services using a personal budget.

- **Carers Personal Budget**: A 'one off' annual payment for a carer to focus on their own developmental and support needs, for example education/training, funding for a holiday or day out.

- **Assistive Technology for Carers**: Use of a pager unit attached to sensors that alerts the carer if a person gets out of bed or requires assistance.

- **Crisis Prevention for Carers:** Provision of a home-based 'sitting' service if a carer is unable to care on a short term basis due to an unforeseen event, for example due to illness, admission to hospital or bereavement.

- **Emergency Card:** A free card issued to carers that identifies them as such if something happens to them, so that people are alerted to the fact that there may be a person requiring immediate care.

- **Looking After Me:** An eight week course for carers encouraging them to focus on their own health and wellbeing, and enabling them to meet people in a similar position.

- **Support to young carers:** Ensuring that they are removed from inappropriate caring roles through provision of sufficient support for the person they care for, and supporting their own needs through direct payments for activities, educational resources and events, opportunities for socialising etc.

- **Access to Advice and Information, training and support groups:** Provided by the Carers Federation (commissioned by Nottinghamshire County Council) and by Nottinghamshire County Council staff across the county.

Further Action Required

Stroke

55. The Care Quality Commission (CQC) carried out a review of care following discharge from hospital during 2010[4]. This identified particular areas of further work identified for NHS Nottinghamshire County:

    - Carer support
    - Aphasia[8] friendly information
    - Access to generic leisure and community services.

56. In addition, there is a need to develop robust systems for the 6 week, 6 month and annual reviews highlighted by the Accelerating Stroke Improvement Programme, as well as full implementation of the Early Supported Discharge in the south of the county.

57. For NHS Bassetlaw, the key priorities are:

    - Development of Early Supported Discharge
    - Support for carers
    - Information for patients.

Long Term Neurological Conditions

58. Following the appointment of the specialist nurses in early 2012, there is a need to support further development of a community rehabilitation service, to include a wider specialist team with speech and language therapists, psychotherapy, physiotherapy, social care support, epilepsy specialist nurse, a generic LTNC specialist nurse and support staff.

59. The initial focus of the service will be for patients with brain injuries, epilepsy, Multiple Sclerosis and Parkinson's disease. This is based on the numbers of patients with these conditions. However, the service will develop to support all patients with neurological conditions who have a need for rehabilitation.

60. It is the intention to work closely with voluntary sector leads such as the MS Society and Parkinson's UK to develop community-led physical activity interventions, with the aim of facilitating community engagement, using local capacity, to enable regular physical activity

[8] Disorder of the central nervous system characterised by the loss of the ability to communicate especially in speech. This can range from having difficult remembering words to being completely unable to speak, read or write.

sessions to support rehabilitation for people, their families and carers with LTNCs. This also links closely with the self care agenda.

2011 Multiple Sclerosis Audit

61. NHS Nottinghamshire County recently took part in the 2011 Multiple Sclerosis audit, conducted by the Royal College of Physicians. Although the PCT performed relatively well in comparison to other areas, the Multiple Sclerosis Society highlighted the national lack of progress since the previous audit. It is the intention to develop a local 5 year action plan for the improvement of MS services to address this.

Sensory Impairment

62. There has recently been the development of a national vision strategy, 'Seeing it My Way' (2011). It is the intention to use this as a framework to develop a Nottinghamshire specific action plan to facilitate a coordinated approach to visual impairment locally.

Statutory and Policy Implications

63. This report has been compiled after consideration of implications in respect of finance, equal opportunities, human resources, crime and disorder, human rights, the safeguarding of children, sustainability and the environment and those using the service and where such implications are material they are described below. Appropriate consultation has been undertaken and advice sought on these issues as required.

RECOMMENDATION/S

It is recommended that:

1. Members of the Health and Wellbeing Board are invited to comment on the current approach summarised in this paper to improving services and support for people with a physical disability or after a stroke. In particular to support the following actions:

   Stroke:
   - Full implementation of the Early Supported Discharge in the south of the County
   - Implement integrated rehabilitation support after hospital discharge
   - Provide improved support for people with communication difficulties

   Long Term Neurological Conditions:
   - Implement personal health budgets for people with LTNC

2. In light of NHS reforms and changes in commissioning arrangements, the Board considers how Nottinghamshire County Council and Primary Care Trusts engage with GP Commissioning Groups to ensure the needs of people with physical disability and long term neurological conditions are effectively and jointly addressed.

CHRIS KENNY
Director for Public Health

For any enquiries about this report please contact:
Mary Corcoran
Consultant in Public Health

Constitutional Comments (LMc 05/04/2012)

64. The recommendation falls within the remit of the Health and Wellbeing Board.

Financial Comments (RWK 11/04/2012)

65. None.

Background Papers

None.

Electoral Division(s) and Member(s) Affected

All.

HWB37

GLOSSARY

A & E	Accident and Emergency
ASI	Accelerating Stroke Improvement
CCG	Clinical Commissioning Group
DH	Department of Health
EMCVN	East Midlands Cardiovascular Network
ESD	Early Supported Discharge
LTNC	Long Term Neurological Conditions
MND	Motor Neurone Disease
MS	Multiple Sclerosis
NCHOD	National Centre for Health Outcomes Development
NICE	National Institute for Clinical Excellence
NSF	National Service Framework
NUH	Nottingham University Hospitals NHS Trust
PCT	Primary Care Trust
PD	Parkinson's Disease
QOF	Quality and Outcomes Framework
SCI	Spinal Cord Injury
SFHT	Sherwood Forest Hospitals NHS Foundation Trust
START	Short Term Assessment and Reablement Team
TBI	Traumatic Brain Injury
TIA	Transient Ischaemic Attacks

Appendix 1
Estimates of prevalence of long-term neurological conditions
Synthetic estimates for Long term neurological conditions based on 2011 registered population (crude national prevalence rates provided by EMPHO)

	Rate per 100000	Bassetlaw	Mansfield and Ashfield	N&E Nottingham	Newark & Sherwood	Nottingham West	Principia	NHS Notts County + NHS Bassetlaw
Sudden onset	-	**1372**	**2285**	**1803**	**1590**	**1164**	**1520**	**9733**
Traumatic brain injury	1200	1317	2194	1731	1526	1117	1459	9344
Spinal Cord Injury	50	55	91	72	64	47	61	389
Intermittent/unpredictable	-	**911-1,537**	**1,518-2,560**	**1,197-2,020**	**1,056-1,781**	**773-1,304**	**1,009-1,702**	**9,578-14,016**
Epilepsy	430-1,000	472-1098	786-1829	620-1443	547-1272	400-931	523-1216	3349-7,788
Migraine	400	439	731	577	509	372	486	3114
Myalgic encephalomyelitis (ME)	400	439	731	577	509	372	486	3114
Stable	-	**385-605**	**642-1008**	**506-795**	**446-701**	**327-513**	**427-670**	**2,733-4,291**
Cerebral Palsy	186	204	340	268	237	173	226	1449
Post-polio syndrome	100-300	110-329	183-549	144-433	127-382	93-279	122-365	779-2,336
Dystonia (Primary idiopathic)	65	71	119	94	83	61	79	506
Progressive	-	**1,410-1,432**	**2,348-2,385**	**1,853-1,867**	**1,634-1,659**	**1,196-1,215**	**1,561-1,586**	**10,003-10,144**
Essential Tremor	850	933	1554	1226	1081	792	1033	6620
Parkinson's Disease	200	220	366	289	254	186	243	1558
Multiple Sclerosis	100-120	110-132	183-241	144-347	127-442	93-412	122-500	779-2,074
Muscular dystrophy	50	55	91	72	64	47	61	389
Charcot-Marie-Tooth Disorder	40	44	73	58	51	37	49	312
Spina Bifida and Congenital Hydrocephalus	24	26	44	35	31	22	29	187
Huntingdon's Disease	13.5	15	25	19	17	13	16	105
Motor Neurone Disease	7	8	13	10	9	7	9	55