Neuro numbers

a brief review of the numbers of people in the UK with a neurological condition
There are 10 million people in the UK living with a neurological condition which has a significant impact on their lives.
Of the 10 million people living with a neurological condition:

- Approximately 350,000 people (0.6% of the UK population) require help for most of their daily activities.
- Over one million people (2% of the UK population) are disabled by their neurological condition.
- Over eight million people are affected by a neurological condition, but are able to manage their lives on a day-to-day basis.
Neurological conditions affect all ages and people may experience the onset of a neurological condition at any time in their lives. There is increased prevalence of neurological conditions in older people as some conditions particularly affect older people and others are life long conditions. The numbers of people with neurological conditions will grow sharply in the next two decades due to improved survival rates, improved general health care and infection control, increased longevity and improved diagnostic techniques.

People with neurological conditions can experience difficulties ranging from living with a condition which may weaken or disable them for periods of time through to needing help for most everyday tasks.
### Approximately 350,000 people require help for most of their daily activities

- **350,000**

This will include most people with motor neurone disease (MND), many of those with primary and secondary progressive multiple sclerosis (MS) and other progressive neurodegenerative conditions, those with severe brain injuries, people who have had a serious stroke (including brain haemorrhage) or those who have advanced dementia.

### Over one million people are disabled by their neurological condition

- **1,000,000+**

They may need help with some daily tasks and are likely to be out of full time employment. This figure includes most people with congenital conditions, such as cerebral palsy, those who have recently had a brain injury or illness, those who have had a stroke, some people living with MND, MS, Parkinson's disease and forms of dementia. It also includes some of those with epilepsy or migraine.

### Over eight million people are affected by a neurological condition, but are able to manage their lives on a day-to-day basis

- **8,000,000+**

This figure includes a number of people living with MS, Parkinson's disease and many more rarely diagnosed conditions, people recovering from stroke or head injury, people with essential tremor and other motor difficulties. It also includes many people living with migraine and chronic tension-type headache and many of those managing their epilepsy.

Many of the people affected in this way will already have experienced an acute phase of their illness and often live with pain, the side effects of medication and the possibility that their condition could worsen, in some cases catastrophically or fatally, at any time. They will often need to adapt their lifestyle which can have an adverse effect on their quality of life. Though these people will often be in employment and with caring responsibilities of their own, there will be periods of time when they may need to be cared for or require help to carry out their daily activities, when they are unable to work or to carry out their lives to the full.
Neurological conditions are the most common cause of serious disability and have a major, but often unrecognised, impact on health and social services.

1% of visits to Accident and Emergency Departments are for a neurological problem.
17% of GP consultations are for neurological symptoms.
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.

Each year 600,000 people (1% of the UK population) are newly diagnosed with a neurological condition.
Each year 200,000 children have an acquired brain injury.

About one quarter of people aged between 16 and 64 with chronic disability have a neurological condition.

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.

30% of the people attending accident and emergency departments for head injury are children of 15 years and under.

However, most neurologically disabled people are not in residential care, but live at home, usually cared for by relatives.

Carers often have to sacrifice their own work or leisure time. For example, family caregivers provide on average between five and 12 hours of care per day to people with moderate and severe MS.

Partners caring for someone with Parkinson’s disease are 40% less likely to get out of the house at least once a week or to take a holiday than their peers. Carers’ health is often compromised – about half suffer physical injuries such as a strained back and half experience stress-related illness. Carers may be all ages. Whilst many carers are elderly, a significant number of children and young people are carers of people with neurological conditions.

There is little systematic collection of data on the numbers of people with neurological conditions in the UK. It is likely that these figures, being based on verifiable data, are an underestimate and show merely the tip of the iceberg. There is an urgent need for systematic collection of data, and further research into the needs of people living with neurological conditions.
<table>
<thead>
<tr>
<th>Condition</th>
<th>Incidence: number of new cases that develop each year</th>
<th>Prevalence: total number of people per 100,000 (and number with the condition in UK)</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s disease / dementia</td>
<td>25,000 per 100,000 in over 65 year olds</td>
<td>1,000 (700,000)</td>
<td>Alzheimer’s Society based on ONS population estimate 1996</td>
</tr>
<tr>
<td>Ataxia (including Friedrich’s ataxia)</td>
<td></td>
<td>5,000 (at least)</td>
<td>Estimate from Ataxia Group of Great Britain and Northern Ireland</td>
</tr>
<tr>
<td>Ataxia-Telangiectasia</td>
<td></td>
<td>0.3 (200 approximately)</td>
<td>Ataxia-Telangiectasia Society.</td>
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</tbody>
</table>
| 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
<p>| Brain tumour                                  | 20 per 100,000 (12,000)                                | 186 (110,000)                                                                      | Hopkins A Clinical Neurology, a modern approach, 1993. OUP             |
| Cerebral Palsy                                |                                                        | 40 (23,600)                                                                        | Scope – based on population studies                                   |
| Charcot-Marie-Tooth Disease                   |                                                        | 0.1 per 100,000 (50-70 approximately)                                              | Estimate from Charcot Marie Tooth UK                                   |
| CJD                                           | 27 new cases in year 2000 (Presently increasing year on year) | 127 cases since 1995                                                               | Alzheimer’s Society                                                    |
| vCJD                                          |                                                        | 65 (38,000)                                                                        | CJD – a guide for patients and carers Brain and Spine Foundation, 2002 |
| Dystonia (primary idiopathic i.e. not associated with another condition) |                                                        |                                                                                     | Dystonia Society – estimate                                           |</p>
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<tbody>
<tr>
<td>Epilepsy</td>
<td>80 per 100,000</td>
<td>500 (300,000 approximately)</td>
<td>Kilson A, Shorvon S. Clinical Standards Advisory Group Services for people with epilepsy: a report of a CSAG committee. London: DoH, 2000</td>
</tr>
<tr>
<td>Essential tremor</td>
<td>2.5 per 100,000 (1,500)</td>
<td>850 (500,000)</td>
<td>Estimate from National Tremor Foundation – Professor Leslie Finley</td>
</tr>
<tr>
<td>Guillain Barré syndrome</td>
<td>2.5 per 100,000 (1,500)</td>
<td></td>
<td>Estimate from Guillain Barré Syndrome Support Group</td>
</tr>
<tr>
<td>Headache</td>
<td>Migraine 400 per 100,000 4 Cluster Headache 4 per 100,000 15,000 (8,000,000) 100 10 3,000 2,000</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Paroxysmal Hemicrania 1 Chronic Migraine 1 Chronic tension-type headache 1</td>
<td></td>
<td>1*Steiner TJ et al, Epidemiology of migraine in England. <em>Cephalalgia</em> 1999; 19:305-6</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4Silberstein SD et al, <em>Headaches in Primary Care</em>. Oxford/Isis Medical Media</td>
</tr>
<tr>
<td>Huntington’s disease</td>
<td></td>
<td>13.5 approximately (6-10,000)</td>
<td>Huntington’s Disease Association</td>
</tr>
<tr>
<td>Intracerebral haemorrhage</td>
<td>2-5 per 100,000</td>
<td>7 per 100,000 (4,000 approximately)</td>
<td>Society of British Neurological Surgeons</td>
</tr>
<tr>
<td>Motor neurone disease</td>
<td>2 per 100,000</td>
<td></td>
<td>Motor Neurone Disease Association</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>4 per 100,000 (2,500)</td>
<td>144 (85,000)</td>
<td>MS Society and MS Research Trust – estimates based on UK area studies and international data</td>
</tr>
<tr>
<td>Multiple system atrophy</td>
<td></td>
<td>1 (600)</td>
<td>Estimate from Sarah Matheson Trust</td>
</tr>
<tr>
<td>Muscular dystrophy</td>
<td></td>
<td>50 (30,000)</td>
<td>Muscular Dystrophy Campaign – estimate</td>
</tr>
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</tr>
<tr>
<td>Myalgic encephalomyelitis (ME)</td>
<td></td>
<td>300-500 (240,000 approximately)</td>
<td>Dowsett E G, Richardson J. The Epidemiology of Myalgic Encephalomyelitis (ME) in the UK 1919-1999 Evidence submitted to the All Party Parliamentary Group of MPs on ME 23.11.99</td>
</tr>
<tr>
<td>Myasthenia gravis</td>
<td></td>
<td>30 approximately (10,000-30,000)</td>
<td>Myasthenia Gravis Association – estimate based on their database</td>
</tr>
<tr>
<td>Narcolepsy</td>
<td></td>
<td>50 (30,000)</td>
<td>Narcolepsy Association – estimate based on patient counts in Europe and America</td>
</tr>
<tr>
<td>Neurofibromatosis</td>
<td>17 per 100,000 (10,000 approximately)</td>
<td>40 (24,000)</td>
<td>Neurofibromatosis Association</td>
</tr>
<tr>
<td>Parkinson’s disease</td>
<td></td>
<td>200 (120,000)</td>
<td>Parkinson’s Disease Society – based on advice from medical adviser</td>
</tr>
<tr>
<td>Progressive supranuclear palsy</td>
<td></td>
<td>6 per 100,000 (3,600)</td>
<td>Estimates range from 100-300 (120,000 approximately)</td>
</tr>
<tr>
<td>Post-polio syndrome</td>
<td></td>
<td>0.1 per 100,000 females at age 14 years (2,500 females in UK)</td>
<td>Nath A et al, The prevalence of PSP in the UK. Brain 2001; 124:1438-1449</td>
</tr>
<tr>
<td>Rett syndrome</td>
<td></td>
<td>24 per 100,000 (14,000 approximately)</td>
<td>Lincolnshire post polio network</td>
</tr>
<tr>
<td>Spina Bifida and Hydrocephalus</td>
<td>(500-700)</td>
<td>240 per 100,000 (100,000)</td>
<td>Rett Syndrome Association UK – figures from Dr Alison Kerr, medical adviser to RSAUK.</td>
</tr>
<tr>
<td>Spinal cord injury</td>
<td>53 per 100,000</td>
<td>500 (300,000)</td>
<td>Estimate from Association for Spina Bifida and Hydrocephalus – from their database of contacts</td>
</tr>
<tr>
<td>Spinal cord problems leading to surgery</td>
<td>1.25 per 100,000 primary spinal tumours (750 approximately)</td>
<td></td>
<td>The First 48 Hours (2000), Spinal Injuries Association</td>
</tr>
<tr>
<td>Spinal tumour</td>
<td></td>
<td></td>
<td>Society of British Neurological Surgeons</td>
</tr>
<tr>
<td>Stroke</td>
<td>240 per 100,000 (100,000)</td>
<td></td>
<td>Spinal tumours – A guide for patients and carers Brain and Spine Foundation 2002</td>
</tr>
</tbody>
</table>
### Condition
- Subarachnoid haemorrhage (aneurysm)
- Tourette syndrome
- Transverse myelitis
- Tuberous sclerosis

### Incidence: number of new cases per 100,000 that develop each year
- 10 per 100,000
- 0.5 per 100,000 (300 approximately)

### Prevalence: total number of people per 100,000 (and number with the condition in UK)
- 40 (20,000-30,000)
- 14 (8,000)

### Source
- Society of British Neurological Surgeons
- Tourette Syndrome (UK) Association – Brian Robertson, Pub. 2000
- Transverse myelitis – A guide for patients and carers Brain and Spine Foundation 2000
- Tuberous Sclerosis Association – based on various published studies

### References


Gloucestershire Health Authority and Department of Social services The Hidden three thousand: a joint study of services for physically handicapped people in Gloucestershire, 1986


MacDonald BK, Cockerell, OC, JOWAS, Sander, Shorvon SD. The incidence and lifetime prevalence of neurological disorders in a prospective community-based study in the UK. Brain 2000; 123: 665-676


Members of the Neurological Alliance

Alzheimer’s Society
Ann’s Neurological Trust Society (ANTS)
Arachnoiditis Trust
Association for Spina Bifida and Hydrocephalus (ASBAH)
Ataxia UK
Ataxia-Telangiectasia Society
BASIC (Brain & Spinal Injury Charity)
Brain and Spine Foundation
British Acoustic Neuroma Association
British Polio Fellowship
Child Brain Injury Trust
Charcot Marie Tooth UK
Dementia Relief Trust
Different Strokes
Encephalitis Support Group
Epilepsy Action (formerly British Epilepsy Association)
Mersey Neurological Trust
Greater Manchester Regional Neuro Alliance
Guillain Barré Syndrome Support Group
Headway – The Brain Injury Association
HemiHelp
HIRE (Head Injury Re-education)
Huntington’s Disease Society
Joint Epilepsy Council
Lincolnshire Post Polio Network
ME Association
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
Pain Concern
Rett Syndrome Association
Sandwell Neurological Alliance
Sarah Matheson Trust (group for people with Multiple System Atrophy)
Scope
Speakability
The Dystonia Society
The Migraine Trust
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