

LONG-TERM NEUROLOGICAL CONDITIONS Fact Sheet

Background

The following background information is from the National Service Framework for long term conditions, Department of Health 2005.¹

A Long-Term Neurological Condition results from disease of, injury or damage to the body's nervous system (i.e. the brain, spinal cord and/or their peripheral nerve connections) which will affect the individual and their family in one way or another for the rest of their life. 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.
- **Stable neurological conditions, but with changing needs due to development or ageing**, for example postpolio syndrome or cerebral palsy in adults

Long-term neurological conditions can cause a range of different problems for the individual including:

- Physical or motor problems
- Sensory problems
- Cognitive/behavioural problems
- Communication problems
- Psychosocial and emotional effects

Around 10 million people in the UK have a neurological condition. These account for 20% of acute hospital admissions and are the third most common reason for visiting a GP.

The Local Picture

There is a paucity of data on people with long-term neurological conditions, not just locally, but also nationally. In lieu of this, prevalence data drawn from national sources is applied to our local population in [Fig. 1](#) to provide some indication of the expected numbers for each of the main conditions in Sutton. However, it is acknowledged that this estimate is based on a comparatively crude approach.

[Fig. 1: Estimated prevalence of neurological conditions in Sutton](#)

¹ Department of Health (2005) The National Service Framework for long term conditions.



Many long term conditions are managed in a primary care setting. Data from GP Registers, the Quality and Outcomes Framework (QOF), includes prevalence of epilepsy, i.e. the percentage of patients aged 18 and over recorded on the GP epilepsy register.

This indicates that actual prevalence of epilepsy in Sutton is 0.7% representing 1,069 people, compared to 0.6% London and 0.8% England. There is little variation in rates in London by local authority but **Fig. 2** shows that Sutton's prevalence of epilepsy ranks marginally highest in the capital. A significant proportion of people with a learning disability also have epilepsy and services are available in Sutton from an independent provider of specialist care and support for people with epilepsy.

Fig. 2: Prevalence of Epilepsy, Sutton compared to London boroughs, 2015/16

Sutton progress

Services for sudden onset conditions, e.g. acquired brain injury and spinal cord injury are commissioned on an individual basis. There are no specialist facilities within LB Sutton, so treatment is by specialist organisations outside the borough. NHS England commissions this area.

Continuing care services are provided, including rehabilitation, and neuro-rehabilitation. The Community Neurotherapy Team is part of Sutton and Merton Community Services, and provides specialist, multidisciplinary rehabilitation and care in the community for people with neurological conditions. It offers access to early supported discharge for stroke patients and outpatient physiotherapy for a wide number of neurological conditions.

What works

The National Service Framework (NSF) for Long-Term Conditions (2005) presented a set of evidence-based requirements to improve the lives and care of people affected. The NSF proposed eleven quality requirements: a person-centred service; early recognition, prompt diagnosis and treatment; emergency and acute management; early and specialist rehabilitation; community rehabilitation and support; vocational rehabilitation; providing equipment and accommodation; providing personal care and support; palliative care; supporting family and carers; caring for people in hospital or other health and social care settings.

Royal College of Physicians. Long-term neurological conditions: Management at the interface between neurology, rehabilitation and palliative care: Concise guideline. Published in March 2008, last updated in 2012. Available from:

<http://www.rcplondon.ac.uk/resources/concise-guidelines-long-term-neurological-conditions>

Recommendations were as follows:

a) General service coordination

Neurology, rehabilitation and palliative care services should develop closely coordinated working links to support people with long-term neurological conditions from diagnosis to death, including:

- proper flow of communication and information for patients and their families

- a designated point of contact for each stage in the pathway
- a needs assessment identifying the patient's individual problems.

b) Neurology services

1. A person who is suspected of having a long-term neurological condition should be referred promptly to a specialist neurological service for investigation and diagnosis.
2. A person who is confirmed to have a long-term neurological condition should have:
 - ongoing access to specialist neurological services for disease-modifying treatment
 - ongoing support and advice with regard to management of their condition
 - support from specialist neurological nurses for practical advice on living with their condition.

c) Rehabilitation services

1. A person with a long-term neurological condition should be referred to a specialist neurological rehabilitation service if:
 - they develop significant disability or symptoms such as incontinence/spasticity management/nutrition/pain/depression which fall within the remit of the rehabilitation physician and may require an interdisciplinary approach, *and/or*
 - their circumstances change in a way that affects their independence or participation in their current environment.
2. A person with significant ongoing disability due to a long-term neurological condition should have timely and ongoing access to specialist neurological rehabilitation and support services which include:
 - initial needs assessment and provision of support
 - ongoing integrated care planning – including an annual multi-agency needs assessment including health, social services, and voluntary sector input
 - co-ordinated service provision in accordance with changing need, including equipment, environmental adaptation, rehabilitation for vocation/leisure, psychosocial support.

d) Palliative care services

1. A person with a long-term neurological condition should be referred to specialist palliative care services if they have:
 - a limited lifespan – usually 6–12 months, *and/or*
 - distressing symptoms – especially pain, nausea and vomiting, breathlessness, which fall within the
 - remit of the palliative physician, *and/or*
 - a need or desire for end-of-life planning, with or without competence issues.
2. A person who is dying from a long-term neurological condition should have timely and ongoing access to specialist palliative care services which include:
 - symptom control
 - planning and support to the end of their life
 - aftercare and bereavement support for their families.

Links to further information

- See also the Fact Sheet on **Stroke**
- NHS Choices. NSF for long-term conditions (including long-term neurological conditions) <http://www.nhs.uk/NHSEngland/NSF/Pages/Longtermconditions.aspx>
- Royal College of Physicians. Management at the interface between neurology, rehabilitation and palliative care: Concise guideline.



<http://www.rcplondon.ac.uk/resources/concise-guidelines-long-term-neurological-conditions>

Priorities for Sutton

- Identify opportunities for greater integration between health and social care, with the support of appropriate voluntary organisations
- Consider scoping the establishment of a primary care disease register to establish the actual prevalence of long term neurological conditions in Sutton
- Develop capacity of GPs to improve the care of people with these conditions