

## Neurological conditions

### Headlines

People with neurological conditions are affected by an abnormality or deterioration in their neuro-motor functioning often with the precise cause not known. Locally, in 2012, 1.6% of adults in Kirklees identified themselves as having a neuromuscular condition. They can have sudden onset, be intermittent and unpredictable, progressive or stable. Therefore appropriate effective healthcare services, social care services support, and support to live as independently as possible are fundamental to support people with neurological conditions. Prevention is difficult with so many of the conditions having an unknown cause. Support to minimise the impact of symptoms is therefore vital.

### Why is this issue important?

Neurological conditions describe a disparate group of diseases, with varied causes, changeable symptoms and unpredictable progression. People with these diseases are affected by an abnormality or deterioration in their neuro-motor functioning, resulting from damage to the brain, spinal column or nerves. The precise causes of many neurological conditions are not known. They can be categorised as conditions with:

- Sudden onset – such as acute brain or spinal cord injuries, cancers in the brain and spine.
- Intermittent and unpredictable presence – such as epilepsy and early multiple sclerosis.
- Progressive development – such as motor neurone disease, Parkinson's disease or late multiple sclerosis.
- Stable symptoms – such as cerebral palsy in adults.

Some neurological conditions are life threatening, most affect a person's quality of life and many cause disability. People with these conditions require appropriate effective healthcare services, some will need social care services support, and carers of people with these conditions will need respite support. There is no definitive list of neurological conditions making it difficult to fully understand the size and severity of the range of conditions<sup>1</sup>. In the UK neurological conditions affect approximately 10 million people, of which 350,000 required some help with daily living. They were responsible for 20% of acute hospital admissions and are the third most common reason to see a GP<sup>2</sup>.

Locally, in 2012, 1.6% of adults in Kirklees identified themselves as having a neuromuscular condition. Of these<sup>3</sup>:

- Slightly more were men – 56% – than women.
- 2 in 5 (36%) were aged 18-44 years, 2 in 5 (41%) were aged 45-64 years and 1 in 5 (22%) were over 65 years.
- 2 in 5 (39%) lived in Greater Huddersfield.
- 2 in 3 (71%) had low life satisfaction, compared to just over 1 in 3 (38%) in Kirklees overall.
- 4 out of 5 (82%) described themselves as having a limiting long-term condition.
- Over 1 in 5 (23%) described themselves as [smokers](#), higher than the Kirklees rate of 19%.
- Over 1 in 4 (27%) are employed in some form, 1 in 4 (25%) are retired and 1 in 4 (26%) are long-term sick or disabled.

Some of the common conditions are:

Multiple sclerosis (MS) – an autoimmune nerve and muscle wasting disease with unknown triggers that affects mainly adults. Peak onset is around 30 years of age. MS affects 1 in 600 people in the UK<sup>4</sup>, twice as many females than males<sup>5</sup>. It can decrease life expectancy but is not a terminal condition. More advanced imaging techniques have led to an increase in the diagnosis of MS in children and it is now thought that around 5% of people who develop MS actually have symptoms before they are aged 16<sup>4</sup>.

Motor neurone disease (MND) – refers to a group of related progressive neuro-degenerative diseases, causing weakness, muscle weakness and difficulties in speech, swallowing and breathing. Incidence seems to be increasing but this may be due to improved diagnosis. Seven in every 100,000 people in England have MND<sup>6</sup>. It generally affects those aged over 40 years, particularly those aged 50-70 years. Average life expectancy depends on the type of MND but ranges from as little as six months to more than five years from the onset of symptoms<sup>6</sup>.

Epilepsy – a diverse set of chronic neuro-disorders characterised by repeated seizures. Epilepsy may have a known cause such as infection, stroke or head injury, a genetic tendency or the cause may not be known. It can start at any age but is most often diagnosed in childhood (arising from birth, infection or accident) or in those over 60 years

(after stroke)<sup>7</sup>. One in 50 people will have epilepsy sometime in their life, but not everyone has it for life. Identifying people with epilepsy is difficult, but active epilepsy affects 5-10 people per 1,000 in the UK<sup>7</sup>. Up to 5% of those with epilepsy are affected by flashing lights<sup>8</sup>. Anti-epilepsy drugs stop seizures and are successful in 2 out of 3 cases<sup>7</sup>.

Parkinson's disease (PD) – a progressive neuro-condition caused by a lack of sufficient dopamine and characterised by a lack of normal movement, gait and brain function but it is not terminal. It affects 1 in 500 in the UK, most aged over 50 years, but 1 in 20 are under 40 years of age<sup>9</sup>. Parkinson's disease should have no impact on life expectancy although sufferers experience increasing disability.

Myalgic encephalopathy/Chronic fatigue syndrome (ME/CFS) – these conditions have a diverse range of symptoms but usually include excessive exhaustion and intermittently impaired cognitive function<sup>10</sup>. Most people suffer major fluctuations with relapses. A few people recover. Epidemiological details are poor, but it is thought to affect between 2-4 people in 1,000 in the UK<sup>10</sup>. It can affect anyone of any age. Many cases are thought to have onset linked to a viral infection. The main impact is on daily living, particularly leading to reduced schooling and work.

Cerebral Palsy (CP) – this describes abnormal brain development or injury as the brain develops before, during or after birth. It is a non-progressive non-contagious condition leading to physical disability. As children with CP grow the impact may change. Approximately 1 in 400 children suffer some form of CP<sup>11</sup>.

## What significant factors are affecting this issue?

As specific causes for many neurological conditions are unknown it is hard to identify any activity for reducing the occurrence of these conditions. Those arising following head injuries or stroke may benefit from other activities to reduce accidents and incidence of stroke. Otherwise the focus remains on managing symptoms via medication and supporting daily living activities as degeneration and disability develops, this needs to be supported through the implementation of national service frameworks and guidance.

The lack of consistency in identification, confirmation of diagnosis or effective treatment can be a source of frustration for both patients and healthcare providers.

## Which groups are most affected by this issue?

Some conditions are apparent from birth, such as CP.

Children and young people are most likely to be affected by epilepsy<sup>7</sup> and ME/CFS<sup>10</sup>. Infants and young children suffering epilepsy often remit spontaneously whilst those who begin in adolescence are more likely to suffer for longer. Duchenne muscular dystrophy usually appears in childhood.

Most other conditions become apparent in those of working age, with PD and MND appearing in older age.

Ethnicity is a factor in MS with those of northern/Celtic origin having a higher prevalence.

Men with MS tend to experience a more severe disease course than women, although more women are diagnosed with MS. Men are diagnosed with MND twice as often as women.

### Where is this causing greatest concern?

There is no geographical variation for neurological conditions.

Local groups such as The Nerve Centre, The Neurological Reference Group; Parkinson's Disease Society and the ME Society have been involved in engagement and consultation events. The general priorities identified by patients and carers were:

- The need for prompt access to specialist clinicians.
- A person centred approach to their care and treatment, with co-operative clinicians.
- Access to a palliative care service to prevent deterioration in their condition.
- Routine support for carers, including respite care in appropriate settings.

### What could commissioners and service planners consider?

Implementation of the recommendations in the long-term conditions national service framework (LTC NSF)<sup>2</sup> is vital, particularly:

- The need for prompt and appropriate referral to specialist clinicians for diagnosis and treatment (QR2, 3).
- Support and rehabilitation (QR4-6).
- Care and support for families and carers.

Recognition of the wider determinants of health and their role in enabling people to live as independently as possible is important. This may include access to housing adaptations or relocation and support in claiming benefits. The current welfare reforms are likely to impact on people with neurological conditions, particularly those retired or claiming long-term sickness/disability benefits.

Services provided need to be adaptable to meet individual need and respond effectively to changes in patients' condition. Links with self-care and their resources for this group of patients is vital to improving self-management of their disease.

The promotion of access to timely palliative care for patients may help delay or prevent deterioration, support people to affect meaningful recovery or provide end of life care.

Various specific NICE guidelines are now available and these should be implemented wherever possible by primary and secondary healthcare and social care. They include CG1377 covering the diagnosis and management of epilepsy in adults and children, CG53<sup>10</sup> covering the diagnosis and management of ME/CFS in adults and children, which has been reviewed but has no new evidence, and various technology appraisals of MS drugs<sup>12</sup>.

## References

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