

Neurological conditions

Headlines

The only preventable factors that lead to neurological conditions are head injury and stroke. Neurological conditions tend to be progressive in their impact on the person. So, the most important improvements are in enabling early diagnosis, then supporting people with neurological conditions and their carers to cope with their condition, in relation to both physical and cognitive functioning as well as the wider impact on daily living.

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, often including headaches and joint pains. They may experience life changing effects as do the significant others in their lives and they often require the support of long term carers. There is no definitive list of neurological conditions and consequently it is difficult to understand the issue in terms of size, severity and trajectory¹. Some of the common diseases are:

- **Multiple sclerosis (MS)** - a nerve and muscle wasting disease affecting mainly adults, with peak onset around 30 years of age. MS affects 1 in 600 people in the UK². Average life expectancy is lower than the general population by about 10 years³.
- **Motor neurone disease (MND)** – similar symptoms to MS with the addition of paralysis. Seven in every 100,000 people in England have MND⁴. Average life expectancy depends on the type of MND but ranges from as little as six months from the onset of symptoms with progressive bulbar palsy to more than five years with progressive muscular atrophy⁴.
- **Epilepsy** - repeated seizures affecting all ages, with a large cohort being children⁵. It affects 5-10 people per 1,000 UK population⁶. Epilepsy should have no impact on life expectancy in otherwise healthy individuals⁷.
- **Parkinson's disease (PD)** - abnormal movement, gait and brain function mainly in adults. It affects 2 people per 1,000 in the UK⁸. Parkinson's disease should have no impact on life expectancy although will increase disability.
- **Myalgic encephalopathy/Chronic fatigue syndrome (ME/ CFS)** - excessive exhaustion and intermittently impaired cognitive function⁹. It is thought to affect 4 people in every 1,000 in the UK⁹.

What significant factors are affecting this issue?

There is little clear evidence of specific causes for neurological problems, apart from head injuries and stroke increasing the risk of developing epilepsy, so it is difficult to identify any activity for reducing the occurrence of neurological problems.

The lack of consistency in identification, confirmation of diagnosis or effective treatment is a source of frustration for both patients and healthcare providers. The long term conditions national service framework¹⁰ highlights the need for prompt referral to specialist clinicians for

diagnosis of patients presenting to their GP with relevant symptoms. The focus needs to be on enabling early diagnosis and treatment as appropriate for the individual and to support people to cope with their condition.

Relationships with the NHS and with social care are important to help those with neurological conditions, e.g. housing adaptations or relocation and support in claiming benefits.

Which groups are affected most by this?

Children and young people are most likely to be affected by epilepsy⁵ and ME/CFS⁹.

Learning disabled people generally have higher rates of neurological problems¹¹.

Where is this causing greatest concern?

There is no geographical variation for most neurological conditions. Epilepsy appears to be 25% more common in deprived areas⁵.

Views of local people

There has been considerable engagement and consultation with local groups such as The Nerve Centre, The Neurological Reference Group; Parkinson's disease Society and the ME Society. A 'visioning event' consultation programme was carried out in 2009 with representatives from these groups, the NHS and council. The main priorities for improvement identified by patients and carers were:

- Prompt access to specialist clinicians for diagnosing and managing deterioration.
- Person centred approach to their care and treatment, with co-operative clinicians.
- Access to 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?

Facilitating earlier diagnosis and treatment will help people understand their condition and how best to manage it.

Any services provided need to be varied and adaptable to meet individual need and respond effectively to changes in patients' condition and to increasing rates of occurrence. This includes improved provision of services closer to home.

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 effect meaningful recovery or provide end of life care.

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