GIG CYMRU NHS WALES

Llywodraeth Cymru
Welsh Government

Neurological Conditions: Annual Statement of Progress

March 2018

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.
This document is also available in Welsh.

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Overview

Neurological conditions can have a very serious and lasting impact on the lives of individuals and their families. Of those people affected by a neurological condition, around 100,000 will have a long-term condition. A long-term neurological condition results from disease, injury or damage to the body's nervous system, such as the brain, spinal cord and/or the peripheral nerve connections, which will affect the individual and their family in some way for the rest of their life. People with neurological conditions may have complex needs which affect their ability to function, not just physical needs, but also psychological and social needs for support, to help the individual achieve their best possible outcome

Some neurological conditions are life-long with possible onset at any time. Others, such as cerebral palsy, are present from birth. Some conditions, such as muscular dystrophy, commonly appear in early childhood; others, such as Parkinson's disease affect older people. Some neurodegenerative conditions, such as multiple sclerosis, motor neurone disease and Huntington's disease, affect people mainly in adulthood and will cause deterioration over time, affecting a person's quality of life and their ability to live independently.

There are more than 250 recognised neurological conditions. Some are more common than others. They tend to be poorly understood by the general public. Levels of awareness are low, even about relatively common conditions, such as epilepsy.

During 2016-17, there has been continuing progress in improving the services for people who have a neurological condition. There are excellent examples of services improving throughout Wales whilst dealing with an increasing and more complex demand for the services.

The challenge

There is an 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.

It is estimated in total there are around 100,000 people living with a long-term neurological condition in Wales[1]. In Wales, each year around 2,500 people are diagnosed with Parkinson's disease, epilepsy, multiple sclerosis or motor neurone disease. The latest prevalence data from Public Health Wales[2] indicates out of the 100,000 people living with a neurological condition, over 41,000 people in Wales are

[1] Wales Neurological Alliance
[2] 2014-15

estimated to suffer from one of the following neurological conditions; parkinson's disease, epilepsy, multiple sclerosis, muscular dystrophy, motor neurone disease and cerebral palsy. In addition, a further 10,000 people each year were admitted to hospital for an acquired brain injury.

The year 2016-17 saw in Wales:

- Over 13,000 people were referred by their GP for treatment due to a neurological condition; this accounted for 1.8% of all GP referrals.
- 97% of paediatric neurology patients were treated within the target time.
- During 2016-17, nearly 19,000 hospital admissions related to neurological conditions; the average length of stay was 3.6 days.
- The total number bed days for neurological patients has fallen by 25% over the last five years. Following an elective admission this has reduced by 37%.
- There were 24,376 adults identified on GP's QOF epilepsy registers in Wales. The prevalence rate has remained stable in 2015-16 and 2016-17 at 0.8 per cent, in line with rates in England.
- There were 198 new patients with a neurological condition referred to a specialist palliative care team in 2016-17.
- The number of people dying from a neurological condition[3] has been increasing; from 673 in 2013 to 809 in 2016. 40% of these deaths were from Parkinson's disease.
- During 2016-17, 188 people died whilst in hospital from a neurological condition (approx. 23% of all neurological deaths). The percentage of people dying in hospital continues to reduce, from 29% in 2013-14 reflecting our aspiration to support people to die at home, if they wish, where possible.

[3] Not including Alzheimer's Disease (G30)

Key achievements

- ***Increasing NHS expenditure on neurological conditions***

NHS expenditure on neurological system[4] conditions in 2015-16 was £314.4m, an increase of £147m (87%) since 2011-12. In terms of spend per head of population, this equates to £101.46 per person in 2015-16. Of this over 21% (£67.2m) was in primary care and the balance (79% or £247m) in secondary care. It represents the tenth biggest NHS expenditure area at approximately 5% of the total budget; an increase of 2% of the total NHS expenditure since 2011-12.

- ***Reduction in the average length of time spent in hospital***

Effective care and treatment should, over time, reduce the average length of time a person needs to spend in hospital. The latest information shows that the amount of time an individual spends in hospital has fallen gradually from 5.6 days in 2011-12 to 3.6 days in 2016-17. The total bed days occupied by neurological patients has also fallen by 23,165 (25.5%) since 2011-12; from 90,943 to 67,778. The length of stay for neurological patients following an elective admission has reduced over the last five years by 37%; from 4.6 days in 2011-12 to 1.7 days in 2016-17. Over the same time period, there has been a small reduction (3.5%) in the length of stay for patients following an emergency admission; reducing from 6.7 days to 6.5 days. The length of stay for patients with Parkinson's disease is the highest of all neurological conditions. However over the past five years this has fallen by 19% from 29 days to 23.4 days.

- ***Reduction in emergency admissions and total emergency bed days***

The number of emergency admissions for neurological conditions has fallen over the last four years and now accounts for 38% of all neurological admissions compared to 42% five years ago. This reduction in the number of emergency admissions reflects the fact that patients and the NHS are getting far better at managing people's conditions. Many of the actions within the neurological health implementation plan will help to minimise emergency admissions.

- ***Increased focus on patient reported outcome measures and patient reported experience measures***

Working with the Stroke Implementation Group, the Neurological Conditions Implementation Group has made good progress in the development and implementation of patient reported experience measures (PREMs) and patient reported outcome measures (PROMs) to evaluate and inform improvements which will improve the quality of neurological and stroke services in Wales over time. This will be the first joint stroke and neurological PROM in the UK.

From April 2018, Wales will have a PREM and a PROM which can be administered, collected and collated on a national level that will be able to identify inequalities in

[4] http://gov.wales/docs/statistics/2017/170426-nhs-expenditure-programme-budgets-2015-16-en.pdf

health and social care provision across Wales, support evaluation of service development and demonstrate change over time.

- ***Supporting health boards to develop effective neurological rehabilitation services***

Whether in the community or in hospital, people need to be placed at the centre of care with their individual needs identified and met so they feel well supported and informed and able to manage the effects of their neurological condition. The NHS must work with social care and the voluntary sector to provide high-quality ongoing support to patients. One of the Neurological Conditions Implementation Group's top priorities is the establishment of a responsive and efficient neuro-rehabilitation service which is provided as locally as possible and offered to all who would benefit from it. Health boards are working proactively with the third sector, involving them in service planning, to deliver an integrated neuroscience care service. In order to facilitate and support the Neurological Conditions Implementation Group and Stroke Implementation Group they have jointly invested £1.2m in the development of neurological rehabilitation services across Wales.

In addition, health boards across Wales have received funding for therapists to train in the Bridges programme, which supports patients in self-management. The programme enables teams to support individuals to feel confident to self-manage, enhancing the efficiency and impact of their care and rehabilitation.

- ***Supporting children and young people with a neurological condition***

Children and young people in Wales with neurological conditions are normally seen within the agreed targets. During 2016-17, more than 97% of children and young people waited for their treatment less than the target time; most months' performance was over 90%.

Areas of focus

- ***Quick and easy access to a first outpatient appointment, when appropriate***

There has been a significant growth in the number of patients being seen in outpatients over the last five years. In 2016-17, across Wales there were 63,539 outpatient attendances compared to 54,932 in 2011-12, an increase of 15.7%. Over that time period, new attendances increased from 20,818 to 23,713 (13.9%) and follow-up attendances increased from 34,114 to 39,826 (16.7%).

During 2016-17, 6,000 patients waited longer than 26 weeks for a first outpatient appointment for their neurological condition. Over time the waiting times for first outpatient appointments will reduce. This will happen as health boards improve local services and support individuals to manage their conditions. This will be done through the development of specialist nurse clinics and therapy-led spasticity services. This will reduce demand for follow-up appointments with a consultant neurologist and free up appointments to allow people awaiting a diagnosis to be seen in a timely way.

- ***Ensure that patients are seen and treated within 26 weeks following a referral***

Across Wales, 20,740 patients were treated for neurological and neurosurgical conditions. During 2016-17, an average of 86% of patients were waiting less than 26 weeks each month from the date the referral was received in hospital to the start of treatment. An average of 98% of patients each month were waiting less than 36 weeks. This is an improvement since 2015-16 when a monthly average of 85% of new patients were waiting less than 26 weeks and an average of 96% each month were waiting less than 36 weeks. We would expect that at least 95% of patients should start their treatment, if required, within 26 weeks from the referral. No patients should wait longer than 36 weeks. Through the Neurological Conditions Implementation Group there is work in hand to improve a patient's pathway of care.

- ***Ensuring appropriate referrals***

In 2016-17, there were 13,122[5] referrals for neurological conditions and neurosurgery by a GP. This is an increase of 1,100 patients since 2012-13 (9%). NHS Wales is starting to develop new models of care which will result over time in fewer patients having to travel to a hospital for a consultant referral and patients will be treated closer to home in community settings.

[5] Betsi Cadwaladr University Health Board data is not included in 2016-17 figures from November 2016 onwards

- ***Increase participation in clinical trials***

In 2016-17, 309 patients were recruited into a neurological health and care research Wales clinical research portfolio study. This was a decrease of 52 patients (14%) compared to 2012-13.

- ***Support for patients with a brain tumour***

Across the UK, almost 11,000 people are diagnosed with a primary brain tumour and over 5,000 people each year died from a brain tumour[6].

In Wales more than a third of people were diagnosed with a brain tumour by an emergency admission to hospital which is far higher than any other cancer type which highlights the importance of raising awareness of signs and symptoms to drive earlier diagnosis and treatment. The most recent Wales Cancer Patient Experience Survey highlighted that only 56% of people with a brain/ CNS tumour found it easy to contact their key worker and less than half had received the information by staff in relation to financial help.

- ***Access to specialist palliative care***

When a person is referred to specialist palliative care, it is important that the referral is acted upon quickly. In 2016-17, there were 16,538 specialist palliative care referrals. Of these, 198 (1.2%) were referrals for patients with a neurological condition.

[6] Brain Tumour Charity

Neurological care in Wales: March 2018

Latest statistics for 2016–17

There are more than **250** recognised neurological conditions

Around **100,000** people in Wales have a long-term neurological condition

An estimated **41%** have parkinson's disease, epilepsy, multiple sclerosis, muscular dystrophy, motor neurone disease or cerebral palsy

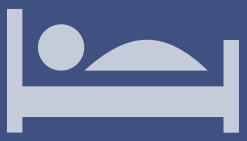
20,000 people were referred to hospital for treatment for a neurological condition

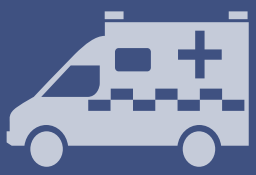
65% of referrals were from GPs

19,000 hospital admissions related to a neurological condition

38% were emergency admissions, a reduction of **4%** since **2011–12**

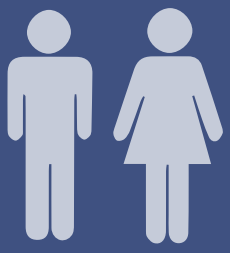
The average length of stay in hospital was **3.6** days





The average length of stay following an emergency admission was **6.5** days

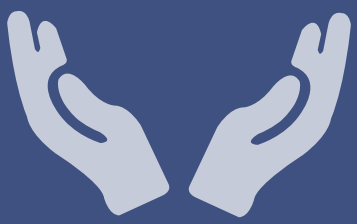
An average of **89%** patients waited less than **26 weeks** each month and an average of **99.5%** each month waited less than **36 weeks**



64,000 outpatient attendances an increase of **15.7%** since **2011–12**

6,000 patients waited longer than **26 weeks** for a first outpatient appointment

198 people with a neurological condition were referred to a specialist palliative care team



809 people died from a neurological condition, excluding Alzheimer's Disease

40% of these were from Parkinson's Disease

23% of people with a neurological condition died in hospital, a reduction from **29%** since **2013**