



# Manifesto 2017

## A call to action for neurology

Neurology is one of the biggest care and research challenges facing us today. The number of neurological cases has reached 12.5 million in England alone. NHS spending on neurological care sky-rocketed by over 200% between 2005 and 2015.

The Neurological Alliance published the results of its inaugural patient experience survey in 2014 - a landmark report that confirmed many people with a neurological condition are not receiving the health and care services they need. We undertook the exercise again last year and are issuing these calls based on what thousands of patients with neurological conditions have told us about their experiences of navigating through the health service.

And as our population continues to grow and life expectancy increases, the number of people with a neurological condition will continue to rise. We need services that can meet this growing demand and we therefore call on all prospective parliamentary candidates to commit to addressing the following issues.

### **1. Access to specialist care must be:**

- a reality for all people with neurological conditions, from diagnosis to the end of life
- available across all care settings – in the home, in the community and in hospital

#### **Why?**

Neurological conditions can vary widely in terms of their impact. They include progressive, incurable conditions, stable conditions, and also sudden-onset neurological incidents that can severely affect a person's life. All types of neurological condition require life-long support. The complex nature of these conditions means that professionals with specific expertise and training are needed to help diagnose and manage them. In addition to providing expert knowledge on conditions and treatment options, specialist care should incorporate tailored care planning, integration of care and multidisciplinary working. Failing to access specialist care can lead to poorer outcomes for people affected by neurological conditions and put pressure on other parts of the health and social care system.

### **2. Primary care professionals must:**

- provide a timely referral or diagnosis for people with neurological conditions
- sign-post patients to condition-specific information where appropriate
- be aware of key signs and symptoms indicating a neurological condition
- be supported with adequate medical school and on-the-job training regarding neurological conditions

#### **Why?**

Our 2016 patient experience survey shows that 42% of respondents saw their GP five or more times before seeing a neurological specialist. Research carried out by the Neurological Alliance has found that GPs in England lack confidence in diagnosing, referring and treating people with neurological conditions. Polling of GPs shows low levels of confidence in the ability of local services and systems to manage neurology patients effectively, and widespread concern over unnecessary delays. It also suggests that GPs feel they would benefit from more support to manage people presenting with suspected neurological symptoms.

### **3. Research into new and better treatments for neurological conditions must:**

- receive ring-fenced UK Government investment and leadership to match the burden and full spectrum of neurological conditions
- be encouraged as part of an environment that promotes clinical trials in the UK

#### **Why?**

The brain, spine and nervous system make up our body's coordination centre, allowing us to move, feel and interact with the world. They are critical to human experience, yet we know relatively little about them. Limited investment in neurological research means that people with neurological conditions have only a small range of treatment options and a reduced chance of cures being discovered in the future.

#### **4. Decisions around treatments for people with rare and complex condition must:**

- be taken in consultation with patients, their carers and voluntary sector groups
- not result in restrictions or rationing based on cost alone
- be considered by Parliament before being implemented - any decisions to restrict the availability of NICE-approved treatments should be taken by democratically-elected politicians

#### **Why?**

The National Institute for Health and Care Excellence (NICE) and NHS England have announced a series of changes to Technology Appraisals, including a new 'budget impact test' for new treatments. The new test would mean that rollout of NICE-approved treatments expected to cost more than £20m in any one of their first three years of use could be delayed for up to three years, or in some cases even longer. This would have a significant detrimental effect on many people with neurological conditions, some of whom need medications and treatments within a specific timeframe to avoid irreversible deterioration of their condition.

#### **5. Mental health needs of those with neurological conditions must:**

- be given particular consideration in the design and delivery of services
- be prioritised as part of the focus on parity of esteem for people with long term conditions

#### **Why?**

Our research suggests that the poorest experience of care is reported by patients who have mental health needs alongside their neurological condition. With a high proportion of neurology patients having a co-morbid mental health condition, this is an area that must urgently be addressed through the delivery of the Five Year Forward View for Mental Health.



## About us

The Neurological Alliance is the collective voice of more than 80 national and regional organisations working together to make life better for the millions of people in England with a neurological condition. We campaign for access to high quality, joined up services and information for every person diagnosed with a neurological condition, from their first symptoms, and throughout their life.

## Our recent reports

- [Falling Short: How has neurology patient experience changed since 2014?](#) (March 2017)
- [Neurology and primary care Improving the transition from primary care for people with neurological conditions](#) (August 2016)
- [Briefing note: Key facts, stats and issues for neurology](#) (April 2016)

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