

Breaking the News – sensitive, supported diagnosis for all

Briefing from the Neurological Alliance of Scotland

Summary

The Neurological Alliance of Scotland is an umbrella body of organisations and groups representing people affected by a neurological condition.

Living with a neurological condition can be a huge challenge for individuals and families, and it's important that everyone involved is able to access the support that they need right from the start.

Some people have positive experiences, but unfortunately, our member organisations tell us that there's a long way to go before everyone gets the support that they need:

- while they are waiting to find out what is causing their symptoms
- when they are told their diagnosis (which includes when people with a brain injury are told what the longer term impact of their condition may be)
- as they live their lives with their condition

What it means to have a neurological condition

Neurological conditions affect the brain, spine and nervous system, and can have a major effect on a person's life. Some people are born with a neurological condition, while others develop a neurological condition as a result of illness or injury.

Every condition is different, but neurological conditions can affect movement, speech, thinking, vision, behaviour, mental health and emotions. Some people live with considerable pain.

While some neurological conditions can be successfully treated or managed, many are lifelong and incurable. Some conditions are progressive, and some are terminal.

Being told you have a neurological condition is life changing, not just for the individual but for their friends and family too. Unfortunately, all too often people struggle to access the support they need at the beginning of their journey with a neurological condition, and this affects their whole future.

How many people are affected?

There are **one million** people in Scotland living with a neurological condition. Neurological conditions account for one in five emergency hospital admissions and one in eight GP consultations in Scotland.

A quarter of all disabled adults of working age have a neurological condition, and neurological conditions are a major cause of disability and ill health in childhood and older age too. The numbers of people with neurological conditions will grow sharply in the next two decades.

Getting it right – sensitive, supported diagnosis for all

Our member organisations tell us that people with neurological conditions need:

- to be told their diagnosis in a supportive, sensitive way, in a private place with time to ask questions and absorb the news
- access to appropriate and timely support at diagnosis and beyond
- to be given information to enable them to understand their condition and prepare for the future
- ongoing specialist support, including from specialist nurses
- support from allied health professionals
- emotional support and psychological services
- access to social care and short breaks for families
- information about support outside the NHS, such as voluntary sector organisations
- access to financial support and welfare benefits, as well as the right to continue to participate in their community

In 2009, NHS Healthcare Improvement Scotland published the *Clinical Standards for Neurological Health Services*.

They set out the standards of care health boards must meet for adults with any neurological condition. These include:

- information for people with neurological conditions and their carers about the condition, the service, and voluntary sector organisations that can help
- a contact point for re-entry into the service for those with long-term conditions
- communication training for staff having contact with people with neurological conditions

- private facilities for discussion with patients and families
- access to specialist care
- appropriate long term and community support
- support to self-manage their condition

The Neurological Alliance of Scotland is concerned that neurological services in Scotland are significantly understaffed – and that this makes it very difficult to provide support at diagnosis and the ongoing support that people need.

In January 2014, we asked NHS Boards to tell us how many consultant neurologists they had in post. Here is what they told us:

- Overall, more than 9% of Scotland’s neurology consultant posts are currently vacant.
- There are 50.6 full time equivalent consultant neurologists to cover the whole of Scotland.

A recent report by the Royal College of Physicians and Association of British Neurologists¹ agreed that one neurologist per 70,000 people was needed to provide adequate care for people with neurological conditions. In Scotland, we currently have one neurologist for every 105,000 people – about two thirds of the number needed to meet this recommended staffing level.

The Neurological Alliance of Scotland has concerns about problems with trainee numbers and succession planning and that if vacancies are not filled services will not be able to meet the needs of the growing numbers of people with neurological conditions.

What you can do

Please ask your local NHS Board:

- what plans it has to continue to support the improvement of services for people with neurological conditions – and in particular to provide adequate post-diagnostic support (such as those listed above and outlined in the NHS HIS Clinical Standards for Neurological Services)
- to outline any issues it faces in recruiting and / or retaining specialist staff such as consultants, nurses and allied health professionals and ensuring that there is an adequate workforce to meet the needs of people with neurological conditions and brain injury.
- whether it is able to meet the RCP/ABN recommendation that one neurologist is needed for each 70,000 people

Neurological Alliance of Scotland

The Neurological Alliance of Scotland is a focused and purposeful forum of not-for-profit organisations and groups representing those affected by neurological conditions in Scotland. The Alliance was launched in 2004 to ensure that neurological services are given priority at all levels of health and social care planning. The Alliance enables neurological organisations/groups to campaign together and speak with an influential voice. The Alliance currently has over 30 member organisations all of whom represent people with neurological conditions. For more information about The Neurological Alliance of Scotland please visit www.scottishneurological.org.uk

¹ Royal College of Physicians of London / Association of British Neurologists (ABN) (2011) *Local adult neurology services for the next decade*. Online at <http://www.rcplondon.ac.uk/sites/default/files/documents/local-adult-neurology-services.pdf>