



THE NEUROLOGICAL ALLIANCE

Information about membership

Why is The Neurological Alliance needed?

People with neurological conditions need and deserve better care and support.

Before The Neurological Alliance was formed in 1994, there was no national voice for neurology as a whole and no-one campaigning to end its 'Cinderella' profile. Today, we are a powerful campaigning coalition of 80 organisations working together to transform outcomes for an estimated 10 million people with neurological conditions in England.

10 million is a big number. It outstrips the 4.6 million people in the UK living with diabetes, and 2.5 million people living with cancer. 10 million is the sort of number that should make decision makers listen, and act.

Yet neurology is starting from a low baseline after years of neglect. We know that people with neurological conditions still struggle to access the care they need and deserve. At the Neurological Alliance we make connections across issues in specific disease areas, then facilitate members to come together to have a louder and stronger voice in achieving change. Together we can transform outcomes for everyone with a neurological condition.

What has The Neurological Alliance achieved?

- **We have successfully campaigned for national leadership and improved data:** The National Neuro Advisory Group and Neurology Intelligence Network were set up as a direct result of our campaigns - two key levers that have driven improvement in other disease areas – and are now starting to drive improvement in neurology.
- **Our biennial patient experience survey is a trusted source of data:** our 2017 survey was described as one of the 'best of the best' in the Patient Library report on patient experience. Our 2018 survey promises to provide richer data than ever before.
- **We publish high quality, influential reports:** For example, our 2016 report Neurology and Primary Care, 2017 report Parity of Esteem, outlining the distinct mental health needs of neurology patients, and 2018 report Going the Distance II making national calls to action for neurology.
- **We are the go-to organisation for policy makers:** As a credible, influential partner – and when necessary, critical friend – of NHS England and other parts of the NHS architecture, we have a seat at the table in all major national policy making forums for neurology.

Our current priorities

Our research shows there are four issues that are most important to people with neurological conditions:

1. 'I received a timely and accurate diagnosis and was given the support I needed throughout the process'
2. 'I feel informed about my treatment and care which is simple to arrange and enables me to live life as I choose'
3. 'My treatment and care is excellent'
4. 'I see scientific innovations benefitting me and my family'

Yet evidence shows that these statements are a long way from being a reality for most neurology patients. Our 2016 patient experience survey found:

- **There are significant delays in referral to specialists and diagnosis of a neurological condition:** 42% of patients report seeing their GP five or more times before seeing a neurological specialist. Almost 20% of patients waited more than 12 months to see a neurological specialist after first seeing a GP
- **Communication between people with neurological conditions and the people providing care is poor:** just 52% of patients felt their diagnosis was communicated appropriately.
- **Care for people with neurological conditions is not joined up:** 82% of patients have not been offered a care plan. Only 56% of patients feel the people providing their care work well together at least some of the time.
- **Information is not routinely provided to people with neurological conditions:** 45% were unsatisfied with information they have received about their condition.
- **There are geographical variations in access to services and quality of services:** 13% reported health services to meet the needs of a neurological condition as 'excellent'

There are several causes of poor neurological care:

- Commissioners (those planning and paying for services) are disengaged from neurology
- There is a lack of clarity in the responsibilities of local and national commissioners in relation to neurological service provision
- There are few incentives and accountability mechanisms relating to neurology in the health service
- Nationally collected neurology data is poor
- Neurology is not a stated priority for the NHS and neurology has suffered from a lack of consistent national leadership.

Our current policy calls are as follows:

- Neurology to be proportionately prioritised in national accountability and incentive frameworks in order to support greater engagement by commissioners at regional and local level
- Better collection and availability of data in order to develop baselines and measure progress
- All people with neurological conditions to be offered a care plan and a named care coordinator

- The National Neuro Advisory Group to be properly resourced in order to provide sustainable national leadership and deliver long term change
- A comprehensive workforce plan to be developed to meet existing and future demand for neurological services
- The needs of people with neurological conditions to be taken into account when planning mental health services

What are the benefits of joining the Neurological Alliance?

- Hearing the very latest updates on policy developments through our member-only newsletters, webinars and meetings
- Having the opportunity to influence public policy through attending meetings with policy makers and contributing to consultations.
- Receiving a detailed report on findings of the patient experience survey for the condition(s) your organisation represents
- Strengthening the voice of the people you represent and stretching your own resources further through working on shared issues such as mental health, rehabilitation, early diagnosis, access to specialists and rare disease
- Promoting your events, publications and news through our newsletter, website, social media and policy networks.
- Networking with your peers in the neurological sector. We regularly bring together member chief executives and policy-leads at member meetings and subgroups.

“Like many members of The Neurological Alliance, my organisation is small. We are dedicated to helping people with a rare neurological condition but without the Alliance would struggle to have a voice in the policy process. The Alliance make it easy for me to ensure the views of the people I represent are included in policy making.” *Caroline Morrice, Chief Executive, Guillain-Barré & Associated Inflammatory Neuropathies (GAIN)*

“For us, The Neurological Alliance acts as an extension of our in-house policy function, enabling us to stretch our policy resource further. Policy makers often prefer to work with one overarching organisation rather than many different stakeholders. Working in coalition strengthens the voice of our respective organisations when speaking independently and collectively.” *Duncan Lugton, Policy and Public Affairs Manager, Sue Ryder*

Membership types

We have three different membership types:

Member

Full membership is open to national voluntary (non-statutory, non-profit) organisations who represent patients, service users, families and carers, who in addition to the full benefits of membership, will have a right to vote at the Annual General Meeting (AGM), have the right to nominate a trustee and an opportunity to influence our strategic direction. Subscriptions are income assessed. Full affiliate membership is open to regional neurological alliances operating on a non-statutory, non-profit basis. Affiliate members will pay a subscription rate which is not income assessed.

Associate

Associate status is open to non-profit professional associations and statutory authorities who will play an active part in the Alliance but do not have the right to nominate a trustee or vote at the AGM. Subscriptions are income assessed. Regional associations of neurological organisations are also associates. They are staff led groups and will pay a subscription rate which is not income assessed.

Corporate supporters

Corporate supporter status is open to for-profit organisations, who cannot vote at the AGM or nominate a trustee, and cannot influence our policy direction, but are able to participate in Alliance events and keep up to date with policy and news affecting people with a neurological condition. Our relationship policy is on our website and ensures that in seeking and securing non-member funding the Alliance has a clearly understood way of working, underpinned by high ethical principles.

Subscription fees 2018-19

The 2018–19 subscription fees, set by our trustees, are as follows:

Income (£)	Members	Associates
Regional group	£1	£1
Under 100,000	£105	£105
100k-250k	£216	£216
250k-500k	£496	£496
500k-1 million	£722	£722
1-2 million	£1,112	£1,112
2-5 million	£2,605	£1,440
5-10 million	£5,583	£2,879
10-20 million	£11,164	£5,888
20 million plus	£16,374	

For more information or to join please contact us

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