

Our response to the Government's call for evidence to develop a 10-year plan to improve mental health for everyone across the UK

July 2022

The Neurological Alliance is a coalition of more than 80 organisations working together to transform quality of life for people affected by neurological conditions in England.

A neurological condition is any condition that affects the brain, spine and/or nerves. There are over 600 known neurological conditions ranging from comparatively common conditions such as migraine and epilepsy to rare conditions such as the ataxias and Guillain-Barre syndrome. 1 in 6 of us live with a neurological condition, and many more are impacted as families, friends and carers.

Neurological conditions can be sudden, fluctuating, progressive and/or lifelong and have a range of different causes including genetic factors, traumatic injury and infection, although the causes of some neurological conditions are still not well understood. Some conditions are terminal and/or life-threatening.

www.neural.org.uk

As well as the mental health impact of being diagnosed with a long-term condition, there is a complex and comparatively poorly understood interplay between the physical and psychiatric, emotional and cognitive impacts of many neurological conditions.

People with neurological conditions are more likely to experience comorbid mental health conditions and poor mental wellbeing compared to the general population. This is evidenced in relation to [epilepsy](#), [Parkinson's](#), and [rare conditions](#) - including rare neurological conditions - amongst many others including traumatic and acquired brain injury. Even within specific conditions, variations of symptoms and people's needs are not well understood. MS Society have found that people with progressive forms of multiple sclerosis (MS) were less likely to get the emotional support they needed compared to people with relapsing forms of MS - 58% vs 44% (My MS My Needs; 2019). People with progressive forms of MS experience progression of their symptoms, some of which may be invisible, suggesting people with less visible symptoms are less likely to access the mental health and wellbeing support they need when they ask for it.

People with neurological conditions are also at increased risk of isolation and loneliness. Accessible community groups and meaningful participation in joint activities can help some enormously, particularly if supported and regularly reviewed by a network of community rehabilitation services.

As will become clear in our responses to other questions in this consultation – neurological conditions do not just impact those with the diagnosis but also parents, guardians, family, friends, informal carers and wider support networks.

Finding out someone close to you has a neurological condition, particularly a life limiting condition, can change a person's life forever. This is particularly true for those who do not

have a wider support network in place. Providing mental health and wellbeing support for parents and/or carers for children with neurological conditions, particularly life limiting conditions such as spinal muscular atrophy (SMA), at diagnosis is vital. This should include well researched, up to date materials detailing options for mental health support including charities, peer support groups, hospices and NHS options, with realistic time frames.

How can we help people to improve their own wellbeing?

Our recent "Together for the 1 in 6" policy reports, informed by the experiences of over 8,500 people with neurological conditions, highlight the significant impact neurological conditions have on mental wellbeing. In England, 89% of children and young people and 82% of adult respondents reported that their neurological condition(s) made their mental wellbeing worse. When asked whether they had experienced a change in their mental health needs due to COVID-19, 44% of adults and 63% of children and young people reported the pandemic had made their mental health worse. For many, the pandemic has acted to worsen their mental health, a finding which is supported by SUDEP Action's Lives Cut Short report which highlighted that 87% of people with epilepsy spoken to as part of their research cited that the pandemic had caused them increased mental strain.

People with neurological conditions report that the combination of a neurological condition and mental health condition can bring them to crisis point. In some cases, not recognising and treating a co-morbid mental health condition can lead to inpatient admissions, early and unnecessary residential care, and in extreme cases homelessness, offending, imprisonment and suicide.

Despite the significant impact of neurological conditions on mental wellbeing, 52% of children and young people and 62% of adults reported not being asked about their mental wellbeing by a health or social care professional in the last three years.

Being asked about your mental wellbeing by a health or social care professional is often a vital first step towards being referred or directed to the support required to meet a person's needs. A lack of early detection, treatment and intervention for emotional, cognitive and mental health needs associated with neurological conditions not only lowers health outcomes, but it can also reduce quality of life and increase disability. People with neurological conditions and a learning disability can be more vulnerable to not having their mental health or their neurological condition well understood by the teams involved in their care. In children, it can often be a factor in lower educational attainment.

There is also a need to address the specific and urgent challenge experienced by some people with neurological conditions including Huntington's disease and Parkinson's. As highlighted in the response to this consultation from the Huntington's Disease Association:

"many [people with Huntington's] are unable to access community mental health support, due to services refusing to accept referrals for patients. This occurs despite the fact that people can have severe and prominent symptoms of mental ill-health. The HDA stresses that this barrier to appropriate support must be addressed urgently, to ensure people who have Huntington's disease can access mental health support on an equal basis to others."

Therefore, we urge Government, NHS England and NHS Improvement to ensure:

www.neural.org.uk

14.NHS Trusts review their local Mental Health Commissioning Policies, to ensure that these facilitate access to specialist mental health support for everyone with a neurological condition, including children and young people.

15.NHS Trust contracts plan for conversations about mental wellbeing in consultations, with referrals and signposting where necessary. This includes timely access to neuropsychology and neuropsychiatry services where necessary.

16.ICBs and NHS Trusts map current mental health and wellbeing support available in their area for people affected by neurological conditions. Appropriate triage, referral routes and a matched care approach must be available in every area, ensuring people can access support according to their needs.

It is important to note that those with terminal neurological conditions, or indeed any terminal condition, should have immediate and ongoing access to comprehensive mental health support.

In addition, and as outlined in our 'Mental Health consensus statement', we urge Government to work with health bodies, healthcare professionals, the voluntary sector and people affected by neurological conditions to ensure that every person with a neurological condition and/or their parent and carer:

1. Has their mental, emotional and cognitive wellbeing effectively and systematically screened to pick up on their changing needs and functioning, from predictive testing, first symptoms and diagnosis, through to the end of their life. They should

then be signposted to support/referred for treatment. Screening must pick up when they may present a risk to themselves, with safeguarding measures taken accordingly.

2. Has access to mental, cognitive and emotional health support and treatment, as needed, which addresses both their needs arising from their neurological condition(s), as well as taking into account their individual needs and preferences. This includes creative support for people who refuse direct mental health input due to lack of capacity.
3. Experience mental, cognitive and emotional healthcare and treatment that is systematically tailored to their individual communication needs, including needs arising as a result of a neurological/ neurodevelopmental condition.
4. Have access to specialised neuropsychological and neuropsychiatric assessment, care and treatment, as well as local mental health services, as needed.
5. Never be denied access to mental health services on the basis of having an organic brain condition, unless they can be referred on to more suitable service.
6. Experience integrated, joined up care from their physical and mental health teams, that takes account of all the care and treatment they are undergoing.
7. Have a regularly updated care plan that encompasses: their goals for their care and treatment, how these are being addressed through their physical and mental health care and treatments, self-management actions, and key contacts in case of relapse/questions.
8. Have access to good quality information and support tailored to their condition and their communication needs, to prevent unnecessary anxiety and enable them to manage all aspects of their condition, including their mental, cognitive and emotional health.

9. Be assured their carers' and family members' mental health needs will be assessed and supported.
10. Be provided with psychoeducation around their condition, including what they can expect, and when to seek additional help.

Finally, we urge Government to address the significant gaps in the mental health and wellbeing workforce in the forthcoming '15 year workforce strategy' - there are currently just 64 consultant neuropsychiatrists in the UK, with up to two year waits for inpatient support. It is estimated that just 3.61 UK psychologists per 100,000 population undertake working sessions in neuropsychology ([here](#)). Improving outcomes for people affected by neurological conditions and their families is contingent on developing and supporting a health and care workforce – including general and specialist mental health workforce – fit for the future.

How can we support different sectors within local areas to work together, and with people within their local communities, to improve the populations wellbeing?

This includes a wide range of public services, including education settings, social care, the NHS, voluntary sectors, housing associations and businesses

Ensuring integrated planning and commissioning of services is absolutely essential to improving the mental health and wellbeing of people affected by neurological conditions. Integrated Care Boards and Integrated Care Partnerships are a helpful step forward in

this respect, by bringing together the different sectors within local areas to work together.

Appropriate support needs to be available for people with neurological conditions and voluntary sector organisations to engage in these structures. This includes ensuring adequate reimbursement for involvement, ensuring role opportunities, materials and meetings are truly accessible for all, and that appropriate learning and development is in place.

Currently however, very few ICS regions prioritise the improvement of services for people affected by neurological conditions, despite the fact that many areas of services (e.g. neurology, neurophysiology, specialised rehabilitation, neuropsychiatry and neurosurgery) will now be commissioned at an ICS level. In parallel, the ability of voluntary sector organisations to engage effectively with 42 different ICS is limited – this is particularly true of smaller national organisations, which typically represent more rare neurological conditions. Their ability therefore to tap into national insight and expertise is critical.

We also urge ICS bodies to appoint patient and clinical leaders for services for people affected by neurological conditions, so that improved and integrated support can be developed.

With the right information on the condition and problems people might experience (e.g. cognition, adjustment, managing symptoms), and education and advice on how to manage such issues, depression and anxiety are less likely to emerge. The voluntary sector provides a wealth of information on neurological conditions, including cognitive, emotional and mental health aspects of conditions. They provide a listening ear when

people need it most, for example through national helplines and local peer to peer support groups. It is essential such information is provided at the time of diagnosis but also at later stages to help individuals to adapt to changes. Patient and carer testimony along with reviews by the Health Foundation and National Voices have found that alongside provision of information and screening, both peer support and supported self-management programmes can contribute to improved wellbeing and enhance confidence in self-care, self-efficacy, and levels of activation.

Ensuring the voluntary sector is actively involved in the development, planning and delivery of services is vital to improving the nation's mental health and wellbeing. Many patient organisations including Alliance members identify people struggling with their mental health due to their neurological condition through services and helplines. At present many such organisations are unable to signpost people to local support due to a sparsity of local mental health and wellbeing support and a lack of local pathways. A more joined up approach to referrals and signposting including improved links with patient organisations who are in direct contact with people with neurological conditions could improve early identification and timely access to appropriate support.

Finally, we urge Government to ensure a population health management approach is in place across England. This would be based upon good quality and integrated data, from which systems can plan appropriate services for their region, as well as foster collaboration between sectors. Importantly, data should be gathered from a varied range of sources (for example, patient experience, service outcome and activities) to allow for the greatest insight possible to be derived.

What is the most important thing we need to address in order to reduce the number of people that are more likely to experience mental ill-health?

- Workforce (across specialised mental health services, across neuroscience more broadly, improving expertise of care workers/GPs/'non-neuro' specialists)
- Removing commissioning barriers to mental health services for people affected by neurological conditions
- Improving the provision of integrated care and services to enable early identification and intervention of at risk populations.

Ensuring the necessary workforce is in place across specialised mental health services and across neuroscience more broadly, including all parts of multi-disciplinary teams.

Both numbers and geographic spread of specialists must be addressed. Improving awareness and expertise around neurological conditions for social care workers, GPs and other non-neurological specialists involved with the care of people with neurological conditions.

Removing aforementioned commissioning barriers to mental health services for people affected by neurological conditions.

Improving the provision of integrated care and services to enable early identification and intervention of at risk populations including people with neurological conditions, at diagnosis wherever possible.

Please share your ideas of how employers can support and protect the mental health of their employees

Having a neurological condition can make getting and keeping a job or staying in school more challenging. The discussion around employment should be considered alongside financial wellbeing more broadly, particularly with respect to the challenges many people face with accessing welfare support.

Employer awareness of the previously highlighted complex interplay between the physical and psychiatric, emotional and cognitive impacts of many neurological conditions would also benefit employees with a neurological condition. Even basic awareness of the relationship between neurological conditions and mental health conditions could make a significant difference, alongside support as necessary.

In our survey of people affected by neurological conditions, we asked adult respondents whether they agreed or disagreed with the statement "I have stopped working because of my neurological condition symptoms". 57% (n=2,142) agreed with the statement, 9% (n=332) neither agreed nor disagreed while 34% (n=1,263) disagreed. Some people also mentioned having to reduce their working hours to better manage their symptoms.

Employers have a legal duty to make reasonable adjustments to ensure people with disabilities can continue to access things including employment and education. Simple changes such as allowing someone to work from home can make a real difference to a person's quality of life. MS Society's 2022 report *Employment without barriers* highlighted the emotional impacts for people who decide to leave work because they did not get the right support from their employer or the Government to remain in their job

(MS Society, 2022). To help people find, move into, stay in and move out of work, the Government must do more. Employers must be supported to take a more holistic approach in supporting people with neurological conditions to keep working if they want to. This includes flexibility around working hours, practices and addressing employers' concerns around costs and difficulties of putting in place adjustments for people with mental or physical health needs.

We asked respondents to our recent patient experience survey whether they had been discriminated against at work due to attitudes towards their neurological condition. 33% (n=1,057) of adult respondents indicated they had faced this kind of discrimination, 16% (n=519) neither agreed nor disagreed while 50% (n=1,606) indicated they had not experienced discrimination of this type. It is concerning that in 2022, one third of respondents to the above question agreed that they had experienced discrimination at work due to attitudes towards their condition. Several respondents noted that they were concerned about disclosing their neurological condition when applying for jobs because of previous negative experiences with not hearing back from employers when they disclosed their condition. This must change.

Government and employers should protect the mental health of employees affected by a neurological condition by:

- Employers ensuring they meet their responsibilities under the Equality Act 2010, particularly with regard to reasonable adjustments.
- Government establishing a statutory right to paid carers leave. As a first step, we would urge Government to support the Private Members Bill tabled by Wendy Chamberlain MP to introduce right of up to 10 days unpaid leave for unpaid carers.

- Improving the provision of employment retention support, for example through the Work and Health Programme and Disability Confident.
- Adopting policies and practices which promote inclusion and opportunity for disabled employees, and deal quickly and effectively with instances of bullying, harassment or discrimination in the workplace. Wherever possible, employers should adopt a disability absence policy.
- Ensuring that recruitment processes are set up in such a way as to encourage disabled people to apply for jobs, and to enable them to participate fully in the recruitment process.
- Including adequate disability awareness training, which covers neurological conditions as a part of a normal induction programme for their employees. Managing staff with disabilities should also be included as part of line manager training.
- Establishing best practice for transition out of work. This includes appropriate career advice for those who are no longer able to continue working in the field in which they have qualifications or experience due to health problems or disability
- Improving and expanding the support available under the Access to Work service, paying particular attention to ensuring timely delivery and customer satisfaction.
- Reviewing levels of public awareness of statutory sources of support including the Health and Work Programme, Fit for Work, Access to Work and employment legal advice helplines and take any necessary action to ensure that people and organisations that need to use these services know about them, and how to access them.

Mental health and wellbeing support for health and social care professionals is also vital. Providers – public, private and voluntary sector – must ensure that such support is available.

What more can the NHS do to help groups who face additional barriers to accessing support for their mental health?

People with neurological conditions can face additional barriers to accessing support due to prohibitive commissioning policies, a lack of health and care professionals with appropriate expertise in their area, short term support for longer term mental health needs, and a shortage of specialised mental health professionals more broadly.

For those with rare neurological conditions such as Neurofibromatosis type 1 (Nf1) a lack of expertise nationwide is a huge problem - it is important that mental health professionals are aware of and educated in these conditions in order to deliver effective care and support.

Many patient organisations including Alliance members identify people struggling with their mental health due to their neurological condition through services and helplines. At present many such patient organisations are unable to signpost or refer people to local support due to a sparsity of local mental health and wellbeing support and a lack of local pathways. A more joined up approach to referrals and signposting including improved links with patient organisations who are in direct contact with people with neurological conditions could improve early identification and timely access to appropriate support.

Regarding specific suggestions to address additional barriers facing people accessing mental health support, Government should ensure every person with a neurological condition:

- Has their mental, emotional and cognitive wellbeing effectively and systematically screened to pick up on their changing needs and functioning, from predictive testing, first symptoms and diagnosis, through to the end of their life. They should then be signposted to support/referred for treatment. Screening must pick up when they may present a risk to themselves, with safeguarding measures taken accordingly.
- Has access to mental, cognitive and emotional health support and treatment, as needed, which addresses both their needs arising from their neurological condition(s), as well as taking into account their individual needs and preferences. This includes creative support for people who refuse direct mental health input due to lack of capacity.
- Experience mental, cognitive and emotional healthcare and treatment that is systematically tailored to their individual communication needs, including needs arising as a result of a neurological/ neurodevelopmental condition. E.g. People with aphasia are at particular risk of mood disturbance but can struggle to access mental health support due to communication difficulties. Ensuring that primary care psychology services and mental health services have designated access to speech & language therapy/ therapists (SLT) who can offer joint sessions could address this.
- Have access to specialised neuropsychological and neuropsychiatric assessment, care and treatment, as well as local mental health services, as needed.
- Never be denied access to mental health services on the basis of having an organic brain condition, unless they can be referred on to more suitable service.

- Experience integrated, joined up care from their physical and mental health teams, that takes account of all the care and treatment they are undergoing. Considering the increased prevalence of mental health conditions in people with neurological conditions, there is a strong case for concurrent screening at diagnosis.
- Have a regularly updated care plan developed and delivered with input and advice from a multidisciplinary team wherever possible that encompasses: their goals for their care and treatment, how these are being addressed through their physical and mental health care and treatments, self-management actions, and key contacts in case of relapse/questions.
- Have access to good quality information and support tailored to their condition and their communication needs, to prevent unnecessary anxiety and enable them to manage all aspects of their condition, including their mental, cognitive and emotional health.
- Be assured their carers' and family members' mental health needs will be assessed and supported.
- Be provided with psychoeducation around their condition, including what they can expect, and when to seek additional help.

What needs to happen to ensure the best care and treatment is more widely available within the NHS for groups who report worse experiences and outcomes from NHS mental health services?

Alongside suggestions and recommendations made in response to other questions in this call for evidence, we would encourage services to deliver on the following:

- “Joined up”, holistic care with a focus on access to multi-disciplinary teams wherever possible, including mental health professionals, to ensure early and appropriate interventions and referrals for people with neurological conditions
- Adopting a “matched care” approach to mental health support and referrals for people with neurological conditions – ensuring people are referred to the right services as early as possible, preventing people from being required to access inappropriate or ineffective services in order to gain access to the most suitable type of support for them
- Addressing workforce challenges facing the specialty including the numbers and geographical spread of the specialist mental health workforce – neuropsychologists and neuropsychiatrists – ensuring that specialist mental health services and support is equitable and available to all, irrespective of postcode
- Ensuring that clinicians have adequate time to ask people about their mental health and wellbeing and refer or direct to support as appropriate

What is the NHS currently doing well and should continue doing, in order to support people struggling with their mental health?

Of the respondents to My Neuro Survey in England who were referred or directed to support for their mental wellbeing, 61% (n=596) noted that it made them feel better or

www.neural.org.uk

more positive. 39% (n=378) reported that the support they were referred or directed to did not make them feel better or more positive. It's clear that most respondents who were referred or directed to support for their mental wellbeing found it to have a positive impact. Learning from areas which have good referral pathways for mental health support is therefore vital.

In addition, people with neurological conditions told us about the value of their health and care professional 'checking in' on their mental wellbeing. As one person told us:

"Every time I have attended the clinic I have been dealt with in an extremely lovely manner. I have mostly seen Dr [anonymous], and she has been fantastic. Whereas she has not specifically asked me about my mental health, she has always asked me how I am and I feel she truly cares. I prefer this approach rather than asking me outright about my mental health."

Liaison psychiatry services in hospitals are a valuable and important resource for identifying and supporting the mental health needs of people with physical health conditions. The introduction of primary care psychology services has also been of help to many but are increasingly overwhelmed by demand.

Paediatric intensive care wards are beginning to invest in family liaison nurses who have capacity to support parents and carers. A pharmaceutical company have trained OneGene Nurses who link with families who have had the gene replacement therapy. As noted by a parent of a child with SMA;

'GOSH also put us in touch with OneGene nurses who have been amazing and I honestly can't fault them...they have been our biggest support since 2 weeks after diagnosis, she

is always on the phone if needed and it's never hard to get hold of her. They have been my go to for everything and I don't know what I would have done without them'

This is a welcome initiative but is currently funded by a pharmaceutical company so only available to those who have accessed a specific treatment, within the hospitals that have signed up to the scheme. These approaches should be replicated within the NHS with priority for these services given to parents and carers without a personal support network.

Providing the right training and support for healthcare professionals to ask about mental health and wellbeing is critical, as it opens opportunities for appropriate signposting and referral. It is also the case that improved training and awareness amongst the general mental health workforce of the complex interplay between the physical and psychiatric, emotional and cognitive impacts of many neurological conditions would also be beneficial. Ongoing work to include neurological conditions in the IAPT curriculum is a welcome step forward here.

Some stroke services acknowledge the need for a matched care approach to psychological support – ensuring timely access to support and intervention matched according to the specific complexity of need. This is an approach that should be expanded to other neurological conditions, particularly more complex conditions, to ensure people are not expected to engage with inappropriate or ineffective support or services through a matched care approach.

Please suggest priorities for future research, innovation and data improvements in relation to people who have worse experience in NHS services, and or often do not experience good outcomes.

We urge Government to ensure a population health management approach is in place across England. This should be based upon good quality and integrated data, from which systems can plan appropriate services for their region, as well as foster collaboration between sectors. Importantly, data should be gathered from a varied range of sources (for example, patient experience, service outcome and activities) to allow for the greatest insight possible to be derived.

We also urge Government to ensure commitments to research into the causes, cures and treatments for neurological conditions, such as recent commitments to fund £375 million into neurodegenerative research are taken forward at pace. Researchers should not face excessive bureaucracy or red tape in attempting to access such funding.

Finally, we urge Government to take heed of the Priority Setting Partnerships undertaken on a wide variety of neurological conditions, including epilepsy, autism and MS, which set out priorities for research which could greatly improve quality of life for people affected by neurological conditions.

We need your support and ideas to develop a comprehensive plan that will help set and achieve our vision for mental health in a decade's time. You do not need to answer every question but can choose those that relate to your experience or expertise

What do you think are the most important issues that a new, 10-year national mental health plan needs to address?

www.neural.org.uk

1. Early intervention and service access
2. Treatment quality and safety
3. Quality of life for those living with mental health conditions

Please explain your choices

All issues highlighted in the list necessitate address as part of this strategy and other public policy interventions to improve mental health support and services, including for people with neurological conditions, and ultimately to improve outcomes and associated quality of life.

However it is our opinion that, taken together, addressing the three issues we have chosen - alongside increased multi-disciplinary working, integrated and holistic care and upskilling health care workforces – will provide the tools for the mental health system to effectively tackle all the issues listed over time.

There is also a need for more comprehensive training of health and social care professionals to identify potential mental health and wellbeing concerns wherever care is being accessed.

What 'values' or 'principles' should underpin the plan as a whole?

Equity – everybody should be able to access the right support for them, no matter who they are, where they live or their ability to pay.

Ambition – the 10-year strategy is an important commitment and a wonderful opportunity for the Government to show it is listening to people affected by neurological conditions. This must be backed by the right ambition and funding.

Cohesion – the neurological community has a wide range of expertise, support and passion to ensure that every person with a neurological condition is able to access the right support for them – we urge Government to engage and support this community as part of the forthcoming strategy in order to achieve our collective aim of improving the nations mental health and wellbeing.

-END-