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ALLIANCE**

My Neuro Survey

Wales Report

Understanding the demand for and impact of services for people living with neurological conditions in Wales

June 2022



Foreword

Prior to COVID-19, the Cross Party Group on Neurological Conditions inquiry on the impact of the Neurological Conditions Delivery Plan (NDCP) heard that people with neurological conditions had experienced poor access to treatments, services and support. [1]

In spite of the NDCP being in place since 2014, in responding to the report, the Welsh Government acknowledged;

"We need to have a better understanding of the demand for and impact of services for people with neurological conditions."

To this end, the Wales Neurological Alliance (WNA) has for the first time, collaborated with the Neurological Alliances of Scotland, England and Northern Ireland to gather evidence from people living with neurological conditions across the UK.

The My Neuro Survey provides an important insight into whether people living with neurological conditions in each of our nations are getting the treatment and support they need.

Over 8,500 people shared their experiences in the survey, 503 from Wales. We are indebted to everyone who shared their experience with us.

The findings from the neurological community in Wales are presented in this report alongside the Neurological Conditions Implementation Group's (NCIG) Position Statement for Neurological Services across NHS Wales report of March 2022.

We hope that this report will go some way in closing the gaps in the Welsh Government's understanding of the demand for and impact of services for people with neurological conditions.

People living with neurological conditions in Wales continue to report substantial barriers to accessing the treatment, services and support that they need from health and social care services.

Whilst we are cognisant that the pandemic has brought with it unprecedented demand on all health and social services, two years hence, the situation for people living with neurological conditions in Wales is now at crisis point and they feel abandoned.

Coupled with this is the uncertainty about what resources are going to be allocated to the Neurological Conditions Implementation Group in Wales after the current funding ends in April 2023.

Urgent action is now required by those who plan, commission and deliver our services to address the shortcomings and ensure that people living with neurological conditions are not left behind in the post COVID recovery planning.



Ana Palazon
Chair Wales Neurological Alliance

About neurological conditions in Wales

There are more than 600 different types of neurological conditions, ranging from the very rare (affecting less than 1 in 2000 people), to more prevalent conditions such as dementia, parkinson's, multiple sclerosis, epilepsy, dystonia and motor neuron disease. [ii]

In Wales, approximately 100,000 people are living with a neurological condition that has a significant impact on their lives.

Neurological conditions are diverse in their underlying causes and risk factors as well as in their associated health outcomes. They are the leading group cause globally of disability-adjusted life years (DALYs) 11.6% and the second leading cause of deaths in the world at 16.5%. [iii]

"Even within a single diagnosis there is not always one common journey for the people living with it. Some people are able to self-manage their condition with appropriate education and support from one or two health care professionals.

While others will need input from a wide variety of specialist healthcare professionals from within the neurology speciality but also across others such as respiratory, urology, oncology, genetics, {care of older people} and end of life care. The timeframe from symptom onset to end of life will vary." (NCIG, 2022) [iv]

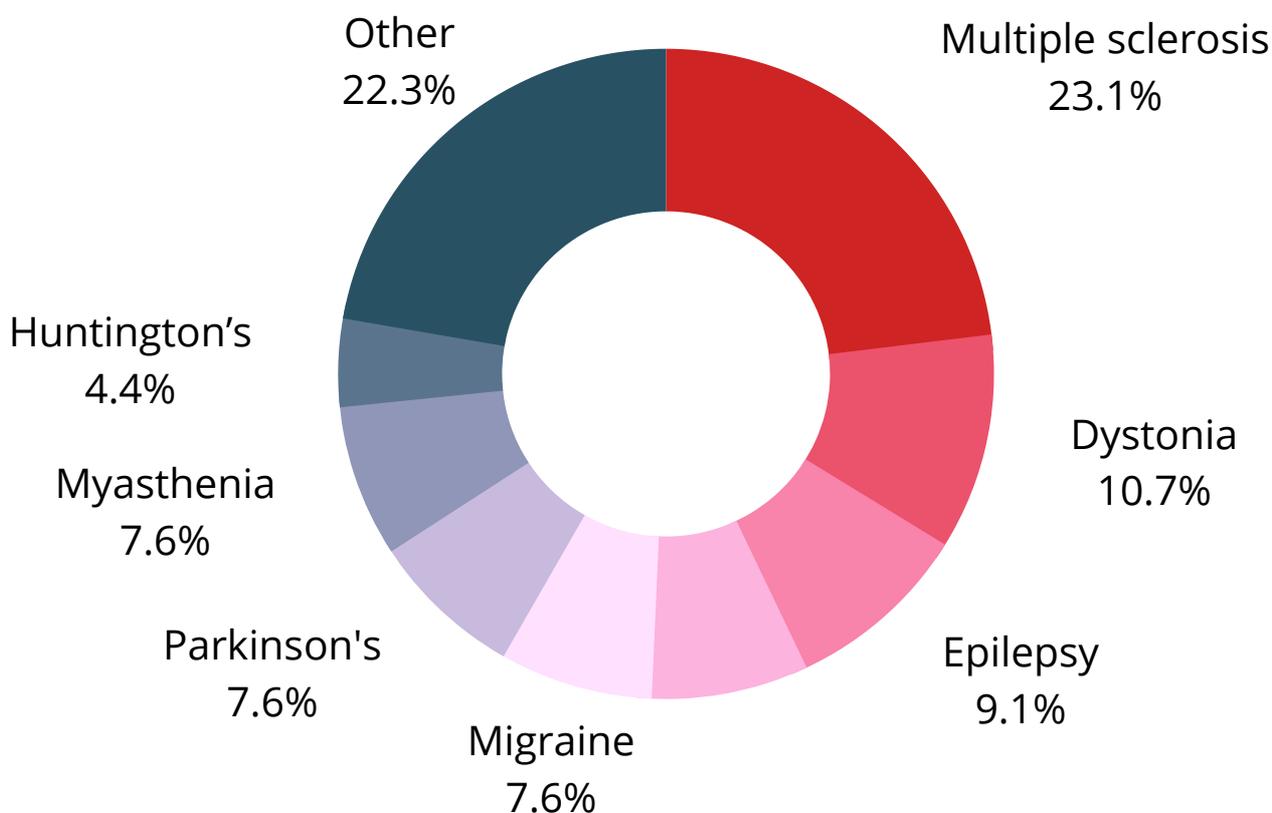
About the My Neuro Survey

8,510 people living with or affected by neurological conditions across the UK completed the My Neuro Survey, 503 from Wales.

Of those who completed the questionnaire, 93% (n=462) lived with a neurological condition; 7% were carers, friends or family members of a person with a neurological condition.

59% (n=295) of respondents were diagnosed within the past ten years, while 37% (n=184) were diagnosed longer than ten years ago.

The most reported conditions were;



Key themes

This report is an overview of the experiences shared with us in the My Neuro Survey.

There were several themes emerging from the My Neuro Survey, these include;

**Delays to
treatments and care**

**Crisis in mental
health support**

**Lack of information
and support**

We present these findings in conjunction with the latest report by the Neurological Conditions Implementation Group (NCIG) which outlines the significant challenges to driving measurable improvements in services for people living with neurological conditions.

Delays to treatments and care

**More than half experience
delays to routine specialist
appointments**

When asked if they had experienced delays to their care or treatments for their neurological condition in the past 12 months; 27% had experienced delays with a first appointment with a neurologist and 51% with a routine appointment.

"Because of COVID, I have not had access to necessary appointments with the neurologist. My condition has deteriorated and he has not seen me in person since my decline."(Respondent)

"Dad had MRI in October 2021. We got the report via post, but still awaiting follow up neurology appointment." (Respondent)

"Most of the time I feel like a neurological outcast" (Respondent)

Accessing a specialist nurse was also challenging over the past 12 months; with 22% reporting problems with a first appointment and 43% with a routine appointment.

"I have not seen a neurologist for at least 7-8 years but would see my nurse specialist annually. However my last face to face appointment was cancelled and I received a telephone consultation with the occupational therapist instead, this was in March 2020, I have not seen my specialist nurse for over three years."
(Respondent)

"People living with neurological conditions need rapid access to diagnostics and must be able to access support from a wide range of health, social care and third sector services if their symptoms change, to optimise their quality of life and wellbeing." (NCIG, 2022)

20% of respondents last had an appointment with a specialist more than 18 months ago, whilst 6% had never seen a specialist at all.

Delays to care and treatments in the past 12 months in Wales



Access to treatments and services helps people living with neurological conditions manage their condition, and to identify early signs of complications and put in place prevention and treatment strategies to avoid unscheduled hospital admissions.



“Without private health insurance my husband would not have seen a neurologist for over a year. His breathing deteriorated. He has now been diagnosed with motor neurone disease.” (Respondent)

“I am 3 years overdue with my ophthalmology appointments, neuro can't act on anything as no feedback from ophthalmology.” (Respondent)

The New Treatment Fund was launched in January 2017 and according to the Welsh Government, since then, it has cut the average time it takes for newly recommended medicines to become available to patients in Wales by 85%, from 90 to just 13 days. [v]

However, for some treatments for neurological conditions like MS, this is not the case. There are medicines which had National Institute for Clinical Excellence (NICE)/ All Wales Medicines Strategy Group (AWMSG) approval prior to the pandemic which are yet to be prescribed to everyone who is eligible for them;

“I should have accessed fampridine but sadly this has been delayed by over 12 months.” (Respondent)

“Tested Jan 2021, awaiting Ocrevus drip from the Walton Centre Liverpool.” (Respondent)

Crisis in mental health support



4 in 10 people report that their mental health needs are not being met at all

A diagnosis of a neurological condition can have a significant impact on someone's mental health and emotional wellbeing. A diagnosis can present in many different ways and can raise all sorts of thoughts and feelings around a person's future and how their condition will play a part in it.

Dealing with the unpredictability of the neurological condition can be hard and can often take its toll on a person's emotions. It can take time to adjust to a life with it.

Too many people are not being asked about, signposted or referred to support for their mental wellbeing.

Psychological well-being is a long-standing issue in the care of people living with a neurological condition.

Whilst we appreciate that the NHS across Wales remains in extremely challenging times, we must also acknowledge that for people living with neurological conditions, the pandemic has served only to further exacerbate both the physical and psychological problems they experience.

43%

Mental health has worsened during the pandemic

30%

Neurological condition makes their mental wellbeing worse

62%

Not asked about their mental wellbeing in 3 years

"Mental health services are non-existent once progressing above primary care."
(Respondent)



There are significant unmet mental health needs among people living with neurological conditions in Wales; 45% (n=166) did not feel that their mental well-being needs were being met.

63% (n=143) said that they would find counselling helpful, but it had not been offered. For others who reached out, support has not been forthcoming or accessible for them to use,

“I asked my specialist for counselling back in January 2021. I still haven’t had an appointment. My marriage has since broken down.” (Respondent)

“Counselling care was offered by telephone but I have severe speech problems!” (Respondent)

General mental health practitioners are lacking in specialist knowledge about the symptoms associated with neurological conditions especially the complex cognitive problems that many experience.

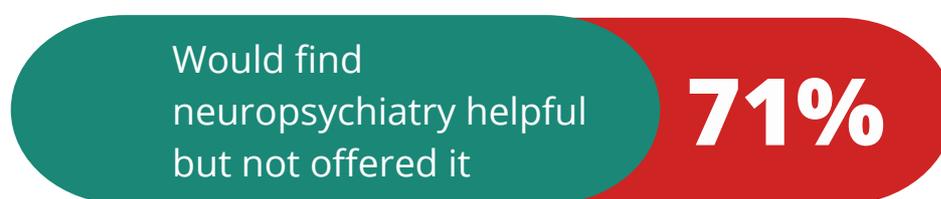
This lack of knowledge means that these practitioners are unable to adjust their intervention to meet the individual needs of people living with a neurological condition and their families.

“A biopsychosocial approach is needed to minimise the impact of a neurological condition on an individual and maximise their health and well-being. This includes timely access to appropriate psychological and psychiatric assessment, treatment, and support.” (NCIG, 2022)

Many people living with neurological conditions need to see a psychologist with expertise in neurological conditions who is embedded in the Multi-Disciplinary Team (MDT) to develop specialist knowledge of the condition.

The biopsychosocial model of health recognises important interactions among biological, psychological and social factors in illness, including those relating to illness management, which contribute to the experience of those diagnosed with a neurological condition.

There is limited psychology provision but for only some people living with neurological conditions in Wales and there are lengthy waiting times where services do exist. For some Local Health Boards (LHBs) who do have specialist neuro-psychology provision, it is restricted to younger people 'with vocational needs'.



"I am unable to access Neuropsychiatry or Neuropsychology as I am too far post injury. I survived a Serious Traumatic Brain Injury 41 years ago so I am finally under the care of a Community Mental Health Team that have no knowledge or experience in "Neuro" Impairments. "Neuro" conditions are rarely temporary and usually For Life! Why not treated For Life?"
(Respondent)

Lack of information and support

"A web address was written on a piece of paper and given to me along with my diagnosis." (Respondent)

The diagnosis of a neurological condition is life changing and for some will impact on their ability to live independently, pursue personal goals, fulfil their roles as a spouse or parent or engage in meaningful occupation. For others it can impact on basic skills such as eating, talking, thinking, breathing, and walking.

"People living with a neurological conditions require the knowledge and skills to be able to manage their symptoms." (NCIG, 2022)

Receiving a diagnosis can mean you have a million questions, yet 35% respondents reported receiving no written information when diagnosed.

When asked if they understood the explanation given to them at the time of their diagnosis, only 37% said they understood all of the information and 17% said they received no explanation at all.

"I feel somewhat alone." (Respondent)

"Seen once by neurologist, diagnosed, told nothing can be done, pain management is all I can do. Released me. No other anything offered except a webpage to look at. Feel quite abandoned and hopeless. Mental health has plummeted." (Respondent)

"Implementing robust, integrated, timely, value-based support and services for people living with neurological conditions is a considerable challenge." (NCIG, 2022)

Delivering services for people with neurological conditions is complex and where they are delivered from can impact significantly on the quality of service people receive;

“Been seen in two different health boards has meant there has been a lack of communication between the two and it has meant my treatment has been delayed.” (Respondent)

“Poor neuro services in {my} health board, we borrow one from another service.” (Respondent)

“As my neuro is based in England but I live in North Wales, I notice a large disparity between the care and services offered. It is a struggle to access services that may be useful.” (Respondent)

“I have cervical dystonia and am treated by botulism injections, my last neurologist was excellent and had a machine that he directed at the muscles and gave the injections, they were much better. His contract ended and he’s gone to Canada but he paid for his own machine and took it with him. Why aren’t hospitals able to offer this service and not expect the consultant to buy his own equipment?” (Respondent)

“Within health boards services that support people with neurological conditions are often distributed over several different directorates and clinical service groups. This can make it difficult to map resources and workforce to identify gaps and solutions and evaluate the impact of service change.” (NCIG, 2022)

Throughout the pandemic, we have seen more use of digital health, like virtual consultations and online patient information. When asked about their experience of telephone or video conference appointments, 51% found them helpful. However, 40% said they would prefer in person appointments.

“Would prefer to be able to see a doctor face to face rather than phone/video calls. Saw my neurologist at hospital and have seen my Parkinson’s nurse and they are always very helpful and understanding. However, to see my doctor proves to be much more difficult which is quite upsetting and worrying when you need to be seen.” (Respondent)

“I have been receiving occipital nerve blocker injections for pain management, and have really been struggling to get appointments to have these. I am profoundly deaf and kept receiving letters in the post for telephone appointments. I am now told it is sorted, but this was after the 4th letter I had received. Access for people living with neurological conditions is particularly difficult in general, but even more so when someone is deaf. The anxiety that it has caused me is huge, and it has even caused delays in my pain management.” (Respondent)

People without digital skills are the group already most likely to experience health inequalities.^[vi] For many people living with neurological conditions, COVID-19 has intensified the digital divide.

For those living with rare neurological conditions, there is lack of access to specialists in Wales.

11%

Didn't have the right technology

9%

Didn't have a private space for remote appointments

“I find it very difficult to travel to my appointments from North Wales to Walton Hospital. Could the botox injections I receive at Walton Hospital for my Cervical Dystonia be provided from either the Countess of Chester Hospital or Glan Clwyd Hospital, Bodelwyddan Please? I cannot be the only person who has to travel from North Wales to Walton Hospital.” (Respondent)

“It would be so much easier if I could be treated at my local hospital instead of travelling to London.” (Respondent)



Notwithstanding the physical and emotional implications of travelling a long distance out with Wales to see a specialist, the economic cost is significantly impacting on people living with neurological conditions also.

"I have to travel every six months to London for treatment, I have to be there early so have to get a hotel which costs £80, then food, then £150 fuel costs. It all adds to the expense of a having a condition and trying to keep as well as possible. It's getting more expensive to keep attending my reviews and is having an impact on the household budget." (Respondent)

The significant financial costs that comes with a living with a neurological condition can take the form of loss of earnings for the person living with the condition and for their carer. There are costs of buying equipment, mobility aids and carrying out home adaptations and there can be additional costs for help with personal care, cleaning and childcare.

"With my condition I was diagnosed, discharged and left to get on with it. I have had to finance all my mobility equipment myself. I am under a postcode lottery."
(Respondent)

A study conducted by the Swansea University Medical School found that people living with some neurological conditions and their families are funding up to 75% of non-medical costs from their own pockets.^[vii] Items like wheelchairs, home and car adaptations are a necessity and make a significant impact for people living independently, stay at home or get out of hospital more quickly, safely and efficiently.

Disability benefits such as Personal Independence Payment (PIP) are meant to help manage these extra costs, but too many are having their benefit reduced or cut altogether. Failures in the PIP process mean that people living with neurological conditions are going through exhausting, demoralising and unnecessary appeals.

Welfare reforms are contributing to deteriorating health as well as compounding poverty and isolation for the neurological community in Wales. Having a neurological condition is hard enough – it is being made even more difficult by a benefits system that doesn't make sense.





Benefits for disabled people which are administered in Wales such as Concessionary Transport Schemes; Housing Benefit; Discretionary Housing Payments and Disabled People's Facilities Grants are vital but do not fully mitigate the day-to-day financial costs of living with a neurological condition or the impact of welfare reforms.

The current cost of living crisis is a real concern for many people living with neurological conditions. They often need more heating to stay comfortable and avoid heightened nerve pain, extra electricity to charge assistive technology devices and petrol to get about due to limited transport options.

9%

Conclusion

This report is a summation of the challenges that remain for people living with neurological conditions when accessing vital services and support to treat and manage their condition; together with the challenges faced by the professionals who are responsible for their care.

It should serve as a catalyst for immediate action.

Pre COVID, the CPG inquiry report concluded that there was a long journey still to travel to ensure that the needs of everyone living with a neurological condition in Wales were met.

Since then, the impact of the pandemic has further exacerbated the problems for people living with neurological conditions across Wales. Many specialist neurological services were redeployed into the emergency response and this has impacted greatly on people living with neurological conditions.

Health professionals within neurological conditions teams have done their utmost to deliver services and support under extremely difficult circumstances. They have prioritised urgent cases, and worked hard to provide as many of their appointments as possible via telephone or video call to avoid people from going to hospital.

The WNA is well aware that there are many people living with neurological conditions who have become deconditioned from shielding and are now exhibiting symptoms of a far more advanced nature than they should be. Function lost in this way can be very difficult for people living with neurological conditions to recover from even over the longer-term.

The role of NCIG was clearly defined with the NCDP; to work in a 'coordinated way, at an all Wales level, to support Health Boards and partners to deliver the actions within this plan and achieve the desired outcomes'.

NCDP created a focus on the needs of people with neurological conditions in Wales. It allowed those involved in implementation to begin to take action to address unmet need and to find solutions to challenges.



However, the lack of management data related to the outcome indicators of the plan and the delivery of diagnosis, treatment, services and support for people with neurological conditions has been a significant problem.

"There has been limited resource to support the work of NCIG. There has been a coordinator and some part-time administrative support which NCIG has shared with the SIG since 2016 and a clinical lead in place one day a week since December 2019." (NCIG, 2022)

Tracking improvements over time without a properly resourced mechanism to gather and publish this kind of data has been challenging.

This lack of resource also means inconsistent roll out of good practice and limited progress in co-production with people affected by neurological conditions;

"There is a lack of robust data across the patient journey that can inform and evaluate service developments and improvements." (NCIG, 2022)

Despite the scale of the change programme that NCIG has been tasked with, the vast majority of NCIG members do not have ring-fenced time within their roles.

People living with neurological conditions in Wales face an inequality in access to emotional, social care and rehabilitation support; physiotherapists and continence advisors that corresponds directly to income, education and employment status.

In addition, unmet health and social care needs are contributing to ongoing symptoms, resulting in physical, psychosocial, and occupational consequences for people living with a neurological condition.

"My condition is at its worst ever, I'm experiencing so many extra symptoms, crushing rib pain all around, such difficulty with my feet understanding to walk, word recognition and bladder problems are all new." (Respondent)



"I feel that I am out there lost in a wilderness and have had to try to find my own way through and fight to get any support that I needed for months or years. Have been promised various things at various times but they rarely come to fruition! Very difficult to get appointments at the time of day required (later afternoon when more likely to be able to attend). Often too ill to get to appointments even with full support."
(Respondent)

Neurology has historically been an underfunded, low priority service and people like those living with a neurological condition quoted above and throughout this report feel abandoned.

Therefore, it is not the case that we are only seeking a resumption to pre COVID service levels. As we emerge from this pandemic, we must utilise every opportunity to improve services for everyone who needs them.

The WNA fully understands the context of the new reality the NHS is now operating within, and we are mindful of the significant pressure that health and social care services are continuing to face.

However, we are cognisant that if the issues which are identified in this report and the subsequent recommendations are not acted upon promptly, it will only present greater challenges for people living with neurological conditions and lead to further pressures on existing services; increasing demand for treatments, rehabilitation, and support services for neurological disorders.

The draft Neurological Conditions Quality Statement is not a sufficiently detailed response to the current crisis in neurological services, nor does it point to a sufficiently bold ambition for neurological services in Wales.

"Unless immediate action is taken globally, the neurological burden is expected to become an even more serious and unmanageable threat to public health."
(World Health Organisation)^[viii]

Recommendations for Action

- Publish the Neurological Conditions Quality Statement and an Action Plan with detailed service specifications, clear outcomes and a strong accountability structure to support the planning and accountability arrangements for the NHS in Wales and bring about necessary improvements to people living with neurological conditions.
- Establish a fully funded and permanent all-Wales network for neurological conditions which can promote best practice and drive improvement.
- Establish a Ministerial Task and Finish Group to gain a better understanding of the demand for and impact of services for people with neurological conditions and ensure the necessary data and its reliability is collected and available on an on-going basis.
- Commit to workforce development and commission a strategy to ensure there are adequate numbers of specialist staff within Wales to meet the needs of people with a neurological condition in a timely manner and in a timely place.
- Establish a national system for the collection, collation and publication of outcomes data on neurological services, working with the research community, people with neurological conditions and the third sector.
- Create a new co-production and participation strategy that mandates and requires NCIG and LHBs to demonstrate the active participation of people with neurological conditions and carers in decisions about improvements to care and support at a national and local level.

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- Ensure that people living with neurological conditions have equitable access to specialist psychology support as part of their care. This includes access to mental, cognitive and emotional health support and treatment, as needed, which addresses both their needs arising from their condition as well as taking into account their individual needs and preferences.
 - The Welsh Government's COVID-19 mental health and wellbeing recovery action plan should include further financial support to the voluntary sector to enable it to mitigate and respond to the continuing and long lasting physical and mental health impacts of the pandemic and cost of living crisis.

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