

## **Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Flaenoriaethau'r Chweched Senedd](#)**

**This response was submitted to the [Health and Social Care Committee](#) consultation on [Sixth Senedd Priorities](#)**

### **HSC PSS 17**

**Ymateb gan: | Response from: [Cynghrair Niwrolegol Cymru | Wales Neurological Alliance](#)**

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## **Blaenoriaethau cychwynnol a nodwyd gan y Pwyllgor Initial priorities identified by the Committee**

Mae'r Pwyllgor wedi nodi nifer o flaenoriaethau posibl ar gyfer ei waith yn ystod y Chweched Senedd, gan gynnwys: iechyd y cyhoedd a gwaith ataliol; y gweithlu iechyd a gofal cymdeithasol, gan gynnwys diwylliant sefydliadol a lles staff; mynediad at wasanaethau iechyd meddwl; arloesi ar sail tystiolaeth ym maes iechyd a gofal cymdeithasol; cymorth a gwasanaethau i ofalwyr di-dâl; mynediad at wasanaethau adsefydlu i'r rhai sydd wedi cael COVID ac i eraill; a mynediad at wasanaethau ar gyfer cyflyrau cronig tymor hir, gan gynnwys cyflyrau cyhyrsgerbydol.

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

### **C1. Pa rai o'r materion uchod ydych chi'n credu y dylai'r Pwyllgor roi blaenoriaeth iddynt, a pham?**

**Q1. Which of the issues listed above do you think should be a priority, and why?**

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There are an estimated 100,000 people living with a neurological condition in Wales.

The Wales Neurological Alliance (WNA) is a forum of organisations and groups representing people living with and affected by neurological conditions in Wales.

The WNA welcomes this opportunity to respond to the Health and Social Care Committee consultation and suggest the following priorities for the Sixth Senedd;

- health and social care workforce;
- access to mental health services;
- support and services for unpaid carers;
- access to COVID and non-COVID rehabilitation services;



- and access to services for long-term chronic conditions.

The WNA recognise that COVID-19 has brought with it unprecedented demand on all health and social services. Furthermore, we appreciate that given the ongoing pandemic, the Committee will have many pressing issues to contend with.

For people living with neurological conditions however, poor access to treatments, services and support pre dated COVID-19.

During the fifth Senedd term, the Cross Party Group on Neurological Conditions (CPG) conducted a short inquiry on the implementation of the Neurological Conditions Delivery Plan (NCDP).

The inquiry heard evidence that progress has been slow, and that people with neurological conditions were experiencing unacceptable levels of hardship.

Contributors described difficulties relating to delayed diagnosis, lack of follow up support, barriers to accessing treatment and medication, low levels of availability of community services and poor experiences of end of life care.

It is undoubtedly true that the NCDP has begun to build the foundations for change. However, the most prominent theme running throughout the evidence submitted to this inquiry was that of the long journey still to travel.

The subsequent report; *Building the foundations for change: The impact of the Welsh Government's Neurological Delivery Plan* was presented to the Welsh Government and the fifth Senedd Health and Social Care Committee with recommendations for action to:

1. End the 'chronic underfunding' of neurological services by increasing investment in health and social care services to meet the needs of people in Wales.
2. Create a new neurological conditions strategy and action plan with clearer outcomes and a stronger accountability structure.
3. 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 in a timely place.
4. 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.
5. Convene a scrutiny and oversight group to hold LHBs to account for the delivery of the plan, to separate accountability from delivery.
6. Establish a permanent all-Wales forum for neurological conditions which can promote best practice and drive improvement based on the current NCIG model. This should include funded posts for a Clinical lead and a coordinator.
7. 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.

8. Ensure all LHBs publish progress reports against outcomes of this plan, which are easily accessible and on LHB and Welsh Government websites, in the context of this simplified outcomes framework.
9. Mandate that each LHB should have:
  - A Neurological Steering Group with cross sector representation;
  - A Neurological Conditions Service User Forum, or other mechanism to support service user participation;
  - A named neurological lead; and
  - Full attendance by the lead or deputy at each NCIG meeting.
10. Explore ways in which Welsh Government can put into effect measures to ensure social care engagement in the delivery of the plan.

In responding to the report, the Welsh Government and Neurological Conditions National Clinical Lead accepted the findings and the majority of the recommendations.

Whilst this was most welcome, it was however in February this year when the Government responded.

COVID-19 has and continues to further exacerbate the problems identified in the report 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.

The WNA is aware of numerous examples of people living with neurological conditions unable to access vital treatments, care and support. They have experienced deterioration in their conditions as a result, and in some cases irreversible deterioration.

We are grateful that the Committee has identified the health and social care workforce as a potential priority area. As you will see from above, the report recommended that the Welsh Government committed to workforce development.

It is vital that capacity within neurological services is increased so that many of the problems identified in the report are addressed and needs are met.

As you will be aware, as with the other delivery plans, the quality statement for neurological conditions will be replacing the NCDP and a draft statement is currently undergoing consultation.

It remains to be seen as to whether the aspirations set out in the quality statement will deliver the necessary improvements to people living with neurological conditions.

The WNA is concerned that the statement in its current form 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, or set out in detail a framework of accountability.

Whilst we await the outcome of the consultation and sight of the delivery plans each LHB will be using at local level, it is evident that there are many people living with a neurological condition in Wales who do not have access to the best possible care at this present time and they need urgent support.

Neurology has historically been an underfunded, low priority service. 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.

It is concerning however to see that in its response to the CPG inquiry findings, the Welsh Government acknowledged that; 'We need to have a better understanding of the demand for and impact of services for people with neurological conditions'.

Given that the NCDP was launched in 2014, the Welsh Government should have a comprehensive understanding of what the demand and impact of services for people living with neurological conditions are.

This statement from Welsh Government substantiates the inquiry findings that the implementation of the NCDP has not delivered, and further, it has exposed the shortcomings of the Neurological Conditions Implementation Group (NCIG).

From the outset, the NCDP required the NHS and its partners to:

- Carry out local population needs assessments;
- Analyse the gap between current provision and the requirements in this plan, and;
- Plan and take action to close that gap.

The Welsh Government must be bold and use this opportunity to learn from the CPG inquiry and develop an implementation and action plan which is fit for purpose, and one which enhances services for people living with neurological conditions so that they can live longer, healthier lives.

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 were identified in the 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.

As the World Health Organisation states; 'unless immediate action is taken globally, the neurological burden is expected to become an even more serious and unmanageable threat to public health'.

The WNA respectfully asks the Committee to;

- prioritise access to services for long-term chronic conditions with particular emphasis on neurological conditions, and;
- request that the Welsh Government establish a Ministerial Task and Finish Group to gain the better understanding of the demand for and impact of services for people with neurological conditions that is required.

People living with neurological conditions in Wales need the Committee to hold LHBs and the Welsh Government to account, and to ensure that the recommendations identified in the inquiry report are acted upon accordingly.

## **Blaenoriaethau allweddol ar gyfer y Chweched Senedd**

### **Key priorities for the Sixth Senedd**

**C2. Yn eich barn chi, pa flaenoriaethau allweddol eraill y dylai'r Pwyllgor eu hystyried yn ystod y Chweched Senedd mewn perthynas â:**

- a) gwasanaethau iechyd;**
- b) gofal cymdeithasol a gofalwyr;**
- c) adfer yn dilyn COVID?**

**Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:**

- a) health services;**
  - b) social care and carers;**
  - c) COVID recovery?**
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#### **Gwasanaethau iechyd**

##### **Health services**

For those living with neurological conditions, access to and quality of treatment, care and support plays a vital role in managing their conditions. The importance of accessing the right medications, health professionals and treatment plans at the right time can mean that symptoms such as chronic pain and fatigue decrease to more manageable levels.

Disruptions and inconsistencies within the NHS were already prevalent for many people living with neurological conditions and as COVID-19 began affecting services within the NHS, the impact on the care of those with neurological conditions has been significant.

The repercussions that Coronavirus had on the care of people living with neurological conditions must not be permanent.

We respectfully ask the Committee to prioritise;

- evaluating the impact of delays and cancellations of treatments and care on people living neurological conditions, and;
- monitoring the pace of service resumption across the NHS.

#### **Gofal Cymdeithasol a gofalwyr**

##### **Social care and carers**

During the COVID-19 pandemic, there has rightly been public recognition of the achievements and importance of the social care workforce. However, Local Authorities and care providers have had to provide care in exceptionally difficult circumstances, coping with increased workforce costs as a result of staff absence, on top of the high number of vacancies and a 30% staff turnover that predates the pandemic.

The WNA has heard from people living with neurological conditions about the negative impact this has on their lives, from 'care deserts' where care cannot be found in certain areas of the country, to a lack of continuity of care or being unable to find affordable, appropriate care for complex needs.

Prior to COVID-19, the WNA gathered evidence on the impact of the Social Services and Well-being (Wales) Act (2014) on people with neurological conditions. This found that the majority of respondents;

- had not been offered or requested a formal assessment;
- did not receive any services from a local council as a result of a care plan;
- did not see any information that would help them with a social care or support need;
- had not been referred to other organisations for support.

The WNA believes that people living with neurological conditions and their carers are being failed by the implementation of the Social Services and Well-being (Wales) Act.

We are deeply concerned that the 'what matters' conversation is not taking place and consequently people living with neurological conditions and their carers are missing out on vital support and services.

The lack of information, advice and assistance not only means that people living with neurological conditions and their carers are not being sign-posted to services that could increase their wellbeing, but it does not afford them a strong voice when deciding what they need to achieve wellbeing either.

The lack of robust population needs assessments of people living with neurological conditions and their carers has meant that the Welsh Government, Local Authorities and Local Health Boards do not fully understand the cohort in their area who may be in need of services.

We respectfully ask the Committee to;

- conduct an inquiry into the social care needs of people living with neurological conditions and their carers.

We believe that such an inquiry would hold the Welsh Government, Local Authorities and Local Health Boards to account for gathering information on the care and support needs of the population and thereby adhere to Section 14A of the Social Services and Well-being (Wales) Act (2014).

Such an inquiry would also provide an understanding of where the gaps in social care service provision are currently.

The WNA is aware that due to understaffing, underfunding, Brexit and the impact of COVID-19, the social care system is in deep crisis. As a result, many people living with neurological conditions and their carers are being denied adequate care and support in their homes.

Previous Health and Social Care Committee inquiries have already documented the impact of COVID-19 on the social care system.

We respectfully ask the Committee to prioritise;

- the health and social care workforce, and;
- holding the Welsh Government to account to end the social care crisis.

We urge the Committee to insist that the Welsh Government and Local Authorities value our social care workers, and ensure that they are paid a decent salary and also paid for their travelling time. This would help retain staff and provide a continuity of service for service users and carers.

## **Adfer yn dilyn COVID**

### **COVID recovery**

The Welsh Government has identified that, 'most people with long COVID are likely to need a rehabilitation approach and that health and care services in the community are ideally placed to provide this'.

Many living with neurological conditions were among those who were the most vulnerable to the virus and were told by the Welsh Government to shield.

The WNA is well aware that there are many people living with neurological conditions who have become deconditioned from shielding and now exhibiting symptoms of a far more advanced nature than they should be. They are also at risk of falls due to reduced muscle strength and mobility.

Furthermore, there are many who now experience mental health problems either caused or exacerbated by social isolation.

We appreciate that the All Wales Community Pathway for Long COVID will be much welcomed by those who live with this debilitating condition. However, it is imperative that existing neuro rehabilitation services are not adversely impacted by this additional demand and that people living with neurological conditions will not lose out as a result.

There must also be adequate support and capacity within NHS mental health services to deal with the mental health needs of people with neurological conditions who have been in the shielding group, or who have been self-isolating because they are clinically vulnerable due to the common coexistence of neurological and mental health conditions.

Tackling the backlog of neurology appointments must be prioritised by the NHS to avoid continued decline in the health, mobility and quality of life of people on these waiting lists - and increased costs to the NHS and social care in the longer term.

We respectfully ask the Committee to prioritise;

- evaluating the impact of delays and cancellations of treatments and care on people living neurological conditions; and
- monitoring the pace of service resumption across the NHS.