



Cynghrair Niwrolegol Cymru Wales Neurological Alliance

Wales Neurological Alliance Response to the Inquiry into the Covid-19 outbreak on health and social care in Wales.

Introduction

The Wales Neurological Alliance (WNA) is a coalition of more than 20 organisations working together to transform outcomes for people in Wales with neurological conditions – disorders of the brain, spinal cord or nerves. There are more than 250 recognised neurological conditions.

Wales has approximately 100,000 people living with a neurological condition that have a significant impact on their lives. Many neurological conditions are life threatening and the majority significantly affect quality of life. Too often, people with neurological conditions in Wales report substantial barriers to accessing the treatment, services and support that they need from health and care services.

In Wales, each year around 2,500 people are diagnosed with Parkinson's disease, epilepsy, multiple sclerosis or motor neurone disease. The latest prevalence data from Public Health Wales (2014-15) indicates out of the 100,000 over 41,000 people in Wales are estimated to suffer from one of the following neurological conditions; Parkinson's disease, epilepsy, multiple sclerosis, muscular dystrophy, motor neurone disease and cerebral palsy. In addition, a further 10,000 people each year were admitted to hospital for an acquired brain injury.

The WNA has spoken to members and conducted a survey to ensure the views and opinions of people living with neurological conditions are included in this inquiry. The WNA has also sent a letter to the Health Minister to highlight issues raised by member organisations.

Difficult accessing services before Covid-19

Notwithstanding the COVID-19 pandemic, people with neurological conditions can have difficulty accessing the specialist care they need. The Cross Party Group on Neurological Conditions launched an inquiry in 2019. The Inquiry report highlighted the need for more significant improvements across health and social care. Some of the main recommendations for improvements were:

- Timely referral to specialist services for diagnosis

- Shorter waiting times and more consultants and specialist nurses
- More psychological support for people living with conditions
- Improved access to medications and treatments

Surveying individuals living with neurological conditions

WNA conducted a survey for two weeks at the end of May 2020 to assess the concerns and difficulties for people living with neurological conditions during the pandemic. This was a Wales wide survey which was sent out to individuals and their carers to complete via the alliance member organisations. The survey was completed by 138 people living with neurological conditions in Wales.

Shielding and Vulnerable categories

The main concern was the confusion about whether or not the individual's condition meant they should be in the shielding category or classed as clinically vulnerable. Some 28% of people who responded who did not receive a shielding letter from the Chief Medical Officer believed that they should be placed in this category. A greater proportion of 44% took the precaution to self-isolate because they believed that they were more vulnerable because of their medical condition. The issue was raised that no formal support for people was given who are clinically vulnerable but are not on the shielding list. For example online food delivery slots and when speaking to employers about returning to work.

The WNA are concerned that people with some progressive and life-limiting neurological conditions, such as motor neurone disease and multiple system atrophy, which compromise people's ability to live independently, and which have a significant impact on their health and wellbeing, were not included on the Government's 'extremely vulnerable' list. We understand that some people with neurological conditions have been added to the list, but data on the conditions people have and who have been added to the 'extremely vulnerable' list is not, as we understand it, publicly available. The concern is that decisions about who qualifies to be added to this list may have been applied differently in different areas.

Support from Local Authorities

The survey highlighted that additional support from local councils was not universally offered with only 32% of people shielding or vulnerable being offered additional support with 65% receiving no contact during this lockdown period. Some responses stated that people felt alone and having to rely on local communities and neighbours. It was also mentioned that people were not made aware at an early stage that if they needed help getting the essentials that they should contact their local authorities for assistance.

Access to Care and support

61% of care received by individuals has been received by unpaid carers who are mostly family members. This has put more pressure on family members to complete all care needs. This is of particular concern with conditions such as Parkinson's, where carers have a mean age of 70.7 (Hand et al 2018). From this particular cohort only 9% relied on paid carers regularly. Many people have seen their care support reduced or stopped by local authorities. Some people living with neurological conditions have chosen to cancel care agencies because of the perceived risks of catching Covid 19 as carers attend several households and appropriate levels of personal protective equipment being available.

Individuals also commented that continuing healthcare assessments had stopped and were concerned about what would happen if these assessments were delayed for long periods of time.

Access multidisciplinary care and therapy.

The survey as expected showed that all routine appointments had been cancelled. Some people had received phone or video calls from some specialist services. From the survey results 42% of people had had their appointments cancelled, 8% of people had chosen to cancel their appointments because of concerns attending NHS sites. Around 24% of individuals had reviews by video or telephone calls.

Achieving an appropriate balance between COVID-19 and non-COVID-19 care has not always been possible since NHS services have been reconfigured in the wake of the pandemic. Whilst this is understandable, as significant NHS resources had to be diverted towards meeting the urgent needs of the rising number of COVID-19 patients - and the scale of the need was not known at the outset - there is no doubt that people with neurological conditions have experienced a significant reduction in their levels of routine care and rehabilitation. There is also the point that many neurological conditions have other co-morbidities and have not been able to access these service causing a detrimental effect on health and well-being.

We have heard of situations where some nurses are single-handedly running outpatient clinics which otherwise would have been staffed by multidisciplinary teams. Most commonly, outpatient services are now being provided via video or telephone.

- Reduced services for people with neurological conditions must not become the new norm as this will only result in worse patient outcomes and higher costs to the NHS as patients run the risk of their condition deteriorating in the longer term.
- It is important that an ongoing impact assessment is made of how these skeleton services are affecting the health and outcomes of people with neurological conditions and what measures are being put in place to ensure that scaled back services remain in operation for the minimum length of time possible.

Mental health needs

The survey has highlighted that 18% of people were struggling with their mental health. With 29% finding it difficult because they could not leave their residence. Consideration should urgently be given to prioritising access to mental health services for all people with neurological conditions after the peak of the COVID-19 crisis, as they are likely be at increased risk of having mental health complications following the social distancing and other measures introduced. The other consideration is that 20% of people were finding it difficult to keep physically active at home which can also have a detrimental mental health affect.

Neurological conditions relate to the brain and nervous system. The interaction between physical needs and broader emotional, cognitive and mental health needs is complex. Changes in the brain can directly affect a person's emotions, cognitive abilities and executive functioning. Conversely, depression or anxiety can coexist alongside neurological symptoms. People's mental health difficulties often have an impact on their neurological condition, triggering or exacerbating it. In times of social distancing, loneliness, social isolation, health

anxiety and change to established routines all serves to adversely affect people's mental health. Mental health services should be provided holistically as part of a person's overall care, delivered by multi-disciplinary teams.

Meeting the wave of pent-up demand for health and care services that have been delayed due to the coronavirus outbreak

People living with conditions have expressed the understandable view that they expect a significant backlog in delivering some medical treatments which could have a long-term impact on the physical and mental health of people with neurological conditions. Careful consideration needs to be given to how best to manage a return to a more normal service to be most effective.

The Association of British Neurologists and the Royal College of Physicians have considered how best to address and prioritise the backlog of patients in order that:

- The most urgent neurological cases are prioritised according to agreed and validated tools, procedures and pathways.
- Cancelled procedures such as infusions are reinstated as quickly as is safely possible, bearing in mind the long-term risks to health of not doing so.
- New diagnoses are prioritised, delivered in face-to-face consultations.

Neuro Rehabilitation

Long term impact rehabilitation is critical for the long-term recovery of people who have, for example, had a stroke or brain injury, as well as minimising the long-term impact of progressive neurological conditions. Therefore it is essential that neuro rehabilitation services are seen as a priority.

Patient stories Experiences

The WNA has been producing with the help of Cardiff University Students patient experiences: <https://www.youtube.com/watch?v=4LRlqq6pq18> – Gwyneth story highlights the fact that because of the neurological condition affecting every part of an individual's life and living in Lockdown.

Our survey included a free text box; some of the comments are included below:

- *“Waiting for assessments re adaptations etc. but no idea when these will happen now. Specialist nurse now working elsewhere within hospital so having delays in replies to messages. Consultant appointment on hold. Physio assessment/speech and language therapy all on hold.*
- *Feeling isolated. Not being able to get a food shop for online. Being out of routine*
- *Devastated that all trials have been suspended particularly MND Smart. This was some hope which doesn't exist at the moment.*
- *Carers and family have been marvellous in dealing with all my needs. Carers should have been given PPE straight away as they were dealing with the most vulnerable. The knock on effect is more people contacted the virus.*

- *Does seem a lot of people with an Epilepsy condition have been ignored by the government, luckily my local chemist have been really good and I have not had to run out of my medication.*
- *As I have had a lot of time off work due to my condition I work in a frontline vulnerable job I have been off work for 12 weeks now as I'm scared to go to work. My boss has suggested next sickness they are having to let me go. I feel very exposed to covid-19 but still no cover letter from GP or government. I also have high blood pressure anxiety and other issues but still no cover letter."*

Key points for the inquiry to consider:

- It is crucial for people with neurological conditions to continue to access specialist services during the outbreak and beyond to maintain their wellbeing including therapists. The NHS in Wales must apply strong leadership in restarting neurology services, using Association of British Neurologists guidance and in consultation with people living with neurological conditions the NHS must set out their priorities for restarting neurology services.
- Isolation and shielding has meant increased anxiety and impacted many people living with neurological conditions mental health. People's mental health difficulties often have an impact on their neurological condition, triggering or exacerbating it. Mental health services must adapt to meet the needs of people living with neurological conditions.
- Ensuring that social care packages are available to those who require support in line with Social Services and Well-being (Wales) Act 2014. Local authorities should support families to feel re-assured that all precautions are being adhered to prevent the spread of Covid 19 to those who receive care in the community. Unpaid carers should be supported as currently a large burden of care is falling on families to cope with carer fatigue and stress.

References

Letter to Health Minister dated 4th May 2020 [https://mssoc-my.sharepoint.com/personal/rebecca_brown_mssociety_org_uk/Documents/MyDocuments/WNA%20letter%20\(003\).pdf](https://mssoc-my.sharepoint.com/personal/rebecca_brown_mssociety_org_uk/Documents/MyDocuments/WNA%20letter%20(003).pdf)

Letter of response from Health Minister dated 28th May [file:///C:/Users/rbrown.MSSORG/AppData/Local/Microsoft/Windows/INetCache/Content.Outlook/ATX0R24X/VG0290520_Outgoing_0%20\(002\).pdf](file:///C:/Users/rbrown.MSSORG/AppData/Local/Microsoft/Windows/INetCache/Content.Outlook/ATX0R24X/VG0290520_Outgoing_0%20(002).pdf)

The Neurological Alliance website. Accessed here <https://www.neural.org.uk/about-neurological-conditions/>, Accessed 10 June 2020.

Neurological Conditions Delivery Plan 2017 <https://gov.wales/sites/default/files/publications/2019-02/neurological-conditions-delivery-plan-july-2017.pdf> Accessed 10 June 2020

Hand A et al (2018) 'The role and profile of the informal carer in meeting the needs of people with advancing Parkinson's disease' Aging & Mental Health; DOI: 10.1080/13607863.2017.1421612

Building the foundations for change: The impact of the Welsh Government's Neurological Delivery Plan 2020

A Cross Party Group on Neurological Conditions Inquiry Report

<https://gov.wales/sites/default/files/publications/2019-02/neurological-conditions-delivery-plan-july-2017.pdf>

Catherine J Mummery and Christopher M Kipps on behalf of the Association of British Neurologists, UK neurology response to the COVID-19 crisis, Clinical Medicine 2020 Vol 20, No 3 May 2020, Accessed here [file:///C:/Users/judya/AppData/Local/Microsoft/Windows/INetCache/Content.Outlook/IF3M59U4/abn%20covid%20\(002\).pdf](file:///C:/Users/judya/AppData/Local/Microsoft/Windows/INetCache/Content.Outlook/IF3M59U4/abn%20covid%20(002).pdf), 10 June 2020

<https://gov.wales/sites/default/files/publications/2019-05/social-services-and-well-being-wales-act-2014-the-essentials.pdf>