Neurological Voices: Living through lockdown

Introduction

An estimated one million people in Scotland live with a neurological condition that has a significant impact on their lives.

The Neurological Alliance of Scotland is an umbrella body of organisations that represent people with a neurological condition and those who support them. We work to improve the care and support that people receive.

For those living with a neurological condition in Scotland, Covid-19 and the subsequent lockdown has posed a significant threat to their physical health and mental wellbeing. Many of our members have produced condition specific reports, links to these can be found on our website www.scottishneurological.org.uk

While those who contributed to this report represent different conditions, experiences and challenges there were clear issues being felt by the whole of the neurological community in Scotland. With this report we seek to give an insight into the experiences of those living with neurological conditions. It is essential that their voices are heard as we move through lockdown and beyond.

The Covid-19 pandemic has had a massive impact on the third sector as a whole, with many of our members projecting at least a third of their income lost this year and beyond. Despite reduced capacity and increased need our members have been responsive, innovative and dynamic. We've set up helplines, call check in services and supported virtual services, clinical, informative and social. We're here for everyone living with a neurological condition in Scotland, through and out of the pandemic.

Contents;

Children with neurological conditions

For children with neurological conditions, parents are reporting the current restrictions causing significant pressure on family life. As schools have been closed since the end of March, parents and family have therefore had the burden of continuing physical care and supporting education provision at home without respite. They are often juggling all of this with home working and caring for siblings as well. In general, community health services have kept in touch with telephone discussions and online appointments if required through NHS Attend Anywhere/Near Me but the longer the situation goes on, the less satisfactory this way of working is. Many children receive their community health appointments at school so the closure of schools means that these are not happening. Access to wider caring support, for example help from grandparents, has also ceased due to the restrictions, (although some families have reported that they have chosen to ignore guidance in order to continue to access family help).

There is great concern from families who are shielding a child and also those who have chosen to shield because they believe their child to be particularly vulnerable, even though they may not have received a shielding letter. There is confusion around how to assess the risk for their family and also who to turn to for advice. The burden and the impact of shielding is being negatively felt by the whole family and affects siblings as well.

From our feedback, families are split between those who feel their children should be prioritised in terms in of returning to school and face to face appointments because of their fear for the long-term damage not having access to intervention is causing and those who do not feel able and confident to return to any sort of outside environment at this time.

> *"The main thing it is affecting is socialisation. Not being able to see other children or extended family. Also, not having the option of our child being looked after by other people is affecting the whole household and our ability to work."*
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> *"Our son has lost almost all his social interactions without school. He often says he misses his teachers. He needs a lot of attention to help him do any school work and as we are working full time at home, it's very difficult to find enough time to do this so we're very worried about his education."*
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> Cerebral Palsy Scotland survey respondents

Emotional Wellbeing

Lockdown, vulnerability and being placed in the shielding category has exacerbated the nation’s mental health. Pre-pandemic, people with neurological conditions were more likely to have a mental health condition than the general population. This general exacerbation in mental health has intensified longstanding problems in the neurological community.

- 65% of those with dystonia experience depression compared to 20% for the general population. Dystonia UK are particularly concerned that lockdown has worsened the feelings of stress, anxiety, and depression in those with dystonia. The charity is concerned that some individuals will be particularly isolated due to their inability to access online methods of information and support.

- Stress is a common trigger for seizures in epilepsy, Epilepsy Scotland’s study found 40% of people have noticed an increase in their seizures since the start of the pandemic, with some losing their long-held seizure freedom.

- Those with Functional Neurological Disorder (FND) had also seen an increase in seizures due to stress.

- Cerebral Palsy Scotland note that 54% of people with cerebral palsy said the pandemic has negatively impacted their mental health. The lack of access to support services and opportunities for exercise has resulted in some of those with CP withdrawing from their relationships and have lost emotional and physical progress.

One person with Huntington’s said;

“I'm worried that there is additional pressure on my family as they are having to look after me and attend to my needs, shopping etc. I am also worried about my mental health and that of my son and daughter.”

- The MS Society said there has been a significant amount of anxiety from their supporters around interpreting information and deciding how it relates to them and their condition. While only 9% of their survey respondents had received a shielding letter, 55% had been shielding or self-isolating during the lockdown period.

- Whilst the FND community were not told to shield, the majority of them decided to stay at home due to overwhelming anxiety.

- Parkinson’s UK Scotland reports that people with Parkinson’s, unpaid carers and family members are reporting increases in mental health symptoms – particularly anxiety, but also depression and hallucinations. There has also been an increase in memory problems and worsening dementia. The number of safeguarding issues raised by Parkinson’s UK staff has also increased significantly.

- Parkinson’s UK Scotland also reported concerns that people without access to the internet were at particular risk of isolation.

> *Now that we've got past the initial problems with PPE and testing, social distancing is having an ongoing impact on the quality of life of our clients. Many would normally have regular visitors or be out and about, but we do not have any visiting now (other than in very exceptional circumstances). We are limiting face-to-face consultations with external health and care professionals unless they are absolutely necessary, but they are now happening remotely in many cases. Many of our clients take part in group activities and socialise together within Dee View Court - this has been changed to online activities via tablets courtesy of a donation to Sue Ryder.*
>
> Sue Ryder

Before coronavirus, people with neurological conditions were already feeling the effects of over-subscribed and underfunded mental health services. The Neurological Alliance for Scotland is particularly concerned that this nation-wide exacerbation in mental health problems will make access to support near impossible and further isolate the neurological community.

Physical Health

People living with neurological conditions are seeing an impact on their physical health as the pandemic leads to reduced access to treatments, physiotherapy and healthcare appointments.

- 44% of people living with epilepsy said the pandemic had affected their epilepsy and 40% said their seizures had increased. Epilepsy Scotland noted that some recorded that they had experienced breakthrough seizures and increased seizure activity since the start of the pandemic: “I had three seizures in one day, I only generally have one a year”.

- Many people with Parkinson’s are reporting worsening physical symptoms, including slowness, stiffness, tremor and fatigue. More than 2 in 5 people in Scotland report that appointments with consultants or Parkinson’s nurses have been cancelled or postponed, and the majority report cancelled appointments with physiotherapists, speech and language therapists and occupational therapists. In addition, the cancellation of hundreds of face-to-face exercise and physical activity sessions which help people to manage their Parkinson's symptoms has led to real concerns about irreversible deterioration in physical health.

- Cerebral Palsy Scotland reported that 70% of people with the condition, and their carers, believe that the current situation is impacting negatively on their physical health.

> *"I am worried that I am developing mobility difficulties and I won't be able to recover the strength in my legs"*
>
> Cerebral Palsy Scotland survey respondent

- People living with some conditions, like Huntington's disease, multiple sclerosis (MS) Parkinson's and dystonia, have had treatments cancelled or postponed due to patient safety or staff redeployment.

- Dystonia UK said that this raises a number of issues including patients being left in pain and experiencing more disabling symptoms that require additional care.

- Scottish Huntington's Association reported that in some situations, the lack of face to face clinical assessment has negatively impacted healthcare.

> "*My husband had leg tremors but I did not know what it was. Reported this on the Wednesday to the nurse and she said that if he had not had a bowel movement then this might be the cause and was advised to keep drinking water and give Laxido drinks. By the Sunday, had to call the nurses again as he was shaking all over, they advised me to call 111. 111 said to phone the nurses back out and had to do this. They then sent out nurse to check and she found that the catheter was blocked and this was what the problem was. After the catheter was changed, he was fine."*
>
> Scottish Huntington's Association survey respondent

- 6% of respondents to MS Society Scotland noted that they had to wait a long time or not been able to speak to an MS specialist when they needed to while 15% had care and support reduced or cancelled.

> *"I am struggling physically. My body is getting more spasms and my legs hurt as soon as I try to walk. I have been diagnosed with Lhermitte's which is very painful and has gotten worse since lock down."*
>
> MS Society survey respondent

People with some conditions are seeing reduced time in clinical care or receiving less support afterwards.

- The MSA Trust reported that many partners and carers of people with multiple system atrophy are accepting discharge from hospital of their loved one just to get them away from hospital and perceived risk of getting COVID-19 with no support. They also found limited or no access to therapists for those who needed it resulted in more rapid decline in overall condition.

> *'mum (83) has come to live with us after 10 weeks in hospital, but we don't really know what we should be doing to help her - with exercise for example, and we did not get much information when we picked her up, we could see the hospital staff were very busy'*
>
> Stroke Association supporter

Accessing support

People affected by different neurological have seen challenges in accessing various resources or support during the coronavirus pandemic.

- The MSA Trust and Parkinson's UK Scotland said that some people had had difficulty/delay in getting access to priority online shopping, deliveries, etc.

- The MS Society reported that 8% said that they are going without essentials because they can't access shops or deliveries.

Many people reported that they were now relying on friends and families to help with accessing essentials and for many people, going shopping themselves had become unmanageable due to the necessary restrictions and systems that had been put into place.

- Dystonia UK shared worries that access to benefits will continue to be limited after lockdown finishes. They anticipate that the predicted economic downturn will bring a period of greater austerity and pressure on government expenditure and the impact will be significant in terms of additional stress and anxiety for dystonia patients.

- The Scottish Huntington's Association also reported additional financial pressures arising out of the current crisis. Many of their respondents had been furloughed, had their hours reduced or could no longer work.

> *"I gave up my job last year, however, my wife has been furloughed and it is unclear how much money she will make. We see our savings dwindling away."*
>
> Scottish Huntington's Association survey respondent

Some people living with neurological conditions have faced anxiety about access to prescriptions or been unable to have equipment adjusted or seen to.

- Epilepsy Scotland reported that 18% of respondents said they were struggling to access their prescription.

- Parkinson's UK Scotland said that the situation for people with Parkinson's was similar.

- Cerebral Palsy Scotland found that 41% of people had equipment needs that required attention and adjusting while 56% of people reported that they had not been able to access PPE.

Across the board people have had reduced access to healthcare appointments and support from healthcare professionals.

People affected by neurological conditions are facing a greater limit on access to things like food and medicine during the coronavirus crisis than the general population. Additional support or planning is needed to ensure that people with conditions, their families and carers do not go without essentials.

- However, MND Scotland received feedback on remote health and social care contact has been generally positive and that MND Nurse specialists have been in regular contact with their patients.

- Sue Ryder reported that thanks to a donation they have been able to buy tablets and these are being used so families and friends can keep in touch. Staff are coming up with really creative ideas about how to use them to keep social connections within Dee View going. For instance, via quizzes that everyone can take part in if they'd like.

- Many of the MS Society and Parkinson's UK Scotland's local groups have started virtual social meetings to stay connected, with some moving many or all of their usual activities online.

> *It's been a great idea and it's been cost-effective. The main downside has been a lack of face-to-face contact for people but even then participants are joining classes early to have a catch-up before things kick off.*
>
> *The engagement we're seeing is brilliant, too. There hasn't been a drop in numbers from what we see in person and we expect it to increase so we may end up reaching a few extra people as we keep things moving.*
>
> MS Society group member

Family and Friends in caring roles

There was a consensus among members that the pandemic is having a significant impact on family, friends, and carers.

Several noted, despite Scottish Government schemes, many people with neurological conditions are relying on their family, friends and carers for support with things like shopping and medicines.

- Almost a third of those with Huntington's said they were worried about the increased pressure on unpaid carers.

- Almost half of Cerebral Palsy carers said COVID-19 had negatively impacted their mental health.

- The MS Society said many people with MS have lost their care workers due to the carer self-isolating and are now relying on unpaid carers, who are often family members.

- Carers for those with MND have said gaining access to statutory support (home alterations and equipment) has been halted and they feel they cannot complain due to the current situation.

- Parkinson's UK Scotland reported that about half of people with Parkinson's who use social care said that they were receiving less care during the pandemic. Some people had cancelled or deferred their social care package because of concerns about the risk of coronavirus. The amount of care provided by family members and friends had increased, with over two thirds of family members taking on more caring responsibilities.

- Representatives from the MSA Trust said they have had an increase in contact from carers who have progressively been burdened due to a lack of respite services. They also note many carers had stopped social care support coming into their homes due to fear of virus spread and a lack of PPE.

> *"No one is checking on us. I can't drive and I can't get any deliveries either. Disabled but not disabled enough for the government to help. I have to walk carrying shopping or get an Uber. Hugely increased costs."*
>
> Epilepsy Scotland supporter

Some said that online methods of information sharing and access to support had disenfranchised those with some conditions, like Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration CBD:

> *"people with PSP & CBD are older in age and may not have embraced the technology needed for online solutions – together with the fact that these conditions have cognitive and motor symptoms they can find using technology challenging e.g. eye gaze issues, fatigue, dystonia and impulsivity."*
>
> PSP Association

- The PSP Association say carer stress is now at a critical stage as the 24/7 burden of care with no support has taken its toll.

This reliance on the community might be underplaying the significant level of need currently felt by those with neurological conditions across Scotland. The Scottish Government and local authorities might not be fully aware of the integral role of family, friends and carers to support those with neurological conditions during the coronavirus pandemic.

However, the ability of family, friends, and carers to support those with neurological conditions is reliant on situational factors e.g. the majority are currently working from home. It is vital the Scottish Government and local authorities do not evidence this perceived ability to cope as an opportunity to cut budgets. Any cuts to funding – social care, community projects and clinical support – will have a significant and devastating impact on the lives of those with neurological conditions.

Recommendations for next steps:

1. Recognise anxiety; Neurological Alliance calls on Scottish Government to recognise the high levels of anxiety being experienced by people with neurological conditions and their carers, and ensure that this vulnerable group is supported by clear and targeted messaging as the restrictions are eased.
2. Share and coordinate information: We ask that Scottish Government to share co-ordinated communications with health and social care professionals and third sector organisations, so that people are likely to receive the same reassurance from their GP, social worker or charity.
3. Meet neurological health needs: Neurological Alliance calls on NHS Scotland to deliver health check-up/reviews of all those living with a neurological condition as NHS services resume, and ensure timely access to essential support, including pain management, physiotherapy and equipment maintenance and provision which was missed during the lockdown restrictions These should be offered as face to face appointments where appropriate.
4. Improve community support: We call on Scottish Government to recognise that people with neurological conditions may need help to access community support (such as help with shopping, collecting prescriptions) for some time, and beyond the lifetime of current restrictions. We ask that the network of community support hubs continues, to ensure that those who need this help do not experience a sudden drop off in support.
5. Information and support for unpaid carers: Neurological Alliance calls on Scottish Government to identify and support those who are providing unpaid care, including those who have started caring during this crisis.
6. Guidance for social care providers: We call on Scottish Government to provide clear guidance for care workers, including personal assistants. This should include an outline of conversations carers and their clients should be having to ensure that both parties feel safe and comfortable with their duties and in their roles. We also want Scottish Government to confirm that no individual care package will be reduced as a result of Covid-19, and that care packages that have been suspended by families due to concerns about coronavirus transmission will be reinstated without reassessment.

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Supporting people affected by Motor Neurone Disease

MSA Trust

MS Society Scotland

Multiple Sclerosis Trust
MS

PARKINSON'S UK
SCOTLAND
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

PSPA

Stroke Association

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