

Cross-Party Group on Epilepsy

09th June 2022

Minute

Present

MSPs

Carol Mochan MSP
David Torrance MSP

Donald Cameron MSP

Invited guests

Maree Todd MSP

Alice Struthers, Neurological Alliance of Scotland

Non-MSP Group Members

Alistair Haw, Scottish Huntington's Association
Anissa Tonberg, Scottish Government
Anna Telfer, Epilepsy Scotland
Avril McLean, Action for ME
Cassie Patterson
Christine Jeans, SUDEP Action
Claire Mellor, Scottish Government
George Allan, SPPN
Gerard Gahagan, Scottish Government
Gill Wilson, Epilepsy Connections
Helen McDade, #MEAction
Hilary Mounfield
Jack Norquoy, office of Liam McArthur MSP
Jacqui Downs, NHS Ayrshire & Arran
Jan Campbell, UCB
Jay Shetty, NHS Lothian
Jenny Preston, NHS Ayrshire & Arran
Julie Dock
Katie Russell
Keith Park, MS Society
Kitty Miller, MS & MND Clinical Nurse Specialist for Argyll and Bute

Kristin McPhee, Scottish Government Mental Health
Laura Ingram, MS Society Scotland Chair
Lorraine MacKenzie
Lynn Young, Salvesen Mindroom Centre
Mary Ramsay, Scottish Tremor Society
Mhairi Coutts, NHS Ayrshire & Arran
Morna Simpkins, MS Society Scotland
Paul Gillon, Veriton Pharma
Philip Robinson, Lanarkshire Epilepsy
Rachel Lloyd, NHS Lothian
Rebekah Canning
Richard Brewster, Scottish Government
Rona Johnson, Epilepsy Scotland
Stephen O'Keane, MS Society Scotland
Steve Brown
Tanith Muller, Neurological Alliance of Scotland
Thomas Mulvey, MS Society Scotland
Vicki Burns, Epilepsy Scotland
Victoria Wareham, Dystonia UK
Zoe Hisbent, office of David Torrance MSP

Apologies

Alasdair Allan MSP
Jeremy Balfour MSP
Jackie Bailie MSP

Liam McArthur MSP
Katie Clark MSP

Agenda item 2. Convenor David Torrance MSP welcomed attendees and welcomed Alice Struthers, the Programme Director of the Neurological Alliance of Scotland.

Alice Struthers

The Neurological Alliance of Scotland have launched a report: Together for the One in Six, findings from My Neuro Service Scotland. Research was conducted across Scotland, with over 800 respondents (784 adults and 50 children and young people) covering 35 conditions.

Being diagnosed with any lifelong condition is going to have a negative impact on mental wellbeing. However, the incremental impact of delays accessing the right care and support, the need to repeat yourself and your story to every medical or social care worker and being told to Google your condition has a devastating but entirely avoidable additional impact. By casting light on these three areas, we hope to demonstrate how bad experiences people are having can be minimised or ideally stopped altogether. None of this can be done without boosting the neurological workforce, providing support for conditions that currently have nothing and better supporting the existing NHS workforce who are exhausted, overwhelmed and on the brink of collapse. We welcome the NHS recovery plan but would criticise it for having underwhelming ambition as well as for not mentioning neurology specifically. The aim to increase the NHS workforce by 10% as quickly as possible does not help those who can't access help today, tomorrow or even next year.

Delays to treatment and care

The pandemic has had a negative impact on waiting times across all areas, but we know people were experiencing delays well before the pandemic started. GPs and non-neurology specialists do not know enough about neurology and there is inequity of care across different conditions as well as across Scotland.

- The majority of respondents have experienced serious delays to treatment and care. Over 1/3 of children and adults experienced delays in receiving a diagnosis over the past 12 months.
- Access to physio is a critical issue with nearly half of adults and over half of children not being able to get an appointment.
- Adults were struggling to access scans and occupational therapy, but children were more likely to find it hard to access wheelchair support. Over half of children who needed a wheelchair could not access one at their point of need.
- Both adults and children experienced a delay accessing a routine appointment with a specialist nurse.

Crisis and mental health support

- People with neurological conditions do not have adequate mental health support
 - Over half of adults have not been asked about their mental wellbeing at all in the last three years. 57% of adults would welcome a referral to mental health support.

80% of adults say their neurological condition has a negative impact on their mental health. 35% of children in Scotland said their mental health needs are not being met at all. Nearly half of children have not been asked about their mental wellbeing at all in their last three years. 22% of children would welcome a referral to mental health support.

- Remote or online appointments do not work for everyone, particularly children
- Children with neurological conditions are being failed by the education system in this country with limited or no provisions being made to support children whose neurological condition impacts on their ability to attend school.

Lack of information and support

- Patients are often not provided with meaningful information about their condition
 - 1/5 of adults and over 1/4 of children were given no explanation of their condition at diagnosis. This means that other than the name of their condition, the clinician failed to provide any explanation as to the cause, symptoms, prognosis or treatment.
 - 30% of adults and 38% of children were given no information about their condition (e.g., leaflets or links to website).
 - Nearly 1/3 of adults and over 1/4 of children felt the way they were told about their condition was insensitive.
- Patient initiated review systems can't work when people don't understand their condition
- Care plans are rarely provided leaving people feeling detached from their own treatment and care.

Conclusion

We know that one in six people in Scotland live with a neurological condition and that there are 600 known neurological conditions, of which the majority are little known, complex and rare. We want there to be more awareness amongst GPs and non-neurology specialists of the frequency and range of conditions. We want GPs to listen to people's symptoms and not discredit them as age, gender, or anxiety related. We want people to be referred more quickly to secondary care to get a diagnosis and for support to be provided at that appointment, along with a full explanation of what that condition is. We want all these people to be seen and heard and taken seriously.

Four recommendations for Scotland:

- To understand prevalence – without knowing the numbers of people who suffer from each condition we cannot plan an adequate workforce.
- To deliver care seamlessly between different parts of the system (between primary, secondary and community care.)
- To address the crisis in mental health, providing support for people throughout their experience living with the condition from the point of diagnosis onwards.
- To prepare for the future care and support of adults and children with neurological conditions once a strategic framework period has ended in 2025.

We also joined with the other neurological alliances across the UK to call for a neurological taskforce to bring together relevant departments health and social care bodies, professional bodies and people affected by neurological conditions to better plan a workforce across the UK, share approaches to common problems and level up investment in areas that do not receive a fair share currently.

Mary Ramsay: I have had essential tremor since birth. I got a call from my neuropsychologist seven years ago, that I should have been seen five years before that. It has now been nine almost ten years and I haven't seen that neuropsychologist. The Scottish Government need to look at the NHS for all conditions. I have learned more about my condition through the National Tremor Foundation. For essential tremor, there is no specialist nurses in Scotland.

Alice Struthers: Unfortunately, your situation is not unique. We need to get a way of providing better information to GPs so they can recognise conditions more readily and make referrals more quickly and with more confidence.

Rona Johnson: Looking beyond 2025, what do you think we have learned from the framework so far, and what should be included if there is a further framework?

Alice Struthers: We have learned it is very complicated to develop and implement strategies, but collaboration is key. Different conditions have different needs, and we need to level up the available workforce to manage different conditions across the country. It is also difficult to improve services in a pandemic. If looking past 2025, we could have a strategy that addresses children and young people with neurological conditions. Transitions is one of the commitments made in the existing framework, but because children and young people are not included in the existing strategy, its quite difficult to improve.

Anna Telfer: What do you think would be the most beneficial recommendation to initially focus on?

Alice Struthers: To get a handle on prevalence to better understand the numbers of people with different conditions across all health boards and work out a workforce that will address those conditions. And for Island boards to have sufficient resources so people are not having to travel significant distances or rely on virtual appointments.

Katie Russell: Questioned the responses across health boards.

Alice Struthers: We got data from all health boards. For 11 of the boards we can look at the results in detail, three of them we did not get enough responses for this.

Tanith Muller: What was the most surprising thing you saw in the data?

Alice Struthers: How long people are waiting for appointments, and that in appointments, people are not getting an explanation of what their condition is, and they are not being signposted onto support. People are already stressed about waiting for their diagnosis, and we have had a lot of people say they were told to YouTube or Google it. This does not help people to manage their condition.

Keith Park: You are seeing a lack of information given to people when they've been newly diagnosed. Is it possible to look at whether that is linked to some of the delays in people accessing specialist nursing?

Alice Struthers: I'm sure it does. It's not something I've looked into, but I think MS is one of the conditions for which the breakdowns are big enough to allow condition specific information throughout the data set, so that's certainly something we can look and see if there's a correlation there.

Vicki Burns: Was there anything in the research about the role of the voluntary sector?

Alice Struthers: There is definitely a role for the voluntary sector. In the NAOs, we talk about how we can provide meaningful information to GPs to allow them to come to make quicker referrals and know more about conditions. There was strong support for third sector

resources, and there was a lot of comments in the research of people putting value on the charities and so the voluntary sector is absolutely critical.

Laura Ingram: Did the research show the number of people with more than one neurological condition and the treatments options available for that?

Alice Struthers: We did ask this, the number was quite high. Questions didn't ask specifically about treatment options. This could be considered for future research.

Agenda item 4. David Torrance MSP welcomed the Minister for Public Health, Women's Health & Sport, to deliver the Government's response to the report.

Maree Todd MSP:

As we move through remobilizing and reforming the delivery of health and social care in Scotland, I am really keen to hear first-hand about the experiences and priorities of the neurological community and that's why we funded the Neurological Alliance to help facilitate this patient survey in Scotland.

The time frame for this survey does encompass the most severe pressure our NHS has ever experienced. There are clear issues highlighted in the report which we're working hard to address through strategies like our any NHS recovery and workforce plans. We know people have faced delays to diagnosis and treatment, and we know that further action and investment is needed to make sure that people with neurological conditions can access timely and sensitive of diagnosis and care. Our NHS recovery plan is backed by more than a billion pounds of funding over the next five years.

The report shows that a high proportion of people feel their neurological condition negatively impacts their mental health. The findings really emphasise the need for more easily accessible, appropriate, high quality mental health support. We are determined to improve access to mental health services for everyone that needs them. To ensure that we reflect the current mental health and wellbeing needs of people in Scotland we're going to set out refocused mental health commitments. That is going to be a key opportunity for us to review and improve mental health support available for people with long term neurological conditions and we will definitely be engaging with the NAOs.

The report urges better data collection and I'm pleased to say a search of primary care data systems being completed for neurological conditions that will be published this summer and that will provide much more reliable prevalence data than ever before, helping to support service planning, which again another specific mask from that present.

The 35 projects funded through the neurological framework since October 2020 have had a direct impact on improving patient care and support and see NHS and 3rd sector working collaboratively together to bring about local improvements and services. As we reached the midpoint of our framework implementation, we're going to shortly publish a report setting out significant impacts made to date and the ongoing work to bring about lasting changes to neurological services across Scotland.

Rona Johnson: How are the Scottish Government planning for post 2025, after the neurological framework comes to an end?

Maree Todd: We are always looking ahead. One of the biggest priorities at the moment is to understand where we are right now and to understand the impact that the pandemic on the neurological population. We have to get to grips with that before thinking ahead. I know the pandemic has been the biggest test for everyone in Scotland, but there are some positives. We have been able to collaborate with people and flex in a way that we have never managed within healthcare before. We've proved during the pandemic we can do it. To reassure you, we are thinking ahead.

Tanith Muller: In the pandemic people who relied on things like day-care centres saw services closing, why are they still not back?

Maree Todd: The pandemic has had an impact on some more than others, like children and young people, and people with disabilities. Nationally, we have to work to improve the situation on the ground, but it will be different solutions in different places.

Morna Simpkins: We heard 44% of adults had their specialist nursing appointments delayed and there was a lack of information given to people when diagnosed. We have recently been told NHS Western Isles are reducing the capacity of their specialist nurse service. Can the government persuade the health board to place more value in that specialist nurse service?

Maree Todd: I don't think the reason they are changing the service is that they don't value it. It is not a challenge as likely to arise in mainland health boards. The Western Isles faced staff absences over the last couple of years highlighting the lack of resilience in the system. When the specialist nurse was off, people got no service at all. Their wish was to build a more resilient system. Specialist nurses are valued.

Helen McDade: We need to move past the pandemic. 25 years ago my daughter was ill for 30 years and didn't see a neurologist and the same experiences are being had today. We need a recognition by the Scottish Government that something has to change in terms of how people with neurological conditions are treated, particularly one which aren't as well recognised.

Maree Todd: There are several changes afoot in the way that the medical profession operates and whilst neurological conditions are often misunderstood, I find this common across my portfolio. We are working across the board to make sure that our health service is responsive, is empathetic, that people can access the care and expertise that they need close to their homes. I'm very clear that the experiences some people are having are not good enough and it is not entirely about the pandemic. I can't wish away the reality of the pandemic, there is no doubt that we are experiencing extreme strain in our health care service right at this moment.

Agenda item 6. Close

**Epilepsy Consortium Scotland (ECS) Secretariat Rona Johnson: 48 Govan Road,
Glasgow G51 1JL**

Tel: 0141 427 4911 Email: rjohnson@epilepsyscotland.org.uk