neurological
alliance
of scotland

Together for the One in Six, findings from the My Neuro Survey in Scotland.

June 2022

Contents

1. Forewords

Program Director

Scotland has sought to champion improvements to neurological care in recent years, with the Neurological Care and Support Framework for Action (2020-2025)[i] and the Neurological Care Standards (2019)[ii]. People in Scotland also benefit from free prescriptions, and free personal care is provided to anyone irrespective of age, whether living at home or in a care home who is assessed as needing it. Nursing care is also free for people of any age living in care homes, provided they are also assessed as needing it.

However, despite new policies and strategies designed to improve neurological care, Scotland shares the same pressures as the rest of the UK. Covid has exacerbated an already stretched NHS, with access to secondary care and social care being particularly difficult. There are shortages in established specialists such as neurologists, neuropsychologists and neurophysiotherapists and a lack of progress with newer specialities such as neuroimmunologists and neuroendocrinologists, amongst others. Specialists who are in post routinely report being at capacity and struggling to cope with demand. The delivery of social care is overly reliant upon unpaid carers, who are predominately women, with a significant proportion being under the age of 18[iii]. Transitions between services, particularly from paediatrics to adults, continues to cause a damaging drop-off in care and support.

Lack of co-ordination between primary, secondary and community care and between health and social care is another major concern. People report lengthy delays between services, promised appointments are failing to be scheduled and people are having to use limited time repeating their history with each health and social care professional that they meet. This report analyses the Scottish responses to the 2021/22 National Neurology Patient Experience Survey (known as #MyNeuroSurvey). This is the first-time neurological experiences have been collected in this way across the whole of the UK. The survey was designed to capture the experiences of both adults and children living with neurological conditions. The questionnaire also captured the experiences of carers.

There were 7881 adult responses across the UK to this survey, of which 10% (784) came from Scotland. 629 children and young people responded across the UK, of which 8% (50) came from Scotland.

This report summarises the responses in relation to existing NHS Scotland Neurology services. It draws conclusions and makes recommendations for systemic change.

References to Scotland data in the report refers to data from respondents with a postcode located in Scotland. UK data refers to data from respondents across the whole of the UK, including Scotland.

It is clear from survey responses that people with neurological conditions are further than ever from accessing care and support which meets their needs to live well. It is imperative that the recommendations in this report are adopted to truly improve the lives of families living with neurological conditions in Scotland.

Alice Struthers,
Programme Director,
Neurological Alliance of Scotland

Foreword by Clinical Neuropsychologist

Many thanks to all the 834 people who participated in this study which gives important insights into the reality of living with a neurological condition. There are sobering conclusions with some basic principles of care and wellbeing for those with a neurological conditions not being met.

With 80%-95% of those who responded reporting that their condition negatively impacts their mental health we need to provide holistic care integrating both physical and mental health and understand, in real terms, that they have equal parts to play in peoples overall wellbeing. Holistic care is something the Scottish Government, the NHS and Health and Social Care supports, in principle, however this needs to be realised at a very practical level for patients.

Change in systems is difficult but change needs to happen and we cannot continue to ignore the growing needs of a significant proportion of the population – it is unethical to do so. It is also, simply put, unequitable that patients with some conditions get a more robust service than others. We know that doing nothing increases poor physical and mental health making it more likely that patients will need more help and support. We need to stop being reactive and start being proactive. Early support at diagnosis with treatment options appropriate of individual needs is critically important.

The pandemic has not made life easy for all of us but particularly those with a neurological condition. Services, and budgets, are stretched to their limits more now than ever. Despite this however we all know of pockets of excellent partnership working, dedicated hard working clinicians, patients who continue to challenge the system and family members who fight for the needs of their loved ones. This work needs to continue and I have great respect and admiration for those who continue, despite setbacks, to confront these inequities and remind us that we all have a duty of care.

The report highlights the need that all of us continue to work together in partnership and makes clear recommendations of how we can start provided a better service – through better understanding of prevalence of different conditions, through integrated delivery of care and building links with the voluntary sector, through addressing the crisis in mental health and critically, thinking ahead beyond the end of the Neurological Framework for Action by preparing for the future care and support of adults and children with neurological conditions.

Dr Fiona Summers
Consultant Clinical Neuropsychologist

2. Introduction

The 2021/22 National Neurology Patient Experience Survey presents a comprehensive picture of the experiences of people living with a neurological condition across the UK. It is the only neurological survey exploring the views of people living with a wide variety of conditions. This is the first time that Scotland has been included within the survey. It is also the first time that the views of children living with neurological conditions have been included.

The survey gathers data on a wide range of topics, including the impact of covid, diagnosis and treatment, experience of hospital care, support for mental wellbeing, access to social care and welfare, education and employment. Its findings therefore present a comprehensive picture of people's experiences of living with a neurological condition in 2021/22. In the absence of nationally collected neurological patient outcome measures- or social care data which is segregated by condition- this approach provides intelligence about how well health and care services in the UK are performing for people with neurological conditions. In particular, it provides a benchmark of the huge impact of living through the pandemic with a neurological condition

The survey was open to the public between October 2021 and February 2022. People could access the survey online or via paper copies as supplied by neurology clinics, although this second option was limited due to infection control measures.

Data on ethnicity was limited despite efforts to engage with minority ethnic groups. Across the UK, 92% of adult respondents described themselves as 'White English / Welsh / Scottish / Northern Irish / British'; only 2% respondents described themselves as being a member of a minority ethnic group.

The survey responses are also biased towards women, with over twice as many women taking part in it.

This report offers the best current understanding of what it is like to live with a neurological condition in Scotland and presents recommendations for improving the health and wellbeing of the nearly one million people who live with a neurological condition throughout the country.

3. Key Findings for Scotland

Some of the key themes in Scotland were consistent with the findings for the UK as a whole:

- Delays to treatment and care. In Scotland almost half of the adults (49%) and more than half of children (55%) experienced delays to access a routine neurologist appointment. However, children experience delays across more services than adults, and five times more children were awaiting diagnosis than adults.

- Mental health support crisis. In Scotland, 4 out of 10 adults (40%) and 3.5 out of 10 children and young people (35%) reported that their mental health needs were not being met ‘at all’.

- Lack of information and support. Receiving a diagnosis is often life changing and requires ongoing support and information. Yet in Scotland a third of adults (30%) and over a third of children (38%) were given no information at diagnosis, and a quarter of children (26%) and a fifth of adults (18%) said they received no explanation.

The findings on the next page illustrate the issues reported by patients and carers in the survey.

Delays to treatment and care

37%	38%
Adults	Children and young people

Waited more than 12 months to get a diagnosis

67% of children and young people preferred face to face appointments

50% of adults believed remote appointments are helpful

Main delays over the last 12 months

- 72% of children and young people and 49% of adults experienced a delay accessing mental health services
- 58% of children and young people and 47% adults experienced a delay accessing physiotherapy
- 53% of children and young people experienced a delay accessing wheelchair services

The mental health support crisis

80%

Adults

95%

Children and young people

said their neurological condition negatively impacts their mental health

- 78% of children and young people and 44% adults said their mental health has worsened through the pandemic
- 57% adults and 22% of children and young people have not been referred or directed to support for their mental wellbeing, but would have liked to have had this support

Lack of information and support

92% of children and young people did not have a named worker (someone to help plan transition to adult services)

- Only 36% adults and 26% of children and young people 'completely understood' the explanation of their condition given at diagnosis
- Of those who received information about their condition, 32% of children and young people and 18% adults rated it as 'poor'

83%

Adults

67%

Children and young people

had not been assessed for social care needs

4. The wider context

Ongoing impact of COVID-19

- **People with neurological conditions and unpaid carers are more isolated**
- **Services are more difficult to access**
- **The burden on unpaid carers is increasing**

The covid pandemic has had a profound impact on people with neurological conditions and unpaid carers. Our **Living through Lockdown Report** found that people's mental and physical health were both profoundly affected, with consistent reports of worsening anxiety and deteriorating symptoms across conditions. People struggled to access the care and support they needed, from NHS and social care services to exercise, transport and shopping. Unpaid carers reported increased pressures and reduced support, many relatives also stepped into caring roles for the first time.

For children with neurological conditions, education was even more disrupted and challenging. Many families struggled with home education, but many were fearful about the implications of sending vulnerable children who do not meet strict vaccination criteria back to school and into social settings. The overall picture was one of isolation.

After two years, the pandemic continues to cast a long shadow over people with neurological conditions and their families. We surveyed 267 people with neurological conditions and unpaid carers about experiences of accessing healthcare online in Summer 2021. Our **Review of Virtual Consultations in Scotland report** found that only 4 in 10 people (41%) had been able to access face-to-face healthcare since the start of the pandemic. About 1 in 3 (32%) had been offered a video appointment. 9 in 10 respondents had been offered a phone appointment. 1 in 5 respondents felt that phone appointments would never be appropriate for them.

According to **Carers Scotland**, the total number of people providing unpaid care in Scotland increased by over a quarter during the pandemic - rising from under 800,000 people to over 1 million.

NHS Scotland and social care services remain under huge pressure as a direct result of the continuing pandemic. People remain less likely to access primary care than before the pandemic. Routine hospital appointments and procedures continue to be cancelled at short notice, and hospitals are running at capacity. Staff absences are adding to the pressures faced by services.

Cost-of-living crisis

- **The cost-of-living crisis disproportionately affects those with neurological conditions**

Many people with neurological conditions already face high living costs and low incomes due to their condition. Households with children with neurological conditions are similarly affected. Over 1 in 4 (27%) of survey respondents in Scotland said that they did not have enough money to manage well, and 1 in 5 (20%) said that they were struggling to cover their costs.

Despite free prescriptions in Scotland, open responses to the survey show that people who have the means are turning to the private sector to access healthcare to reduce their waiting time for treatment, creating a two-tier system. Those without financial means are left to wait.

This survey fieldwork took place before the recent fuel and other inflationary price increases. These findings suggest that the cost-of-living crisis will become an even greater issue across the neurological community in Scotland. Where people on low incomes are already struggling to meet their housing, heating and food costs, the increase in daily living costs will push even more households over the edge and into extreme poverty.

Households forced to make choices between heating and eating will already have sacrificed other activities involving transport and access costs, with only prescribed, access-supported activities remaining as available options. People with neurological conditions and their families risk being isolated in their homes, with reduced physical activity and no social contact beyond their household.

> **“I only manage my prescriptions because I don’t have to pay for them as I live in Scotland thankfully.**
>
> - Adult with cerebral palsy

> **“All care and treatment I have had for PPPD has been in the private sector (including neurology appointments). I am lucky enough to have a good job and private health insurance but have still had to source all info and help (CBT and physio) by myself. I would be in despair if I was reliant on the NHS.**
>
> - Adult with Persistent Postural Perceptual Dizziness

Health and care services for people with neurological conditions

- **Access to care and support is very variable, and there are concerns about charging for social care**

The Scottish Government's **Neurological Care and Support Framework for Action 2020-2025** sets out a vision for driving improvement in the care and support for adults with neurological conditions in Scotland with £4.5m of development funding.[iv] Discussions are ongoing to develop a supplement to the Neurological Framework for children and young people living with neurological conditions.

The Scottish Government has also committed to creating a National Care Service for Scotland. This provides an opportunity to reform and improve the experience of adults and children with neurological conditions, as well as the unpaid carers who support them.

While the Scottish Government has legislated to provide free personal and nursing care for all adults, we are concerned that not all council areas are making funding available as they should. Wide variations in charging policies and eligibility for care remain, and shortages of social care workers mean that it can be impossible to access care packages in parts of Scotland. We welcome the Scottish Government's commitment to remove all charges for home-based care, but it is not clear how this commitment can be met in light of workforce pressures.

We are also concerned about ongoing charging for people living in care homes. In 2019, self-funding residents and their families faced average weekly charges of £995 with nursing care, and £894 without nursing care.[v] We believe that charges for people in care homes risk penalising those who require the highest levels of care as a result of their neurological condition.

Prevalance of Neurological Conditions in Scotland

- **The Scottish Government, NHS Scotland, the new National Care Service, health and social care partnerships and local authorities must do more to collect data on neurological conditions.**

Data on the numbers of people affected by neurological conditions in Scotland is very poor - and we believe that all statutory bodies must prioritise action to improve this. In 2003, the Neurological Alliance of Scotland estimated that about one million people in Scotland were living with a neurological condition. Nearly two decades on, there remains little data on which to base an up-to-date estimate.

The Association of British Neurologists has estimated that neurological conditions account for between 10% and 20% of acute medical admissions.

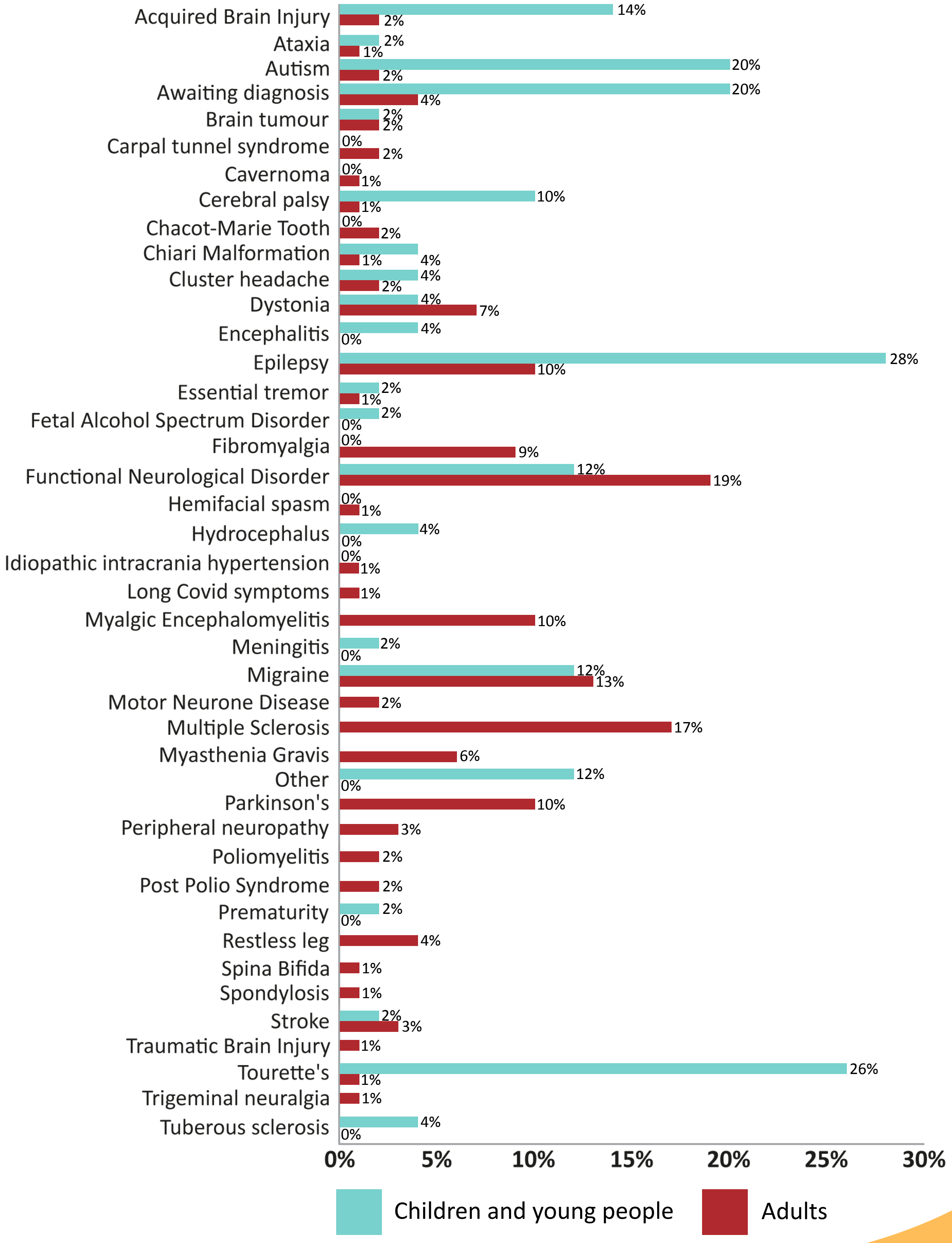
The Scottish Burden of Disease study estimates that neurological conditions contribute 10% of the overall burden of disease in Scotland. However, these figures only include seven listed neurological conditions. Most conditions are excluded. For example Functional Neurological Disorder (FND) is not included. FND is the second most common reason for referral to neurologists after headache. It is also the condition with the highest number of responses in our survey. 19% of adult respondents and 12% of children and young people in Scotland told us that they had FND.

The lack of reliable data means that planning to meet the needs of people with neurological conditions is- at best- a guess. The Scottish Government's Health and Social Care **Workforce Strategy** was published in March 2022, and it does not specifically address neurological conditions.[vi]

In light of current waiting times for people to access services, and Scotland's ageing population, it is vital that statutory organisations commit to collecting condition-specific and pan-neurological prevalence data so that they can plan and resource the services that people need.

Responses by condition in Scotland

We collected responses from people across a wide range of neurological conditions, including those awaiting diagnosis. The chart below shows how many responses we received from respondents in Scotland.



5. Important themes

Sex

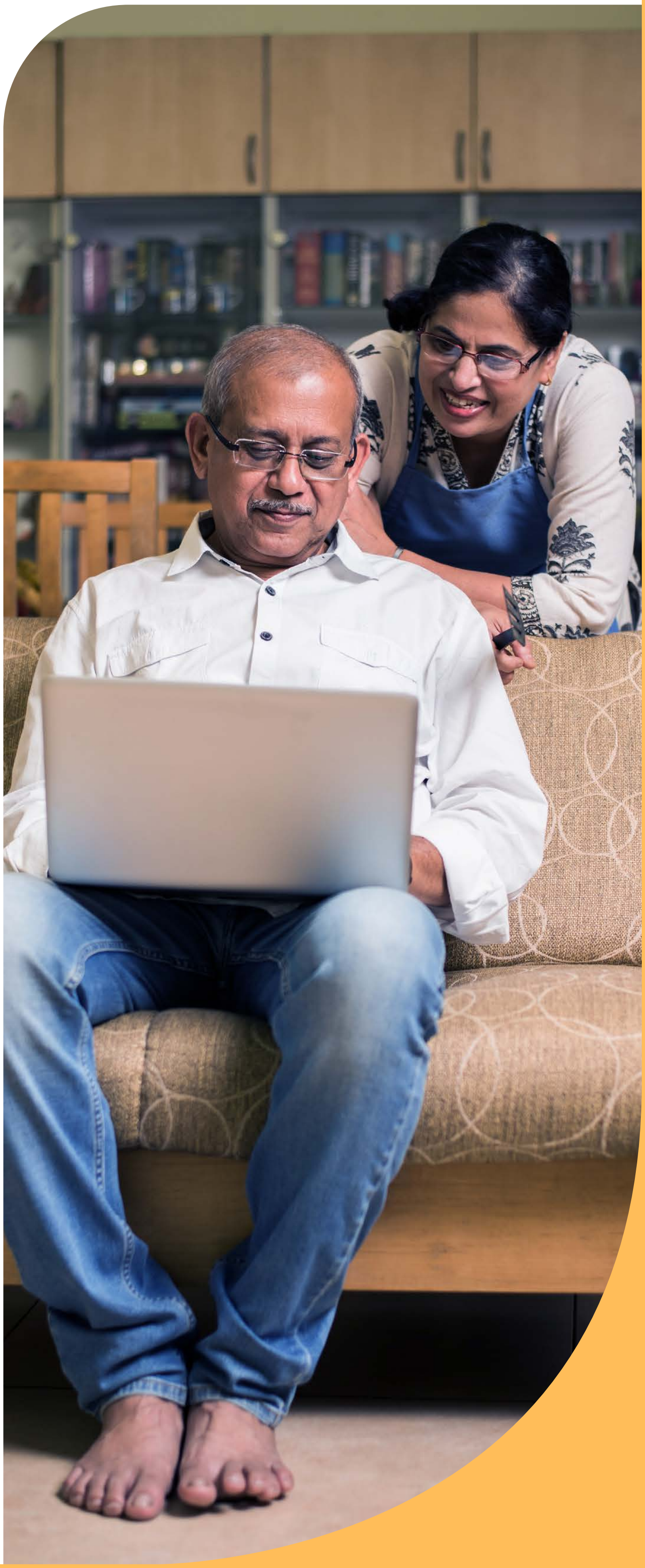
Women across the UK are disproportionately affected by some neurological conditions:

Condition	Women	Men
ME	70%	30%
MS	75%	25%
Migraine	75%	25%
Dementia	70%	30%
Fibromyalgia	87%	13%

This is reflected in our survey, with more women than men taking part.

Carers

Unpaid carers are really important. 52% of adults and 58% of children and young people **from our survey** in Scotland rely on an unpaid carer.



Income and deprivation

Wider evidence suggests that people from low-income communities are more likely to have a neurological condition, in particular dementia[vii], head injury[x] and stroke.[ix]

Social deprivation also has a bearing on access to health and diagnostic services, ability to access remote appointments, ability to pursue patient-initiated review or follow up, and on ability to self-manage. Those in the poorest postcode areas in Scotland are waiting the longest for some services including routine appointments with a specialist nurse, mental health services, occupational therapy and wheelchair services.

Multiple conditions

60% of adult respondents in Scotland live with more than one health condition, in line with the UK as a whole (59%). Living with more than one health condition can make treatment more difficult. It increases the risks of medication problems, and fragmented care often makes life more complicated.

Pain and quality of life

The experience of pain may be underestimated for those with a neurological condition. 59% of both adult and child and young people respondents live in moderate to great pain caused by their neurological condition. While adults' experience of pain is similar to the UK as a whole, the situation is much worse for children and young people in Scotland, 59% of whom reported moderate to great pain compared with 48% across the UK.

79% adults in Scotland said that their condition has a moderate to great impact on their ability to participate in life events, and 78% said their neurological condition has a moderate to great impact on their day-to-day activities. Both of these are in line with the UK as a whole (80%).

88% of children and young people in Scotland reported that they are struggling with day-to-day activities. This is much higher than for the UK as a whole, where 76% of children and young people reported this.

Employment

25% of adult respondents in Scotland have had to leave work due to their employers' action (or inaction) in line with the whole UK (28%). 61% had to leave work due to their neurological condition symptoms (58% UK) and 28% respondents had been discriminated against at work (32% UK).

More adults in Scotland were out of work due to their disability (33%) than across the UK (29%).

Education

Children and young people with a neurological condition in Scotland have a more negative experience of being at school compared to those across the UK. Only 57% of children and young people in Scotland agreed that their school had made useful changes to allow them to attend, which compares with 63% for the UK.

54% of children and young people in Scotland said that staff and teachers listen to them at school. Again, this is much lower than the 62% measured for the UK. 49% said that other children at school are friendly, which compared with 59% in the UK.

Children's Services

Children's services for those living with a neurological condition, are not good enough. They are disconnected and there is a lack of responsibility for those accountable to children, resulting in a lack of integration from child to adult services. Service providers often lack understanding of neurological conditions, and common features such as fluctuations. The Neurological Framework only applies to adult services, so there has been no systemic attempt to deliver much-needed improvements in care and support for children and young people.

6. Scotland in Focus

a. Delays to treatment and care

- **The pandemic has had a negative impact on waiting times across all areas**
- **GPs and non-neurology specialists do not know enough about neurology**
- **There is inequity of access to care across Scotland**

Our research shows that in some areas, people with neurological conditions have continued to receive great care through the pandemic.

However, the majority of respondents have experienced serious delays to treatment and care, which across the UK have been made worse by the pandemic. 69% of people with MS were not able to speak with a specialist when they needed to.[x]

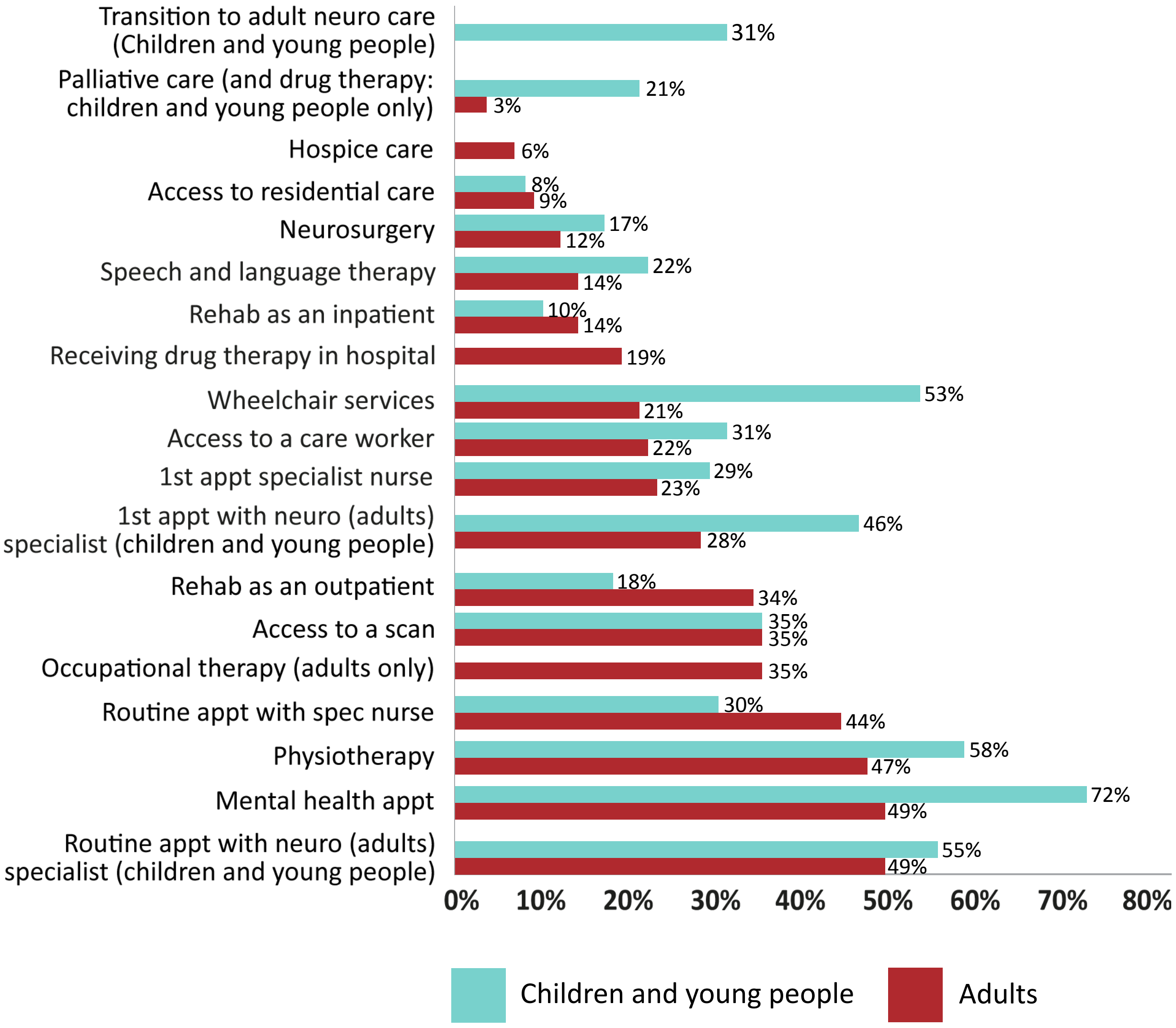
> **I have had excellent care since diagnosis and can't thank the staff enough.**
>
> - Adult with Dystonia

> **21 weeks later, I had an echocardiogram of my heart and, at the moment, that's it. I am still waiting for the Physiotherapy to start (8 months later)...A lot of the hospital appointments got postponed.**
>
> - Adult with stroke

> **Was told today we were receiving good news. After a year and a half on [a] waiting list we have now been move to priority. Unfortunately, that is a priority waiting list.**
>
> - Parent of young person

> **It took 3 years to get initial neurologist appointment, a further 6 months for specialist neurologist appointment.**
>
> - Adult

% service delays experienced



Waiting times

The Waiting Times Standard in Scotland states that 95% of patients across all conditions should receive an outpatient appointment within 12 weeks and 100% patients should receive treatment within 12 weeks.[xi]

Only 25% of adult respondents and 44% of children and young people **from our study** saw a neurologist within 12 weeks of referral.

37% of adults and 38% of children and young people in Scotland waited more than 12 months to get a diagnosis. This is worse for young people than in the UK as a whole where only 30% waited for more than 12 months.

Adults in our survey waiting over 12 months to get a diagnosis are most likely to be those with peripheral neuropathy (64%), ME (58%) and fibromyalgia (49%).

Neurological conditions are often hard to diagnose, and a recurrent theme in the survey is the lack of knowledge amongst GPs, with some dismissing symptoms as anxiety rather than referring onto neurology.

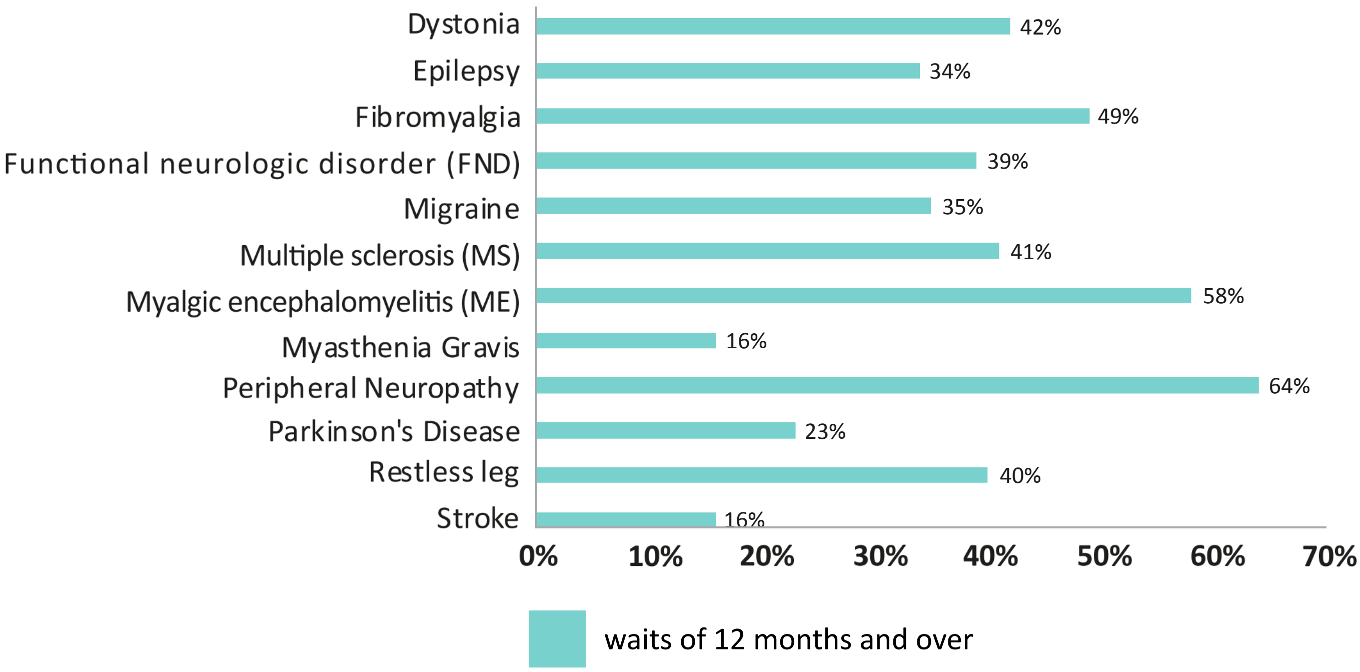
> **“It is essential that GPs and physiotherapists learn more about neurological conditions and are able to recognise the symptoms. I suffered greatly - and would be still suffering - if the new GP had not taken over.**
>
> - Adult with dystonia

> **“GPs need better training. I’m not expecting them to recognise every disease, but to know when to refer.**
>
> - Adult

49% of adults experience delays accessing mental health appointments. Those with FND and ME have borne the brunt of this, with 75% adults with FND and 72% adults with ME experiencing an appointment delay in the past 12 months.

> **“ I am reliably informed that most GPs have not had any training in this condition.**
>
> - Adult with ME

Waiting times to get a diagnosis by condition

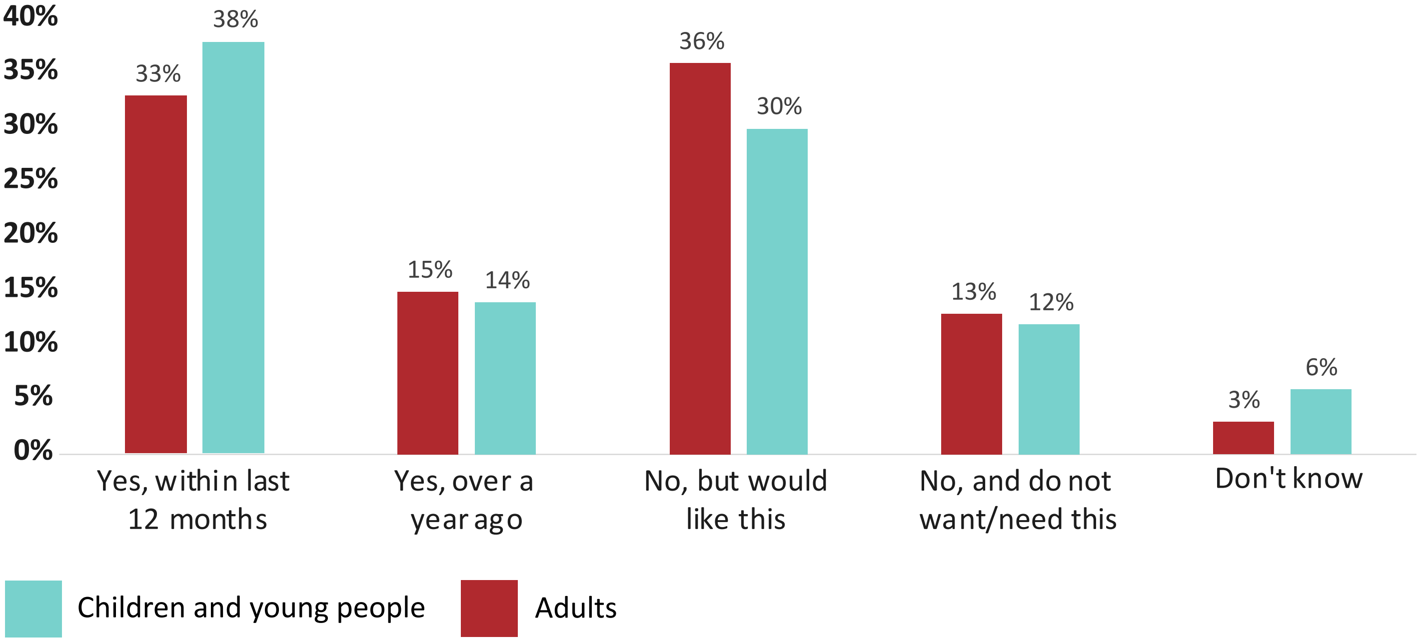


Specialist nurse

Access to specialist nurses is very difficult in Scotland in line with the UK. Issues include long waiting times, conditions without specialist nurse provision and variability of provision between NHS Boards. This further widens health inequalities across Scotland.

> **“Never been referred to a first seizure clinic. Never had access to an epilepsy nurse.**
>
> - Adult with epilepsy

Appointment with Specialist Nurse



Of those who have access to specialist nursing, 15% of adults and 14% of children and young people last saw a specialist nurse over a year ago and 36% of adults and 30% of children and young people have never been offered an appointment with a specialist nurse but would like one. 33% of adults and 38% of children and young people had seen a specialist nurse in the last 12 months.

23% of Scotland adult and 27% UK adult respondents had experienced delays accessing their first appointment with a specialist nurse. 44% of Scotland adult and 43% UK adult respondents had experienced delays accessing a routine appointment with a specialist nurse.

There is only one ME specialist nurse available in the whole of Scotland. ME charities have been calling on the Health Department to provide more specialist nurses for 20 years.

Some charities, including the MSA Trust, Cerebral Palsy Scotland and Scottish Huntington's Association have filled that gap by employing their own nurses, allied health professionals, and care coordinators, but integrating this provision with NHS services can be challenging.

> **“ I have had very little support since being diagnosed with Myasthenia Gravis. Years later and having deteriorated considerably over the past two or three years I am still awaiting to attend and see the Myasthenia Nurse in Glasgow.**
>
> - Adult with Myasthenia Gravis

> **“ As far as I'm aware there is no such thing as a specialist in cerebral palsy which I think is very detrimental to both my physical and mental well-being.**
>
> - Adult with cerebal palsy

Delays impacting children

It takes a child roughly six months from seeing a GP to having a first appointment with a neurologist, but 16% of children and young people waited over a year to get their referral from the paediatrician to the neurologist.

Table of delays comparing Scotland with the UK in the last 12 months

Service	Scotland children and young people	UK children and young people	
Access to residential care	8%	13%	Best performing for Scotland
Rehabilitation as an inpatient	10%	18%	
Rehabilitation as an outpatient	18%	31%	
Treatment (drug therapy or palliative care)	21%	28%	
Speech and language therapy	22%	46%	
Routine appt with specialist nurse	30%	36%	
A scan	35%	46%	
Routine appt with specialist	55%	60%	
Brain surgery	17%	16%	No major difference between Scotland and the UK
1st appt with specialist nurse	29%	26%	
Access to carer or care assistant	31%	33%	
1st appt with specialist	46%	44%	
Transitioning to adult neurology care	31%	25%	Worst performing for Scotland
Wheelchair services	53%	39%	
Physiotherapy	58%	54%	
Mental health appointment	72%	60%	

In an analysis of delays over the past year in accessing 16 forms of treatment and care, children in Scotland fared the best in the UK across eight areas. These include: outpatient rehab, inpatient rehab, treatment (drug or palliative care), speech and language therapy, access to scans, access to residential care, getting a routine appointment with a specialist and getting a routine appointment with a specialist nurse.

However, compared with children across the UK, children in Scotland had the most delays accessing mental health appointments, transitioning to adult neurology care and with access to wheelchair services. UK data indicates that delays transitioning to adult care were more likely to impact those living with multiple conditions (51%) than those with a single condition (34%).

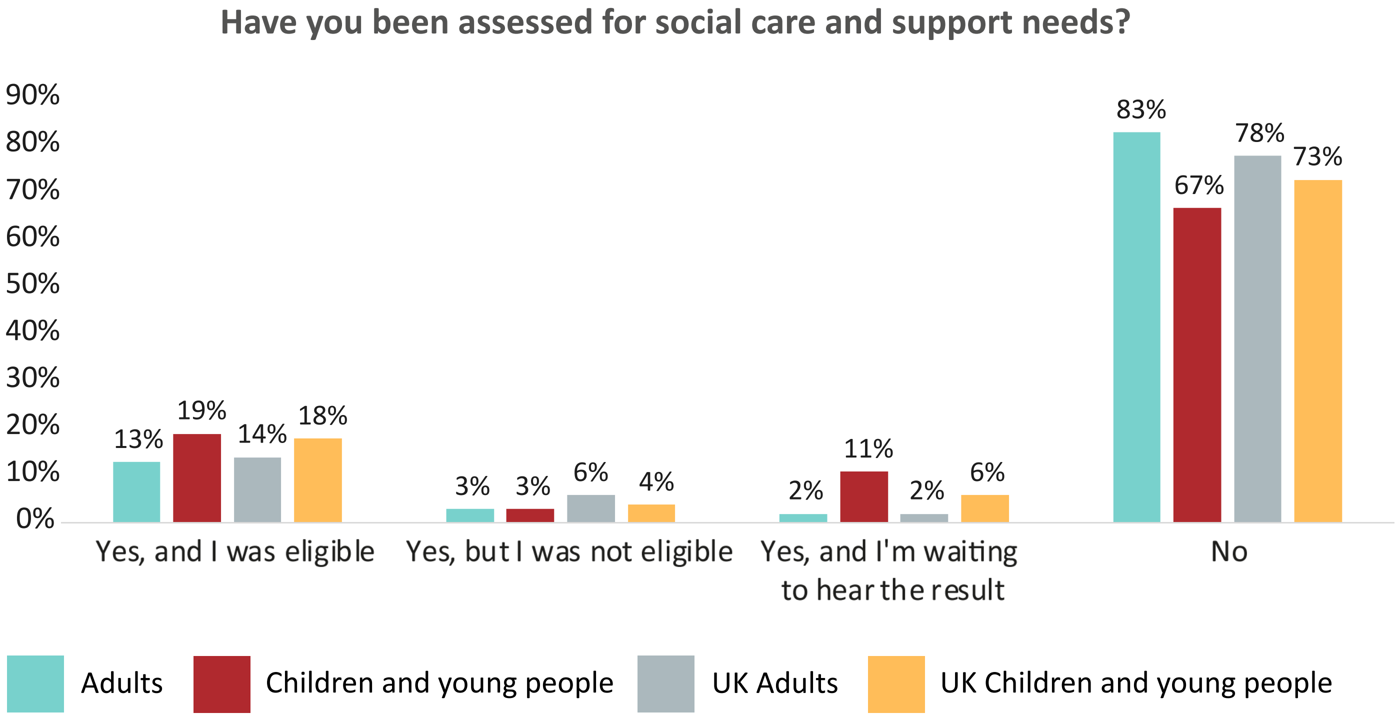
92% of children and young people in Scotland did not have access to a named worker – a professional who's involved in the young person's care and helps with the transition to adult services.

> **“ I have Cerebral Palsy. I will be 40 years old this year and I haven't seen a neurologist or physio since I was at school, I have never been offered any kind of mental health support for my disability. It feels as if people with cerebral palsy don't matter as soon as we reach the age of 18, it's like we stop existing to the professionals.**
>
> - Adult with cerebral palsy

> **“ I am only 19 years old but feel my life and prospects have been curtailed since leaving school abruptly in 2020. Attending mainstream school with very little transition interventions has been detrimental to my health and well-being. Nobody from social work seem interested in my well-being.**
>
> - Adult with inoperable plexiform neurofibromas

Social Care

83% of adults in Scotland had not been assessed for their social care and support needs – this is higher than the UK (78%).



There are particular issues for those conditions where there is no care pathway. For example, people with ME often struggle to access social care support. 70% of adult respondents with ME had multiple conditions. Many of them commented that their ME diagnosis obscures their doctor's ability to help them with their other condition.

24% of adults and 32% of children and young people who have social care support, said their experience of social care has worsened over the past three years. 31% of adults said they do not feel involved at all in making decisions about their own social care.

> **“ There is no care path for myalgic encephalomyelitis. There is no acknowledgement in primary care of vulnerability or care needs. Disability denial is common in primary care, within the DWP for financial support and in social care provision.**
>
> - Adult with ME

> “This survey assumes that there are services - health and social - for people with ME. There aren’t any services. None at all. Not only is there no interested neurology clinician in my area there are none in the whole of Scotland, where I live. Clinicians - in neurology and in wider healthcare - and civil servants simply have no idea of the size of the disease burden, which is large, nor the impacts on individual lives, which are usually severe. There is a desperate need for action.
>
> - Adult with ME

b. The crisis in mental health support

The survey highlighted a crisis in mental health support in Scotland, in particular:

- **People with neurological conditions need more mental health support**
- **Remote or online appointments do not work for everyone**
- **Children are being failed by the education system**

Living with a neurological condition can have a significant impact on mental wellbeing. Our survey found that 35% of adults strongly agreed that their condition has a negative impact on their mental wellbeing.

40% of adults in Scotland said their mental health needs are not being met ‘at all’. Over half of adults (55%) in Scotland have not been asked about their mental wellbeing in the last three years. 57% of adults would welcome a referral to mental health support.

Common causes of stress and mental distress include:

- **Lack of information about the condition**
- **Financial matters**
- **Lack of access to support and services**
- **Fears about how a condition may develop or progress**
- **Guilt about the impact of the condition on others**
- **Pressure on relationships**
- **Isolation and feelings of being abandoned**

> **“ After the movement disorder clinic there is no other support. This is very difficult to manage as I feel my mental health is probably worse than I realise.**
>
> - Adult

> **“ After 13 years, finally got a diagnosis, but was then discharged and nothing since. I feel abandoned. Any ‘new’ issues get swept under FND and get dismissed like I’m wasting their time. Constantly having to explain to medical professionals what it is and 50/50 chance they say all in your head / not real or just roll their eyes and don’t listen to a word you say.**
>
> - Adult with FND

Importantly, one size does not fit all – and for certain conditions, psychological or psychiatric interventions are inappropriate or unnecessary. A "mental health" label can act as a barrier to some people's physical health needs being met and can cause anxiety and frustration.

People diagnosed with a condition with no organic marker, such as Functional Neurological Disorder (FND) or Myalgic Encephalomyelitis (ME) report feeling disbelieved or ignored. Many respondents said they felt accused of exaggerating symptoms. This experience is also common when a person's clinician has limited experience with a condition.

> **"My GP has advised that if FND is confirmed there will be little treatment available.**
>
> - Adult with FND

> **"The professionals make you feel like you are making it up. This has had a massive effect on my mental health, and I have hit breaking point, I can't get any help**
>
> - Adult

> **"I feel sometimes like I'm not believed, as if I'm viewed as a liar. It's frustrating.**
>
> - Adult

> **"My brain tumour has been operated on and I am on 'watch and wait' for the remainder of it. My surgical care was good but other support and help were non-existent. I was made to feel unimportant and as if I was making a fuss because my tumour is only grade 1 and told that my cognitive fatigue and changes were not related.**
>
> - Adult with brain tumour

Disrupted education

Children and young people with a neurological condition talked about the strain of disrupted education. They said they were missing out on normal activities and friendships. There were common fears of being told off by teachers and school staff, or of being accused of making things up. Some services are only available through schools, and so not being able to attend school can limit a child's access to occupational therapy and speech and language therapy.

For anyone at any age, receiving a life-changing diagnosis is extremely difficult. For conditions which have limited treatment options, the impact on mental health is enormous. Anecdotally, many people referenced all support dropping off as soon as they had a diagnosis.

The majority of children and young people in our survey attended mainstream primary and secondary schools (29% primary, 37% secondary).

Not all mainstream schools consider the varying needs of children with neurological conditions. Lack of awareness of neurological conditions can make life difficult for both the child and their parents or carers. 70% of children said their attendance at school has been affected by their neurological condition.

Disrupted schooling has an impact on core learning but also on social development and mental health.

> “ **My school has also been horrible in helping me with my condition. I have been shouted at, told off and denied access to things I need to make my life easier. If they actually helped me my life would be so much easier but instead, they treat me like I'm faking it. I wish schools had more training and there were more laws to make sure this didn't happen.**
>
> - Young person

> “ **As the parent of a child with FND who is unable to attend school I'm appalled at the lack of knowledge of the condition within the education remit. My son has been off school for a year now and no adaptations have been made for him to return. There is no support for this condition.**
>
> - Parent of young person with Functional Neurological Disorder

Access to Child and Adolescent Mental Health Services (CAMHS)

Difficulties accessing Child and Adolescent Mental Health Services (CAMHS) were reported by many respondents, with some waiting longer than 12 months. There has been a surge in demand for CAMHS in recent months. As of 31 December 2021, 10,021 children were referred to CAMHS, up from 7,822 for the previous quarter.[xii]

> **“I am suffering from anxiety and depression. I can’t sleep and hardly go to school. I have asked for help, but nothing is happening with CAMHS.**
>
> - Young person

> **“We have been waiting over 12 months for the first appointment with CAMHS after being diagnosed by paediatrics.**
>
> - Carer of young person

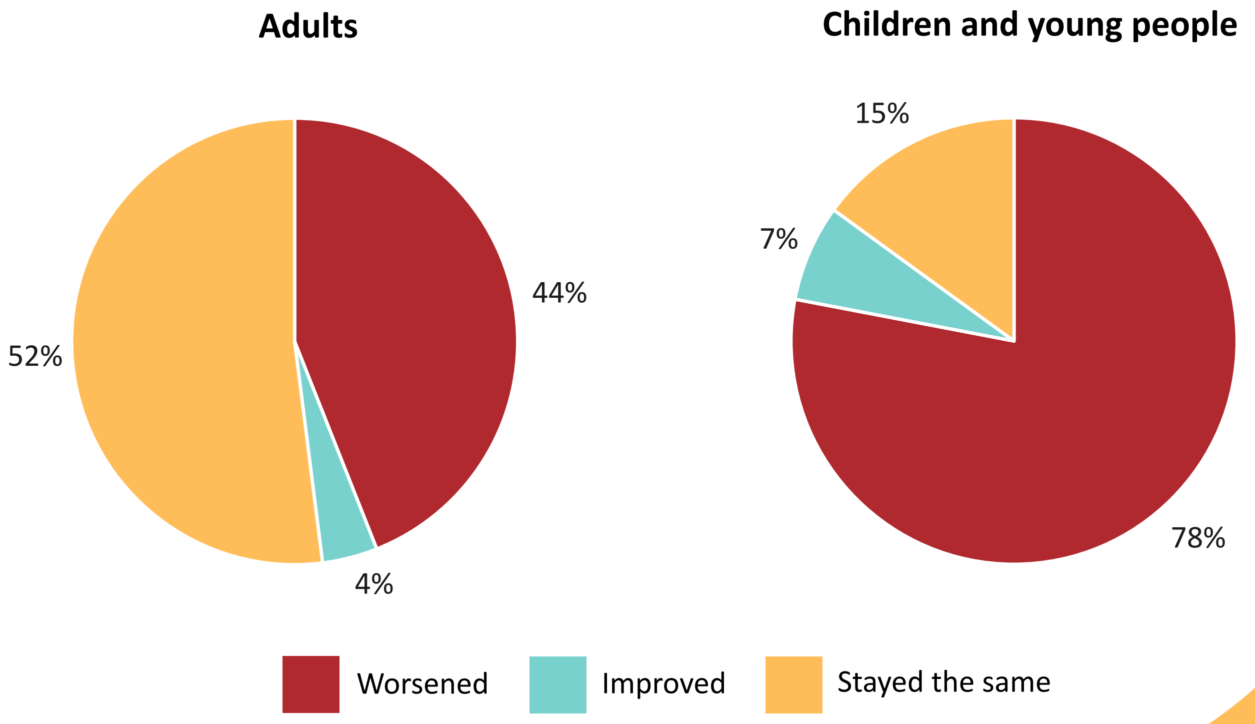
Covid

Covid has undoubtedly had an impact on mental wellbeing for both children and adults. The past three years have been extremely difficult for Clinically Extremely Vulnerable (CEV) people who have been shielding and who have therefore been very isolated.

For those who are not allocated to the Clinically Extremely Vulnerable list, covid has still been extremely difficult. In particular, restrictions on support for face-to-face appointments puts pressure on the individual to advocate for themselves and remember all the information provided to them.

> **“I would say the hardest parts of my condition is that I have been sent to the neurologist to diagnose me [but] I was not allowed anyone else in the appointment with me because of covid and that has impacted upon my fiancée’s understanding of the condition.**
>
> - Adult with FND

Mental wellness through the pandemic



On an operational level, covid has also reduced the availability of doctors available to treat neurological conditions. A report by the MS Society, **Neurology Now,** published in 2021 says 23% of MS professionals were redeployed away from MS services during the pandemic.[xiii] Clinics also had to introduce time between appointments to ventilate and clean rooms, impacting the number of patients able to get appointments in one day. Cancellation of appointments were frequently mentioned by respondents, causing significant stress.

> **“The pandemic and its mismanagement have driven my depression and despair to almost unbearable levels.**
>
> - Adult with ME

> **“I was referred to a neuropsychiatrist by my GP but this appointment never happened - I was seen by another neurologist instead, despite the fact that I have existing mental health issues and anxiety and stress are a major trigger for my migraines**
>
> - Adult with migraine

Virtual consultations

The move to online appointments has not worked well for those whose condition or anxiety makes communication difficult.

The move to virtual appointments through the pandemic has been particularly tough for some children, impacting compliance attending the meetings as well as triggering difficulties in communication.

> **“Seeing themselves in the computer causes their tics to become so much worse to the point they struggle to say what they want to.**
>
> - Parent of child with Tourette’s

> **“I was referred to inpatient residential stay via pain management clinic which was cancelled due to covid. I was offered video session by zoom but I didn’t feel I could follow them due to deafness. I was told because of this my referral was cancelled.**
>
> - Adult

> **“Teenager refuses to join online appointments and struggles to talk on the phone. Needs to be face to face appointments.**
>
> - Parent of young person

Mental health support

There is a range of mental health services available to people in Scotland, including neuropsychology, neuropsychiatry, counselling, talking therapies including Cognitive Behavioural Therapy and face to face support groups. However, here is inequitable access to these mental health services across health boards.

Across the UK, 26% of adult respondents from Scotland had been referred to neuropsychology compared with 18% throughout the UK, but Scotland had the lowest number of respondents referred to general therapy or counselling. (42% for Scotland compared with 48% UK).

Very few children and young people reported accessing a psychiatrist, psychologist, or therapist. but those who did reported that these interventions were very helpful. This support is subject to very long waiting times and is very hard to access. 95% of children and young people said that their neurological condition negatively impacts their mental well-being. Action is needed such as establishing peer support groups, training school counsellors and providing other support for children living with neurological conditions.

Only 3% of adult respondents in Scotland had been referred to a social prescribing link worker, in line with the UK as a whole.

Although 57% of adults in Scotland would welcome a mental health referral, 45% of those who had accessed mental health support said it has ‘made no difference’. It is not clear whether this reflects the quality of the mental health support that they have received, dissatisfaction from those whose mental health intervention was inappropriate or unwanted, or the fact that mental health symptoms can be hard to treat successfully.

c. Information and support

- **Patients are often not provided with meaningful information about their condition**
- **The Patient Initiated Review system often does not work**
- **Care plans are rarely provided. Patients do not feel involved in planning their care**

Receiving a diagnosis is often life changing; accurate information about the condition, common symptoms, medication and prognosis are vital to ensure the individual is a partner in their care and support. However, 30% of adults and 38% of children and young people left the consulting room with no information about their condition. Just 14% of adults and children and young people were directed to an NHS website and only 13% of adults and 16% of children and young people were given information about the condition from a charity.

Even where charity information was most widely given, it was given to a minority of people. Charity leaflets were most likely to be handed out for stroke (33%) and Parkinson's (24%). Those with ME (61%) and peripheral neuropathy (56%) were least likely to receive any information about their condition.

Of those who received information, children and young people were less satisfied. Children and young people in Scotland were the least likely in the UK to rate the quality of information they received as 'excellent'. 32% rated the information they were given as 'poor'.

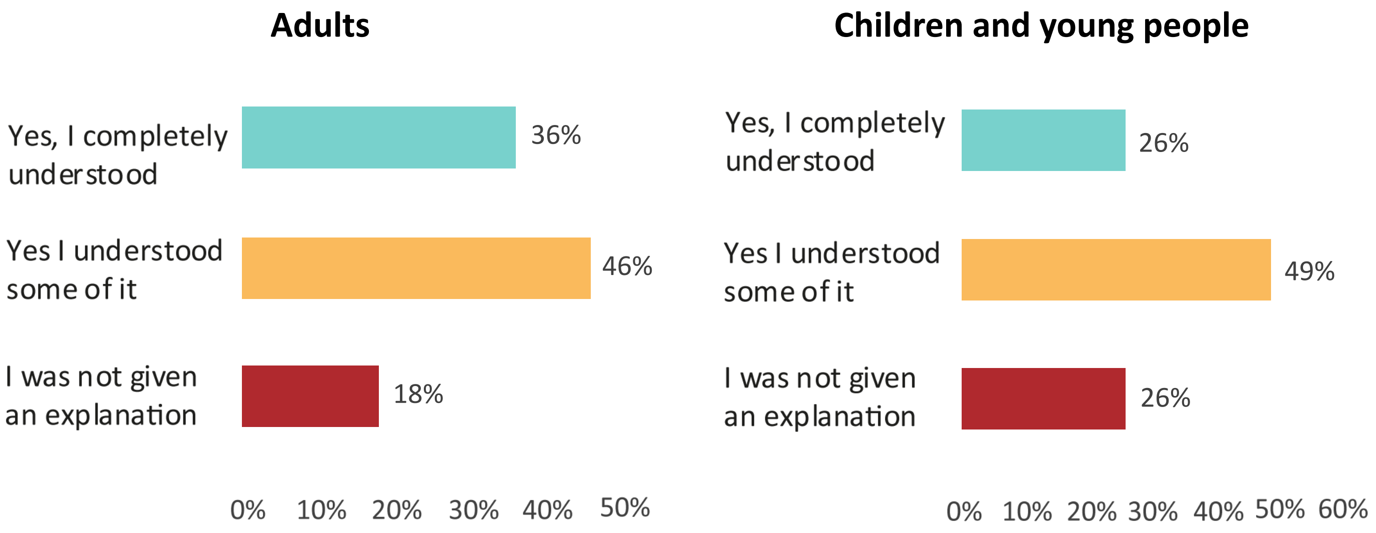
Adults in Scotland who received information were much more likely to rate it as "excellent" than the UK (23% vs 16%). There is still clearly lots of room for improvement in Scotland.

The lack of explanation of a condition, and lack of signposting to help following a diagnosis is particularly difficult for those receiving a diagnosis over the telephone.

> **"I was given a diagnosis of FND over the telephone during lockdown. I was told to look at a website which would explain it to me. No follow up appointments made with doctor or a nurse specialist etc. This was a bit of a shock to be told over a phone but with very little detail.**
>
> - Adult with FND

> **"After being admitted to hospital with suspected MS, I was discharged with nothing but details of a website and a letter stating that I will be seen by Physiotherapy and a follow up with a neurologist. I can barely walk and need a frame or a stick at all times. I was upset and frustrated to find out that none of the referrals had been made and I am now without any care - not even a referral from my GP to get back into the care system.**
>
> - Adult with MS

Did you understand the explanation given to you at diagnosis?



Risks arising from poor information

Given the lack of information that people report they have received, there are significant dangers of people not understanding their condition, with huge implications for shared decision making, self-management, and Patient Initiated Review.

Those who need to be pro-active about opting into the healthcare system through Patient Initiated Review may be at particular risk. Patient Initiated Review is a new process whereby the person is responsible for opting into ongoing appointments for their condition if they feel that they need support.[xiv] The purpose of PIR is to ”reduce the overall demand for review appointments” and ensure only those who need an appointment receive one.[xv]

The Neurological Alliance of Scotland is concerned that PIR is only suitable for people who have a good understanding of their condition.
These findings suggest that many people with neurological conditions may be missing out on the high-quality information that they need to engage with their care via PIR.

We are also concerned that PIR may not be suitable for everyone with neurological conditions, particularly those with complex conditions or for people whose condition has an impact on their mental health, insight or cognition or who face other barriers to care, such as low health literacy.

We are concerned that some people may miss out on the care that they need if they must contact services to arrange their own appointments.
In addition, not all everyone who is directed towards online resources will be able to access them. Deprivation plays a key part in the inability to self-advocate, and for those without access to the internet, smart phones or sufficient data capacity to be able to research services for their condition online, ability to self-advocate is heavily compromised.

> **“ After my second generalised seizure, the doctor came to me in hospital and said they were going to medicate me. I was the one who had to say oh, is it epilepsy then? And they said oh yeah. Which wasn’t a great way to find out and I wasn’t given any follow-up information except that I wasn’t allowed to drive.**
>
> - Adult with epilepsy

Insensitive diagnosis and unplanned care

The survey asked people whether their diagnosis was handled sensitively. Just 40% of adults and 28% of children and young people said that delivery of their diagnosis was definitely handled sensitively. Some respondents reported finding out about their condition accidentally.

People with neurological conditions should work with health professionals to develop a care and support plan. However, 82% of adult respondents and 69% of children and young people respondents in Scotland had no care and support plan. Of those who did have one, 35% of adults said they were not involved in it at all but would have wanted to be. This trend is reflected across the rest of the UK. (79% UK have no care plan; 35% in the UK wanted to be more involved).

People consistently feel detached from their treatment and care. 32% from all groups said they don't feel involved in decisions affecting their care.

> **“I have no care plan with my GP and only visit when I can no longer cope. They have no interest in the illness and are more likely to offer me antidepressants or be told to volunteer ‘to get me out of the house’**
>
> - Adult with ME/CFS

> **“Nobody should ever leave the appointment with a neurologist with a diagnosis and an apology for having run out of leaflets about the condition. This impacted so much more on my mental health than if I'd had a written responsible source of information about the diagnosis and where to find more information. This impacted on me for years and its only now I'm beginning to accept the diagnosis, 7 years later.**
>
> - Adult

> **“Very much, there's your diagnosis. Problem solved. On you go!**
>
> - Adult

> “I have very little faith in my neurologist which is distressing to me. He gives me very little information- I have to do my own research and turn to charities. He gives me no hope that I will live a better life with my epilepsy under control. He is not interested at all in how poor my quality of life has become
>
> - Adult with epilepsy

> “As a PPS person, I feel my condition is unknown in the medical profession. I’ve not had any offer of help with my condition and as such, have just managed my condition on my own. I’ve noticed a decline in my mental health possibly due to lockdown but possibly because my health is deteriorating too.
>
> - Adult with post-polio syndrome

> “This survey has raised the idea that I’m obviously meant to have a care plan which I don’t so I’m going to follow that up with my doctor
>
> - Adult with FND

7. Conclusion

One in six people in Scotland live with a neurological condition – that is, any condition affecting the brain, spinal cord or nervous system. There are an estimated 600 different neurological conditions, many of which are rare and complex. The vast majority have a significant impact on quality of life and many cause pain.

We believe that a positive difference could be made at each of the three main stages of the patient journey.

At the beginning

When initial concern over a symptom or symptoms motivates someone to contact their GP, they should be seen quickly. Too often, receptionist-led triage acts as a barrier to accessing a GP. We believe that GP appointments must be available to assess people with neurological symptoms.

GPs must listen to the whole problem and not dismiss symptoms as being common age-related issues, gender-related issues or anxiety. It is important for GPs to know when a referral to neurology is needed.

GPs need to have ready access to clinical information and specialist advice about neurological conditions, enabling them to have more confidence about when to refer and what advice and treatment to provide.

Seeing a specialist

Waiting times are too long. Health and care bodies need to understand the need for specialist staff to diagnose and support people with neurological conditions.

Waiting for an appointment with a specialist can be extremely stressful. Postponements and cancellations must be avoided where possible

When someone sees a neurologist for a diagnosis, it is essential that information is imparted in a clear and sensitive way, with signposting to immediately available and accessible support. Where a diagnosis is not time-sensitive, we would strongly recommend face to face appointments are made available, and for family and / or friends to be present.

After the initial appointment, people should know three things:

1. That they have a care and support plan, and they can be as involved as they like with the plan
2. They are at the centre of their care; their care and support will be co-ordinated across health and social care, and they can be involved in decisions affecting them
3. That help is also available via the neurological third sector and to have details of a relevant charity, either as a leaflet or provided as a website

Nobody should ever leave a consulting room, feeling like they are:

- making things up
- left without further support
- unimportant

People should be empowered with:

- Knowledge of the health and care support that they can access
- Information about their condition
- Signposting to third sector and community-based supports, including to support with social security benefits where needed

The picture for children and young people is generally at least as poor, if not worse than it is for adults in most sections covered by this survey. Delays in diagnosis and treatment, the enormity of coping with schooling and retaining friendships when education is disrupted, managing conflict with teachers and school staff, declining mental health, a lack of information and support for parents and carers, all lead to a difficult picture for young people.

In addition, there is a big reduction in support for people as they transition from child to adult services, between the ages of 16 and 18. More needs to be done to support children during this period. This includes ensuring support does not reduce as the child transitions, and for mental health support to be prioritised.

8. Scotland recommendations

The Neurological Alliance of Scotland makes the following recommendations to address the three core issues affecting neurological care and support in Scotland.

1. Understand prevalence

Service planners need to understand exactly how many people live with each different neurological condition in Scotland to plan the right workforce. The system for coding each condition needs to be adjusted so that each primary care and secondary care professional can accurately record numbers. This data needs to be used to improve services.

- There needs to be a neurological workforce that is fit for purpose

2. Deliver care seamlessly between different parts of the system

- **Primary, secondary and community care**

Improve communication and information sharing between primary, secondary and community care so that GPs are able to refer when needed and be able to offer expert advice.

- **Health and Social Care**

Improve co-ordination, communication and cooperation between health and social care services

- **Links with the voluntary sector**

Ensure the health and social care system recognises and supports the services and information that third sector organisations can provide

3. Address the crisis in mental health

- People with neurological conditions are more likely to suffer from mental health problems. Mental health support should be provided at the point of diagnosis and made available to people throughout the management of their condition. We urge specialist neurological mental health support to be available both for paediatrics and adults.

4. Prepare for the future care and support of adults and children with neurological conditions

The current Strategic Framework for Action on Neurological Care and Support will run out in 2025. It is clear that there is still a lot of work to be done, and we look forward to working with Scottish Government and others to develop a new strategy for adults and children with neurological conditions in Scotland.

We also join with other UK Neurological Alliances to call on the UK Government, Scottish Government, Welsh Government and Northern Ireland Executive to prioritise services for people with neurological conditions and establish a Neuro Taskforce. The taskforce would bring together relevant Departments, health and social care bodies, professional bodies, people affected by neurological conditions and the voluntary sector to:

- Assess the current neuroscience workforce and set out plans to ensure it is fit for the future
- Share approaches to common problems, such as addressing longstanding barriers to accessing mental, emotional and cognitive support, driving down waiting lists for elective care, improving the quality and analysis of health and care data and supporting transition between paediatric and adult neuroscience services.
- Assess the level of investment in research into the causes, impacts and possible cures of neurological conditions and set out plans to level up investment in areas that do not receive a fair share currently.

9. Our members

25% M.E. Group
Support for Severe M.E.

action for m·e

Alzheimer Scotland
Action on Dementia

ATAXIA

Brain & Spine Foundation

BRAIN TUMOUR ACTION

brainstrust
the brain cancer people

cerebral palsy scotland

Child Brain Injury Trust
hope for tomorrow - today

Dochas Centre
Supporting Unpaid Carers

Dystonia UK

epilepsy connections
Supporting people with epilepsy

epilepsy scotland.org.uk

FND HOPE UK
FUNCTIONAL NEUROLOGICAL DISORDER

Funding Neuro
Pioneering Treatments
Accelerating Cures
Saving Lives

gain

Lanarkshire Epilepsy

#ME ACTION SCOTLAND

the ME association
me

MND Scotland
Supporting people affected by Motor Neurone Disease

MS Therapy Centre Lothian

MS Therapy Tayside

Multiple Sclerosis Trust
MS

MSA Trust

Multiple Sclerosis
National Therapy Centres

MS Society

MS CENTRE - MID ARGYLL

Muscular
Dystrophy UK
Fighting muscle-wasting conditions

myaware
Fighting Myasthenia
Together

MY
NAME'5
DODDIE
foundation

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

PSP

Qnis
THE QUEEN'S
NURSING
INSTITUTE
SCOTLAND

revive MS

SarcoidosisUK

SCOTTISH HEAD
INJURY FORUM

scottish
huntington's
association

Scottish Post Polio Network

Spina Bifida
Hydrocephalus
Scotland

Sue Ryder
palliative,
neurological
and bereavement
support

the
migraine
trust

THE
OXYGEN
WORKS

THE SCOTTISH CENTRE FOR CHILDREN WITH MOTOR IMPAIRMENTS
Craighalbert Centre

thistle

TOURETTE
SCOTLAND
SUPPORTING
WHAT MAKES US TIC

SRNA
connect. care. cure.
Siegel
Rare Neuroimmune
Association

10. References

[i] https://www.gov.scot/publications/neurological-care-support-scotland-framework-action-2020-2025/

[ii] https://www.healthcareimprovementscotland.org/our_work/standards_and_guidelines/stnds/neurological_care_standards.aspx

[iii] https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/social-care/social-care-in-scotland#:~:text=Unlike%20healthcare%2C%20some%20elements%20of,and%20are%20not%20means%20tested.

[iv] https://www.gov.scot/publications/neurological-framework-funding/#:~:text=In%20December%202019%2C%20we%20launched,linked%20to%20implementing%20the%20Framework.

[v] Scottish Care Homes Census 2018-19 (2020) https://publichealthscotland.scot/publications/care-home-census-for-adults-in-scotland/care-home-census-for-adults-in-scotland-statistics-for-2009-to-2019/

[vi] https://www.gov.scot/publications/national-workforce-strategy-health-social-care/documents/

[vii] https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(22)00005-9/fulltext

[viii] https://jnnp.bmj.com/content/74/8/1060

[ix] https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(18)30030-6/fulltext

[x] https://www.mssociety.org.uk/sites/default/files/2021-10/Neuro%20Report%20V3.pdf

[xi] https://www.gov.scot/policies/healthcare-standards/waiting-times/#:~:text=The%20current%20waiting%20time%20consists,their%20treatment%20within%2012%20weeks

[xii] https://publichealthscotland.scot/publications/child-and-adolescent-mental-health-services-camhs-waiting-times/child-and-adolescent-mental-health-services-camhs-waiting-times-quarter-ending-31-december-2021/

[xiii] https://www.mssociety.org.uk/sites/default/files/2021-10/Neuro%20Report%20V3.pdf

[xiv] https://www.nhsfife.org/services/all-services/trauma-and-orthopaedics-service/patient-information/patient-initiated-review-pir/

[xv] https://www.nhsaaa.net/media/8328/stop-press-extra-modernising-op.pdf

neurological
alliance
of scotland

The Neurological Alliance of Scotland

We are 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.

www.scottishneurological.org.uk

Email: info@scottishneurological.org.uk

Registered with the Scottish Charity Register
(084555)