neurological
alliance
of scotland

Recommendations for better mental health support for people affected by neurological conditions

MAY 2024

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1. Executive Summary

In June 2022, the separate Neurological Alliances from the four nations of the UK published their Together for the One in Six report(s). This report detailed the findings of the four patient experience surveys that were undertaken by each of the Neurological Alliances. The findings in Scotland were similar to those across the rest of the UK with one of the key findings being that there is a crisis in mental health support for people living with neurological conditions.

As Clinical Neuropsychologist Dr Summers noted in her foreword to the Scotland report, living with a neurological condition can have a detrimental impact on an individual's mental health and that it is imperative that we develop a holistic approach to neurological care and support.

> *'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.'*
>
> Dr Fiona Summers
> Consultant Clinical Psychologist

The evidence that is detailed in this report clearly demonstrates the need for change that Dr Summers references, yet no action has been taken to address the mental wellbeing needs of people living with, or affected by, a neurological condition in Scotland.

The Scottish Government does acknowledge that support for Mental Health and wellbeing is a public health priority and is taking steps to address this through its Mental Health and Wellbeing Strategy and Delivery plan, published in November 2023.

However, this plan does not refer to the complex interaction between neurological conditions and mental wellbeing or seek to address the lack of care and support, for mental health and wellbeing, that is available to the neurological community. Publication of this plan will not improve services alone. Along with the mental health community, we were disappointed that the recent Scottish budget (December 2023) did not announce an increased investment in mental health services. There is no indication that the Scottish Government will meet its own target of increasing mental health spend to 10% of the NHS budget or have any impact on prevention of mental illness.

It is with this in mind that we have developed the following recommendations.

Our recommendations

1. Scottish Government and other statutory bodies should properly fund the neurological third sector to deliver social support in the community, to enable earlier intervention, and reduce the demand for statutory services. When we talk about social support, these services could include one-to-one check-in services, peer support, social prescribing for exercise, and connectivity
2. Scottish Government should work with NHS Education for Scotland (NES) and other key partners to develop and implement a training package for the neurological workforce on mental health awareness in order to better equip the neurology workforce to provide mental health support
3. Health professions to introduce reviews to consider mental health, cognitive health, and physical health issues across all neurological conditions at neurology appointments
4. Health professionals must recognise the value of unpaid carers and signpost them to supportive organisations, including organisations in the third sector
5. Support the general mental health workforce to better understand neurological conditions and be able to tailor their approach for people with neurological conditions
6. Encourage the culture of joint working between mental health, neurology, other related specialities and the neurological third sector to better put people with neurological conditions at the heart of their treatment

If we are to realise the system change that Dr Summers refers to, it is imperative that the Scottish Government adopt these recommendations.

Introduction

Neurological conditions are the leading cause of disability worldwide and the second leading cause of death globally. Research published in 2024 puts the cost of neurological conditions in the UK at £96bn, which is 4.3% of its GDP[1].

The Neurological Alliance of Scotland[2] is an umbrella group of nearly 60 charities that represent people with a neurological condition and those who support them. We work to improve the care and support that people receive. The majority of our members are single condition charities, and together they cover 31 different neurological conditions. They are specialists in those conditions. We also have pan-neurology charities amongst our membership who are experts in supporting people with their symptoms across many conditions.

Following the publication of our “Together for the 1 in 6” report[3] in 2022, and through concern of the commonality of mental health concerns across all neurological conditions, our policy group formed a mental health subgroup to make recommendations to better support the mental health of those with neurological conditions. We have used our ‘Together for the 1 in 6’ report along with reports from our member charities and other organisations, and anecdotal evidence from our members to highlight the inequality of service provision across Scotland as well as the inequity of access to care between conditions themselves.

It is estimated that between 40% and 60% of neuroscience patients also have some neuropsychiatric co-morbidity, which has a strong impact on quality of life[4]. Some neurological conditions have a direct impact on mental health because of the way that the condition affects the brain. There are higher rates of psychiatric comorbidities in people with epilepsy compared with the general population but they may go undiagnosed and untreated[5]. Other conditions with high comorbidities with mental illness include Parkinson’s, Huntington’s, progressive supranuclear palsy and brain tumour.

People diagnosed with these conditions can find it especially hard to access mental health support. This is often because neither neurology teams nor mental health teams are confident about supporting people whose care and support needs are complex and require an understanding of both the neurological condition and the mental health symptoms that the person is experiencing, and the way that commonly used treatments may interact with these. Sometimes having a neurological condition can exclude people from accessing mainstream mental health services.

All neurological conditions are likely to impact mental wellbeing, causing stress and anxiety. This can be particularly acute before a diagnosis has been given. Before a diagnosis, people with more complex conditions, or those who are at an age where other more common causes could be at play, often have to fight to see a specialist and report that they are often ‘not believed’ which is very isolating. Having systematic, worsening and seemingly unrelated physical problems causes huge amounts of worry. Receiving a diagnosis might be a relief in the sense of understanding what is happening, but neurological conditions are often life-changing, and once the dust settles, there is often a sense of abandonment, isolation and uncertainty.

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[1] https://impact.economist.com/perspectives/health/mitigating-global-impact-neurological-disorders
[2] https://www.scottishneurological.org.uk/about/
[3] https://www.scottishneurological.org.uk/files/one-in-six-findings-from-my-neuro-survey-in-scotland-final.pdf
[4] neuropsychiatry-neuropsychology-service-specification.pdf (england.nhs.uk)
[5] https://www.sign.ac.uk/media/1079/sign143_2018.pdf chapter 6

Fast acceptance of a diagnosis and successful ongoing self-management depends largely on the support that person has available to them, the manner in which the diagnosis has been made and the level of information that has been provided to them at that time, including signposting to organisations (including charities) that can help. Being told to google a condition later, or being overloaded with complicated information can lead to a period of denial and a lack of ability to self-manage symptoms. There are not many neurological conditions which can be treated, but those which do have a treatment available, such as relapsing forms of MS have better outcomes where treatment is started early. The longer the delay in initiating treatment (whether due to waiting times to see a specialist, availability of the right treatment or denial of being ill in the first place), the further the disease will progress and the more complicated it becomes to treat, both of which are triggers for more serious challenges such as the development of clinical depression.

It is recognised that both mental health conditions and neurological conditions are common so it is not surprising that there are many people having to deal with both conditions. The diagnosis of a neurological condition will undoubtedly exacerbate and complicate any pre-existing mental health concerns. These interactions can lead to referrals being dismissed, or people being discharged from mental health services, when it becomes known that they are living with a neurological condition. A neurological diagnosis shouldn’t restrict someone from accessing mental health services.

Scale of the challenge

The sheer number of people with a neurological condition - one in six people - translates to roughly one million people in Scotland who actively require mental health support to live well and to prevent mental illness from occurring.

Providing support effectively on this scale is a huge challenge. The development of online technologies through the Covid pandemic has accelerated acceptance of virtual consultations which has widened access to people who have the right technology. However, factors like age, disability and income can provide barriers to online participation. Importantly, some neurological conditions make it particularly challenging for people to access support using the phone or internet because intelligible speech using a keyboard and even eyegaze technology can become impossible.

Furthermore, many people prefer face to face support, for a variety of reasons, including building rapport with a counsellor or therapist and being able to read non-verbal communication.

Another challenge is in encouraging people to access support, when there is still a stigma around needing support for mental health. The stigma would be reduced if mental health support was seen as standard provision and addressed from the start of the journey just as physiotherapy or a specialist nurse should be.

Functional Neurological Disorder, which is one of the most common conditions seen in neurological practice, and which causes a range of symptoms including functional seizures, impaired mobility and speech and movement disorders, causes similar levels of disability to MS and epilepsy. It is a stigmatised disorder, and one in which access to psychological services is very important as the roots of the condition for some patients might be psychological or trauma. FND is so difficult to manage as it is classified as neuropsychiatric and therefore it needs a multidisciplinary approach to treatment. However, in many cases neurologists are not the right people to help.

Stigma is possibly more acute in rural communities where people cannot easily retain anonymity when accessing mental health services. Anecdotal examples from the MS Therapy Centre, (Snowdrop Centre) in Lochgilphead includes people deciding not to access psychiatry where they have a pre-existing relationship with the psychiatrist or mental health nurse, for instance they are related, or they attended school together. Islanders coming to the mainland for mental health support can feel vulnerable when travelling to a mental health unit as their anonymity is compromised by being seen by members of their community. Some have said they benefit more from face-to-face counselling yet have chosen to have telephone counselling with a counsellor on the mainland instead.

A third challenge, is where people have to make multiple attempts to access the support that is right for them.

As this case study from the MSA Trust demonstrates, it takes great determination not to give up:

"[This is] my experience of accessing mental health services. I was referred after initial diagnosis to the NHS mental health department and at the end of the first phone call I was discharged basically because I wasn't suicidal. It seemed their resources meant that they had to prioritise. I then sought help online and googled local counsellors but none seemed quite qualified in my needs, it was all life coaching, self-harm, eating disorders etc.

I then reached out to an online service where I filled in a questionnaire as to what my needs were. Someone then called me to ask for further details and said "no problem" and that they'd find a suitable counsellor for me. I never heard anything back from them.

Last of all I paid for an online zoom session which wasn't very helpful.

Eventually I registered with the local hospice thanks to advice from the MSA Trust's digital coffee morning and I started going to the weekly 'Living Well' sessions where I mentioned having trouble accessing mental health services. They referred me to their counsellor, and I had an appointment within 6 weeks, and I now have a weekly appointment lasting 1 hour." (Person living with Multiple System Atrophy)

Evidence

Across our communities, we have been collecting evidence to support the need for a change of approach given to better supporting the mental health needs of people with a neurological condition.

In May 2023, a coalition of MS charities published a joint policy position with recommendations for supporting the mental health of people with MS[6]. We have used these recommendations as a starting point for setting out recommendations across all neurological conditions.

In June 2023, Epilepsy Scotland published ‘Epilepsy on the Mind’[7] where 85% of all respondents thought epilepsy had some sort of impact on mental health. Epilepsy is highly correlated with mental illness due to the stress of living with the unpredictability of the next seizure. A third of their respondents said they had depression and perhaps due to over half (51%) of all respondents finding it very difficult or difficult talking about mental health, the majority (69%) said they would seek support from family and friends. Only 27% said they would talk to their epilepsy specialist.

In January 2024, Parkinson’s UK Scotland published a report: ‘Scotland Can’t Wait’[8] which includes a section on the lack of services to identify and support people with the mental health impacts of Parkinson's. It reported that 30% of people with Parkinson's have anxiety, and 40% depression, while over half will experience hallucinations at some point in their condition.

The 3-yearly MSA Trust survey (2022) confirmed that psychological issues are common with Multiple System Atrophy (MSA), with 72% reporting depression, 58% reporting anxiety, 55% reporting stress and 45% reporting emotional lability. 63% felt the help they receive for emotional needs was poor to very poor and the majority of unpaid carers also reported feeling depressed (61%) and anxious (64%) but 43% had no support with this[9].

Poor mental health can lead to destructive behaviours including smoking, drinking excess alcohol, taking drugs, gambling or other impulsive behaviour. This is particularly true for those who have suffered a traumatic brain injury.

The key finding from our “Together for the 1 in 6” report[10], was that anyone with an undiagnosed or diagnosed neurological condition is more likely to suffer from poor mental health than the general population. Untreated, this cohort is therefore at greater risk of developing serious mental illness. Acknowledging this and putting measures in place which focus on developing the mental health awareness and skills of the neurology workforce, encouraging more partnership working within the NHS and with the neurological third sector, and supporting the general psychology workforce with information about neurological conditions and their impact, will play a hugely positive part in mitigating against this risk.

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[6] https://mstrust.org.uk/news/charities-working-together-mental-health-ms

[7] https://www.epilepsyscotland.org.uk/wp-content/uploads/2023/06/Epilepsy-on-the-Mind-final-report-16-June-2023.pdf

[8] https://www.parkinsons.org.uk/sites/default/files/2024-01/Scotland%20Can%27t%20Wait%20report.pdf

[9] msa-needs-surveys-summary-Web.pdf (msatrust.org.uk)

[10] https://www.scottishneurological.org.uk/files/one-in-six-findings-from-my-neuro-survey-in-scotland-final.pdf

2. Where are we now

In June 2023 the Scottish Government published its Mental Health and Wellbeing strategy[11] detailing its long-term approach to improving the mental health and wellbeing of everyone in Scotland. In the document (which refers back to the 2017 strategy and the 2020 Mental Health Transition and Recovery plan), the Scottish Government states that 'the current system is not delivering as we would wish…' and that 'there can often be issues with finding the right help, sometimes with dreadful consequences.'

Another aspect that is explored in this new strategy document is mental health inequalities. In this section, there is an acknowledgement that some groups of people have poorer mental health and wellbeing than others. People with neurological conditions fall in to this category as they are more likely to experience poor mental health than the general population; this is true for individual conditions such as Multiple Sclerosis[12], Parkinson's[13] and epilepsy[14] as well as neurological conditions generally with 80-95% of people who live with a neurological condition saying that their condition negatively impacts their mental health[15].

Despite qualifying as one of the groups of people who have poorer mental health, current levels of support do not meet the needs of people living with a neurological condition.

Case Studies: barriers to accessing mental health support

"I was diagnosed at 16- very little mental health support then, and when it was provided it was via CAMHS with a general overview of mental health and how to deal with it. Nothing was really relating to how I was feeling about being diagnosed and learning to manage with MS and its symptoms.

In adult life I've been told I can't have antidepressants due to my lesions (I have never heard of this before, and it doesn't seem to be a common opinion).

In my case as well, a lot of cognitive impairment has been mistaken for mental health and when reaching out for help it's very much just a "it is what it is" response. As you can imagine that's very difficult to deal with and even harder without support.

Much like for everyone else, the waiting times for mental health support is horrendous but the waiting times for physical health investigations also created anxiety- scans taking months to be booked, then months to be read and then to finally get the results and to be told it's too late to give any input now." (Person with multiple sclerosis)

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[11] https://www.gov.scot/publications/mental-health-wellbeing-strategy/

[12]Marrie RA, Fisk JD, Tremlett H, Wolfson C, Warren S, Tennakoon A, Leung S, Patten SB; CIHR Team in the Epidemiology and Impact of Comorbidity on Multiple Sclerosis. Differences in the burden of psychiatric comorbidity in MS vs the general population. Neurology. 2015 Dec 1;85(22):1972-9.

[13]https://www.scottishneurological.org.uk/files/scotland-cant-wait-report.pdf

[14]https://www.epilepsyscotland.org.uk/wp-content/uploads/2023/06/Epilepsy-on-the-Mind-final-report-16-June-2023.pdf

[15] Together for the One in Six, Findings from My Neuro Survey Scotland, June 2022

The carer of someone with cerebral palsy said:

"We tried to access CAMHS, but it is GP referrals only. The effort to explain to a new GP that there is a dual diagnosis of a mental health condition is a barrier which gets procrastinated about. We need some help, but the thought of dealing with it is depressing too."

These stories above illustrate how difficult it can be for people living with neurological conditions to receive support for their mental health and wellbeing. But these are not isolated incidents as the findings from the Together for the One in Six report highlight:

- 40% of adults living with a neurological condition in Scotland said their mental health needs are not being met 'at all'
- 35% of children and young people living with a neurological condition said their mental health needs are not being met 'at all'
- Over half of adults with a neurological condition (55%) in Scotland have not been asked about their mental wellbeing in the last three years
- 57% of adults with a neurological condition would welcome a referral to mental health support
- 49% of adults and 72% of children and young people living with a neurological condition experienced a delay in accessing mental health services

If we are to improve the experiences of people living with a neurological condition and make it easier to access the right support at the right time it is therefore imperative that we consider and address specifically the complex interaction between mental health and wellbeing and neurological conditions.

It could be argued that some of the key commitments outlined in the Scottish Government Mental Health and Wellbeing delivery plan will address some of the issues affecting people living with a neurological condition. Commitments such as,

- building community capacity
- focus on prevention and early intervention
- improving access to Mental Health support

However, there is no consideration as to how these commitments will be realised in relation to people living with and affected by neurological conditions.

3. The range and value of the neurological third sector support

The neurological third sector as a whole recognises the importance supporting the mental health of people living with a neurological condition, and that of their carers, and the difference that early intervention with mental wellbeing can make. It is not just the neurodegenerative conditions that have a big impact on mental wellbeing. Conditions which are unsupported, unpredictable and fluctuating in nature cause significant frustration, stress and anxiety as well as more challenging mental illnesses including PTSD and clinical depression.   Suicide rates in people with epilepsy are at least three times higher than in the general population.[16].

Increasingly, neurological charities are extending their services towards provision of mental health support and are having to raise additional funds in order to be able to provide and continue to provide these specialist services due to the growing demand. Epilepsy Scotland reports a 125% increase in calls to their helpline since 2017. More importantly, many of these calls are becoming more complicated to deal with as the issues coming through are becoming increasingly complex, including a greater number of issues to do with mental health. Often, their helpline is the first time anyone will receive any kind of mental wellbeing support. Despite this, Epilepsy Scotland and other neurological charities do not receive funding from statutory services for providing this social and mental health support.

With their condition-specific expertise, provision of mental health and wellbeing support from charities can be very targeted and individualised. However, where mental illness has been left to develop, it can be too late for charities to intervene effectively, as this case study from Epilepsy Connections shows:

"One gentleman who we support had experienced many traumatic events in his life alongside diagnosis of epilepsy. He required specialist Mental Health support to treat Complex PTSD. The gentleman has been on the waiting list for an NHS trauma counselling service since before COVID lockdowns. We were able to offer the gentleman short-term in-house counselling, however it was clear that he required specialist support beyond what we could offer. The gentleman is still waiting to be offered sessions with a community-based mental health provider."

The critical point here is that early intervention can support mental wellbeing and prevent serious mental illness from developing. Neurological charities are not necessarily equipped to deal with conditions like suicidal ideation, clinical depression, auditory and visual hallucinations, panic attacks, trauma and post-traumatic stress disorder. It is important to highlight that in the absence of support from the NHS, people in crisis are increasingly turning to the third sector.

Some examples of neurological third sector interventions to support mental wellbeing include:

- Ataxia UK
  - Runs a helpline which offers advice on a multitude of issues including end of life care and mental health support
- Epilepsy Scotland
  - Runs a holistic mental wellbeing service, including breathing and relaxation classes, a 10-week check-in service (available both for people with epilepsy as well as parents and caregivers) peer support groups, 1:1 support sessions both in person and remotely across the whole of Scotland, access to professional counselling and a national helpline which provides advice and support

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[16] https://www.sign.ac.uk/media/1079/sign143_2018.pdf

- MND Scotland
  - Offers practical, emotional and financial support to people with MND and their family and friends. This includes online group peer support, 1-1 counselling and bereavement support. There is access to specialist advisors to support advocacy challenges and 1-1 support with maximising welfare and benefits alongside the provision of grants
- MS Society
  - Offers a range of emotional support including an MS helpline and online forums
- MS Trust
  - Has helpline and online forums, plus a podcast series focused on wellbeing
- Parkinson’s UK
  - Has trained advisers covering local areas via a free helpline, local groups and partnership projects offer support and therapeutic activities, local physical activity opportunities, telephone peer support, online forum
- The Brain Tumour Charity
  - Runs a free professional 8 week counselling service for anyone diagnosed with a brain tumour and their loved ones as well as specialist relationship counselling

This list is not exhaustive and visibility of all the support on offer through Neurological Alliance of Scotland charities is available here.

4. Savings to the NHS through neurological third sector services

Research from the Mental Health Foundation (MHF) and the London School of Economics[17] indicates that mental health problems cost Scotland £8.8bn per year, the largest proportion falling to the 15 - 49 age group. These costs do not include issues arising from dementia, alcohol or substance misuse, deliberate self-harm or suicide, but do include the economic cost of people unable to work due to depression or other mental illness.

Living with a long-term physical health condition, including a neurological condition, is recognised as putting people at increased risk of mental illness. Our “Together for the 1 in 6” report[18] noted the stark fact that 80% of adults say their neurological condition negatively impacts their mental health. The MHF report evidences the cost savings to adopting a preventative approach to mental illness, including provision of brief psychological interventions such as the ones offered by NAoS member charities listed above.

Being diagnosed with a neurological diagnosis can be a life-changing event for many. NAoS would like to see mainstream mental health support starting at the point of diagnosis.

However, many neurological conditions are difficult to diagnose, and this means that many people live for a long time with considerable anxiety about what their symptoms many mean for them but without having a confirmed diagnosis that may enable them to access support. For those affected by prolonged uncertainty, there is a need for support to be offered from the point that initial investigations (including scans and other diagnostic tests) are underway.

Conversations about mental wellbeing should be seen as an ongoing topic with opportunities to ask how people are managing at their annual reviews. We also want to encourage Health Care Professionals to manage difficult conversations about diagnosis and signpost to mental health support immediately. Anecdotally we know that professionals might not ask about mental health if there’s no-one they can refer that person on to.

Where people cannot access mental health services via the NHS, neurological charities are plugging the gap:

Gary’s story:

“I’m Gary, a 43-year-old man with cerebral palsy and I live in Ayrshire. I like going out to meet people and having a good time. I enjoy going on the computer. Down to me having bad hands moving, I type with my big toe. I have a big keyboard with an overlay over it so I don’t hit the wrong button when I am typing. As well that, I love going out for a meal and going to gigs with my family and friends.

I need support to do most things for myself. In my eyes, my CP is a part of who I am, and I would like to make people aware that having this isn’t bad. In my eyes, my brain works but my body doesn’t.

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[17] https://www.mentalhealth.org.uk/sites/default/files/2022-06/MHF-Investing-in-Prevention-Report-Summary.pdf

[18] https://www.scottishneurological.org.uk/files/one-in-six-findings-from-my-neuro-survey-in-scotland-final.pdf

In lockdown, I had time to think about my past and I didn't know how to deal with it, so I asked Cerebral Palsy Scotland if they knew anywhere I could get support and they told me about Joy. I think Cerebral Palsy Scotland having this service is great for Scotland because people with Cerebral Palsy know where to go.

Joy asked me what things were worrying me then we talked about them one by one. She supported me on how to deal with them inside my head and now I can move on with my life. Joy taught me some skills to use if I feel way again.

If I didn't get support from Joy I feel I would find it hard to move on with my life, without getting myself upset and then feeling bad because people saw me like it. I would have kept the bad feelings inside my head.

When I was speaking to Joy I could open up, and speak about my feelings, no matter what I told her it stayed between us. I think without Joy's support I couldn't move on." (Names have been changed to protect anonymity).

Early intervention and prevention of mental illness has a clear cost benefit, and one good example is the approach taken by NHS Lothian called the Psychology Adding Value - Epilepsy Screening (PAVES) and early intervention for children and young people with epilepsy at risk of mental health problems[19]. Screening for mental health during routine epilepsy clinics and providing early intervention can avoid referrals to CAMHS, saving £718 for every avoided referral. Suicide is a risk factor for people with epilepsy, and so preventative mental health support needs to be provided at the very outset, from diagnosis.

CAMHS as a provider of mental health support comes under criticism both for the lengthy waiting times to be seen, but also for following a one-size-fits-all approach to mental health. People with complex conditions including epilepsy require a more adaptable and personalised model of support, which is partly why the PAVES intervention has been so successful.

Epilepsy Connections explains the challenges with CAMHS:

"The team at Epilepsy Connections are often told about the general length of waiting times to access vital Mental Health services. Notably, Child and Adolescent Mental Health Services (CAMHS) have extremely long waiting times for children and young people to be seen. Often, families are waiting for an appointment, only to find that the model of care is unsuitable to their child or young person's needs, leading to a lack of engagement and feelings that they have waited 'for nothing'. This is often the case if their child is neurodivergent or has a learning disability/ behavioural issue in addition to epilepsy."

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[19] https://shtg.scot/our-advice/the-psychology-adding-value-epilepsy-screening-paves-and-early-intervention-for-children-and-young-people-with-epilepsy-at-risk-of-mental-health-problems/

5. What we'd like to see

When asked what the priorities should be for the NHS, 39% of respondents to a 2023 NeuroLifeNow survey stated 'improvements to mental health care services'. In addition, over 70% wanted health and care staff to have a better understanding of neurological conditions and symptoms[20]. We know that people with neurological conditions are finding it difficult to access support for their mental health and wellbeing. We would like to get to the point that all people who need mental health support are able to access this in a timely and person-centred manner.

The examples below demonstrate the enormous benefits of partnership working. The neurological third sector is uniquely placed to provide tailored support however, this needs to be recognised, signposted to, and funded by Scottish Government.

This example of good practice from Epilepsy Connections which runs a Social Supports Self-Management Programme, highlights the benefits of a holistic approach between mental health and wellbeing:

"We often find that new referrals begin their journey by speaking with the Fieldwork team who can provide support with general listening ear support, welfare benefits, housing applications and answering questions about epilepsy. After this, people may choose to come along to one of our workshops to improve their own knowledge and understanding of living with epilepsy. Some people may need to access our internal counselling service if they are struggling with their mental health. Counselling provides a space for people to talk about the stress, anxiety, depression, loss, and stigma they may experience living with epilepsy.

Then, some people may choose to take part in Epilepsy Well Connected (a 6-month self-management programme which takes place over Zoom). After this, they may become regular attendees of our support groups and social activities, or even choose to volunteer with us.

We have seen the benefit of this holistic approach in improving the mental health of people with epilepsy, and we believe that these services should be available to everyone with epilepsy regardless of where they live.

As all these services are available internally at Epilepsy Connections and people remain linked in with their fieldworker throughout. This also means that they don't have to 'rehash' their experiences with a new organisation when accessing each service. This streamlined approach means that clients are not lost within the signposting process.

People access our services on a rolling basis and they are able to dip in and out as and when they need. Many clients report that it is helpful to just know we are here to support them with epilepsy related issues as and when they arise."

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[20] https://neurolifenow.org/wp-content/uploads/2023/08/16-NLN-Report-Mar-Apr-23-Full-Report-1.pdf

Another example of best practice from Parkinson's UK Scotland, highlights the benefits of joint working:

"Parkinson's UK Scotland is piloting a programme of personalised online support tailored for people with Parkinson's who are experiencing anxiety, depression or low mood. This is done in partnership with SAMH (Scottish Action on Mental Health), Glasgow Life and online mental health service provider Silvercloud. The Parkinson's teams in NHS Greater Glasgow and Clyde are referring people who may benefit from support to the service. We hope that people's experiences will help us to create a helpful and sustainable service that can be rolled out more widely."

Finally, as part of the data gathering exercise for this report, we asked all of our 57 charity members to send us examples of where people with neurological conditions are able to access great mental health support through the NHS. Not one charity was able to provide an example.

6. Recommendations

The Scottish Government clearly acknowledges that support for mental health and wellbeing is a public health priority and is taking steps to address this, however their plan does not consider the specific needs of people living with neurological conditions. The recommendations listed below would not only address this oversight, but it would support the Scottish Government to meet some of the key commitments outlined in their Mental Health and Wellbeing delivery plan.

1. Scottish Government and other statutory bodies should properly fund the neurological third sector to deliver social support in the community, to enable earlier intervention, and reduce the demand for statutory services. When we talk about social support, these services could include one-to-one check-in services, peer support, social prescribing for exercise, and connectivity

What is clear from the evidence in our Together for the One in Six report is that people with neurological conditions find accessing mental health and wellbeing services challenging. This is despite the range of services that are provided by our member organisations and the third sector in general. These services, as the examples in this report highlight, are a vital support for the neurological community but they are still not enough.

As the Scottish Government state we need to build community capacity; this will only be achieved if funding is provided to the neurological third sector so they can increase the number and range of services they are able to provide.

2. Scottish Government should work with NHS Education for Scotland (NES) and other key partners to develop and implement a training package for the neurological workforce on mental health awareness in order to better equip the neurology workforce to provide mental health support

Workforce is a key issue impacting on all aspects of health care, and mental health is no different. Increasing the number of mental health professionals would undoubtedly improve access to care and support but there is a need for more immediate action to address this problem. Increasing awareness and understanding of mental health and wellbeing within the neurological workforce is a vital first step in achieving the cultural shift towards providing the holistic care that Dr Summers advocates in our Together for the One in Six report.

3. Health professions to introduce reviews to consider mental health, cognitive health and physical health issues across all neurological conditions at neurology appointments

This is another vital step to achieving the cultural shift to a holistic approach to neurological health care. As is outlined above, 80-95% of people have reported that living with a neurological condition has a detrimental impact on their mental health[21]. Unless this approach is adopted, the complex interaction between a person's neurological condition and their mental health will never be addressed.

The only way this can be achieved is to ensure that every neurological appointment assesses all aspects of physical and mental health, taking into account the effects that physical symptoms have on mental health and wellbeing, and vice versa.

4. Health professionals must recognise the value of unpaid carers and signpost them to supportive organisations, including the third sector

Receiving a diagnosis of a neurological condition is often life-changing and requires ongoing information and support. This is not only the case for the individual receiving the diagnosis but also their family and friends. A diagnosis such as this can alter the dynamics of relationship as conditions progress or as people adapt to and learn how to manage their conditions. This process can affect people's perception of self, or how they view their role in a family and more widely their role in society. All of this can have an impact on the mental health and wellbeing of all people affected by neurological conditions, not just those living with the condition.

It is therefore vitally important that these support networks have access to services that enable them to manage their own physical and mental health and wellbeing. If we don't provide this crucial support to friends, family and carers then a vital source of support for people living with a neurological condition will be put at risk.

5. Support the general mental health workforce to better understand neurological conditions and be able to tailor their approach for people with neurological conditions

To achieve the required cultural shift towards providing a holistic approach to managing the physical, cognitive and mental wellbeing of people living with a neurological condition, all health care practitioners need to have a better understanding of the interactions between the physical, mental and cognitive symptoms of neurological conditions.

Recommendation 2 provides the route to achieving this aim within the neurological workforce while the successful implementation of this recommendation will be the first step to achieving this in relation to the general psychology workforce.

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[21] https://www.scottishneurological.org.uk/files/one-in-six-findings-from-my-neuro-survey-in-scotland-final.pdf

6. Encourage the culture of joint working between mental health, neurology, other related specialities, and the neurological third sector to better put people with neurological conditions at the heart of their treatment

What is apparent from the evidence presented in this report is that there is a clear division between neurological care and the care and support for mental health and wellbeing. This division exists at a Governmental level where there is a clear distinction at ministerial level as to which Minister has responsibility for what aspects of care. The Minister for Public Health and Women’s Health leads on Neurological care and support while the Minister for Social Care, Mental Wellbeing and Sport is responsible for Mental Health.

This siloed approach and separation is mirrored throughout healthcare provision and until this culture of joint working is adopted, it is people living with neurological conditions that will suffer.

7. Conclusion

In conclusion, this report touches on some of the considerations that should be made for everyone suffering from a neurological condition, from migraine through to ME, right from the start. We have flagged some the challenges and barriers to accessing mental health support, including the limited provision of individualised, suitable, specific and targeted mental health services across Scotland; the difficulties in accessing mental health services for certain neurological conditions whose symptoms mirror certain mental illnesses, or for people who are of an age where other more common causes are misdiagnosed; and we have touched on some of the barriers to how people access mental health services, including the additional challenges faced by rural populations and the ongoing need to tackle the stigma in accepting help for mental health and wellbeing.

Whilst no-one would argue with having a bigger and more robust mental health workforce, our recommendations mainly focus on areas where we can make a difference, which is a cultural shift within the neurological workforce.

Our focus is also on prevention, rather than waiting for a much more expensive intervention at a point of crisis. Offering support to people at every stage of their neurological 'journey' is proven with examples like the PAVES study, to improve wellbeing and reduce the need for CAMHS or adult mental health services, having a significant positive financial impact.

Our recommendations are straightforward and uncomplicated, requiring only an acceptance that the current model of separating neurological care from mental healthcare, does not work and that more openness, signposting and partnership working is required. Brain health and mental health cannot easily be separated and nor should they be.

The division in Scottish Government between 'brain' and 'mind' has led to a very siloed approach to policy making, with some neurological conditions including dementia and stroke falling outwith the Scottish Government's neurology team. This is a problem as mental health policy doesn't specifically include neurological conditions when they often go hand in hand. Despite this, it seems that correlations between neurology and related mental health conditions are well understood by policy makers.

There has never been a more critical time to address the mental health needs of those with neurological conditions and we stand ready with our expertise to support the Scottish Government to deliver our recommendations.

8. Signposting to other useful organisations

NHS Breathing Space: https://www.nhs24.scot/breathing-space
The Mental Health Foundation https://www.mentalhealth.org.uk/
Scottish Action for Mental Health: https://www.samh.org.uk/
Mental Welfare Commission for Scotland: https://www.mwcscot.org.uk/
Samaritans Scotland: https://www.samaritans.org/scotland/samaritans-in-scotland/
Change Mental Health: https://changemh.org/
Bipolar Scotland: https://bipolarscotland.org.uk/
Penumbra: https://www.penumbra.org.uk/
See Me: https://www.seemescotland.org/
Scottish Recovery Network: https://www.scottishrecovery.net/

9. Appendices

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