

The mental health impact of a neurological condition on children and young people

June 2025



Aims of this presentation



To inform children's services about the specific needs of children affected by neurological conditions relating to their mental health



Highlight the impact on mental health for those who cannot access support due to lack of understanding of their condition

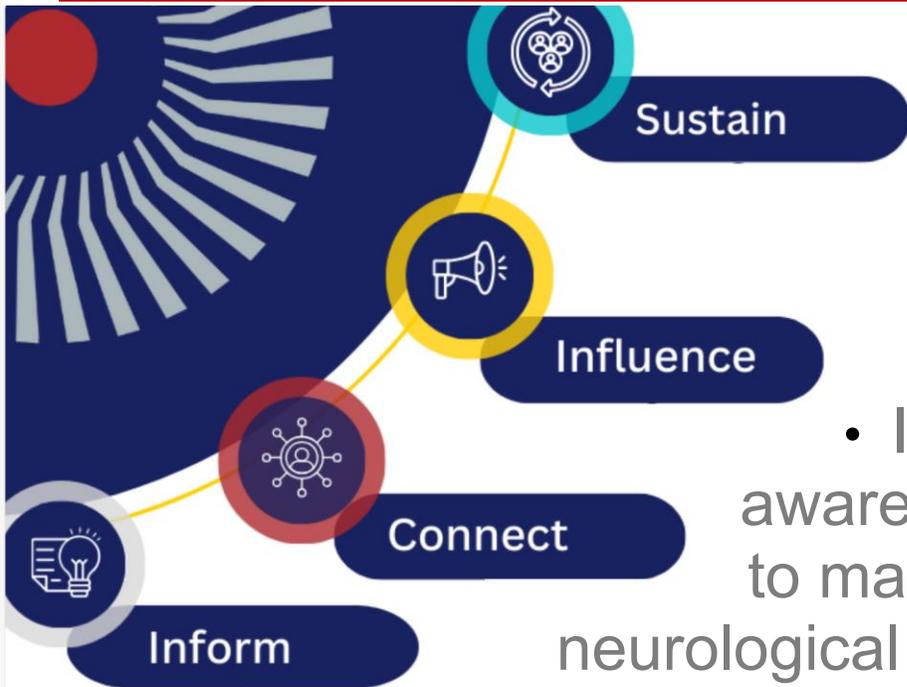


Share sources of help and advice that are available

In this presentation

- About The Neurological Alliance of Scotland
- Overview of Neurological conditions
- Challenges in Education and Children's Services
- Transitions
- Impact on mental health
- Recommendations
- Further research and reports
- Overview of third sector services

About the Neurological Alliance of Scotland



- We represent almost **60 charities and groups** supporting people with neurological conditions in Scotland

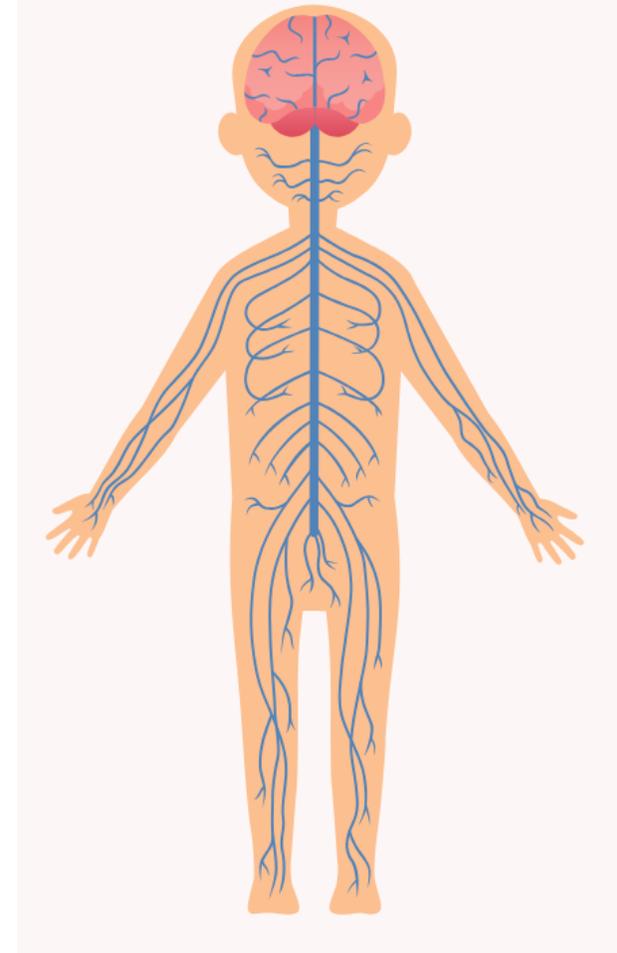
- **32 conditions** plus 10 pan neuro charities

- In partnership with our members we inform policy, raise awareness and support improvements in services. We aim to make sure that the experiences of people with neurological conditions - and those around them - are recognised.

- We do this by raising these issues directly with the Scottish Government, NHS bodies and other groups; and by contributing to publications and consultations, sharing information between members, and working with other bodies on common issues.

What is a neurological condition?

- A neurological condition is any condition that affects the brain, spinal cord and/or nerves. Because these systems control your mind and body, neurological conditions can affect the way you think and feel and interact with the world.
- Neurological conditions can be caused by a variety of factors, including genes, the environment, bacterial or viral infections and traumatic injuries or accidents. It's not always possible to tell what causes a neurological condition, although research is ongoing.
- There are over 600 known neurological conditions, many of them are considered rare, and some of them are life-limiting. Many of those affected have additional support needs. Significant needs that are not being met that can lead to mental health challenges both for people affected and carers
- [Directory of Life Limiting Conditions - Together for Short Lives](#)
- [Rare conditions | NHS inform](#)



Not all symptoms of Neurological Conditions are visible

Mental health, cognition and memory

Typically these difficulties can manifest themselves through impulsivity, anger, irrationality, compulsive behaviour, forgetfulness, lack of awareness of self and others.

Pain and fatigue

Many neurological conditions cause pain and fatigue which can impact across all areas of life.

Visual and hearing difficulties

Other sensory difficulties may also occur.

Speech, language and swallow

Conditions which impact the muscles used to control speech, language, swallow and interpretation of other people's speech may have a big impact on a person's ability to communicate with you. It is important not to confuse communication with cognitive difficulties.

Mobility, balance and co-ordination

Living with any neurological condition can cause practical difficulties when moving about. Conditions that impact the nerve signals to muscles, may lead to weakness, seizures, tremor or muscle wasting. This will have an impact on a person's ability to live independently.

Bladder and bowel

Several common conditions impact the functionality of the bowel and bladder leading to incontinence.



How common are Neuro conditions in Children and Young People?

There is limited data on prevalence of neurological conditions – and this presents real challenge. **Without knowing prevalence we cannot adequately plan services.**

Estimates of prevalence for some conditions were gathered by the Scottish Government in 2022:

[Neurological Conditions: estimating the prevalence in Scotland of selected conditions using GP and Hospital Admissions datasets](#)

Some statistics we do know:

- Epilepsy 5 - 10 per 1 000
- M.E. 2 - 4 per 1 000
- FASD 3-5% of the general population (or 1 in 20)
- Cerebral Palsy 1.6 – 3.4 : 1 000 live births
- Spina bifida 1-2 per 10 000
- Retts disease 1:10 000 girls born each year, rare in boys
- **1 in 6 people in the UK live with a neurological condition**



Early intervention is key to prevention of mental health difficulties

Evidence shows that the brain is not fully developed until around the age of 25. Young people with neurological conditions tend to be complex to manage, their condition fluctuates and therefore prognosis is even more challenging to predict.

Despite the deep emotional impact of neurological conditions, the mental health support available for children is still falling short. As detailed in our **Today's Challenge, Tomorrow's Hope** report nearly seven in ten carers (**69%**) said that mental health services are not meeting their child's needs. **One in five** children cannot access any mental health support at all.

Children with complex neurological needs require mental health professionals who understand the intersection between neurology and psychology. Generic counselling or mental health advice often misses the mark and, in some cases, causes harm.

“CAMHS made everything worse for her. They didn't seem to understand much about her condition at all.”

It is worth noting that some young people with complex neurological conditions remain eligible and are managed by children's services until they reach the age of 26 years.

Disrupted education and disconnected services

Disrupted education

Supporting CYP with Neurological Conditions in Education

In MyNeuroSurvey, 60% of the carers of CYP stated that their child's neurological condition significantly affected their ability to work or study.

- Neurological conditions can impact cognitive functioning, fine and gross motor skills and can have symptoms of poor mental health, leading to a wide range of Additional Support Needs.
- The type of support needed will vary depending on the condition, and where in the course of the condition a CYP is (some conditions are stable – others are fluctuating).
- Some CYP will need specialist provision, others may need significant support in mainstream. Most cases will require a Child's Plan, and in complex cases a Coordinated Support Plan (CSP) should be considered.
- Children and Young People with neurological conditions will often require an enhanced transition between settings.
- It may be useful to refer to information from condition-specific charities and organisations.



Disrupted education

Attendance

- Most neurological conditions will lead to a child or young person having additional support needs. These needs need to be met in their education. Not all neurological conditions are present from birth, and a review to assess need should take place as soon as possible after symptoms arise.
- Most neurological conditions will also have symptoms of poor mental health, this can impact a child or young person's ability to cope in the school, and can impact attendance.
- A CYP's needs not being met in education impacts their ability to work or study, and in some cases attend school. It can also impact their mental health.
- If a child or young person with (or suspected of having) a neurological condition is struggling to attend school it is important to consider the impact of their condition, and if all needs are being met, before considering the issue to be Emotionally Based School Avoidance (EBSA).
- If symptoms of their neurological condition are preventing a child from attending school, the guidance for supporting children who are unable to attend school due to ill health applies.

“The SG’s School Attendance and Absence Statistics Collection (SG, 2022c) consistently show children and young people with additional support needs as having lower attendance rates than pupils with no additional support needs”

Education Scotland

Disconnected children services



42% said they were unable to access a social worker



48% said they had not been able to access counselling services and of those who had accessed counselling, 29% said it did not meet their needs.



82% had been unable to access neuropsychiatry services



60% had not been able to access neuropsychology services



61% had been unable to access respite care

"There is no-one taking a holistic view. Each medic is only concerned with their area of interest/expertise: neurosurgery, urology, ophthalmics [sic], chiropractics, podiatry. My mum has to try to provide a complete picture of how i [sic] am affected to all the medics but also to all the other people like school"

(My Neuro Survey 2024/Scotland data)

Safeguarding

Keeping Children and Young People safe is of absolute importance.

There have been cases however, of safeguarding or FII concerns being raised against parents of children and young people with neurological conditions.⁵

These can arise because some of the symptoms of neurological conditions can be misunderstood as safeguarding concerns.

- In acquired conditions, such as Brain Injury or Encephalitis there may be a sudden change in a child.
- In fluctuating conditions, such as FND, symptoms may come and go.
- In emerging conditions such as PANS PANDAS or Long Covid, there may not yet be published guidelines, or sufficient research leading to symptoms not fitting a known pattern.
- Parents and Carers may be extremely stressed with challenging symptoms and a battle for support, and so may appear uncooperative.

Practitioners, therefore, need to reflect critically on all information gathered – its source, credibility, integrity, validity, whether it corroborates, challenges or contradicts the current assessment and analysis. They also need to be aware of any potential for bias and the difficulties of working solely on the basis of information that is contested.

Transitions

When is a child not a child?



AGE	12	13	14	15	16	17	18+
UNCRC / CYP (SCOTLAND) ACT 2014	CHILD	CHILD	CHILD	CHILD	CHILD	CHILD	ADULT
FRONTLINE NHS SERVICES	CHILDREN'S SERVICES				ADULT SERVICES		
SPECIALIST NHS SERVICES	CHILDREN'S SERVICES				DEPENDS ON SERVICE		

There is a lack of clarity across statutory organisations as to the definition of a 'child'

This blocks access to services

Daily Record

Schoolgirl's body left on bedroom floor for nine hours as cops and ambulance "argued" over removal

Poor transition services

We found the transition from child to adult services very difficult and were left with little support for our cared for person for 6 months despite being assessed as needing it as there were no local services that could meet their needs.

(My Neuro Survey 2024/Scotland Respondent)

This period can be made even more challenging if there are no adult services to transition into (such as for cerebral palsy).

This can have notable impact on a young person's mental health and wellbeing.

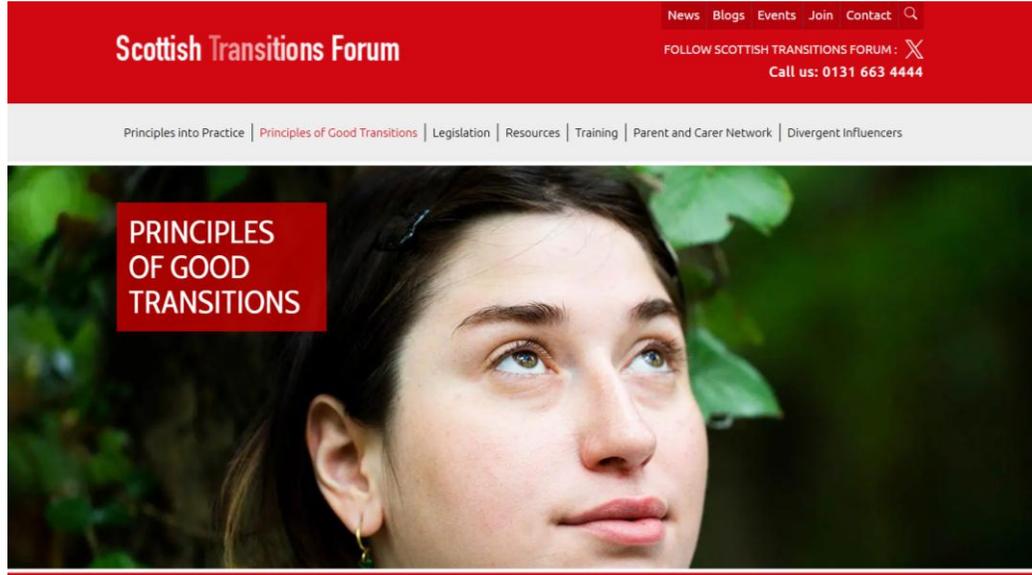
The period when a young person transitions from child to adult services can be incredibly challenging and too frequently causes disruption and stress, resulting in unmet needs.

Often, young people and their families have to cope with this transition alone. As our **Today's Challenge, Tomorrow's Hope** report illustrates, **82%** of children and young people told us they had no named transition worker.

As the child becomes an adult the local authority involvement disappears. Have not had contact with social workers since child left school.

(My Neuro Survey 2024/Scotland Respondent)

Transitions – good practice



The [Scottish Transitions Forum](#) provides a wealth of information to support young people, parents and carers and professionals through the transition from child to adult services

ARC Scotland's [Compass](#) tool supports young people, professionals, and parents and carers to plan the transitions process to meet their individual circumstances.



A Compass for transitions

Free online tools for young people with additional support needs and the adults in their lives

[Explore Compass now >](#)



Impact on mental health

UNITED NATIONS CONVENTION ON THE RIGHTS OF THE CHILD

Article 23 gives special attention to children with disabilities, and ensures support to ensure they are able to access all their rights. Article 2 ensures they are not discriminated against.



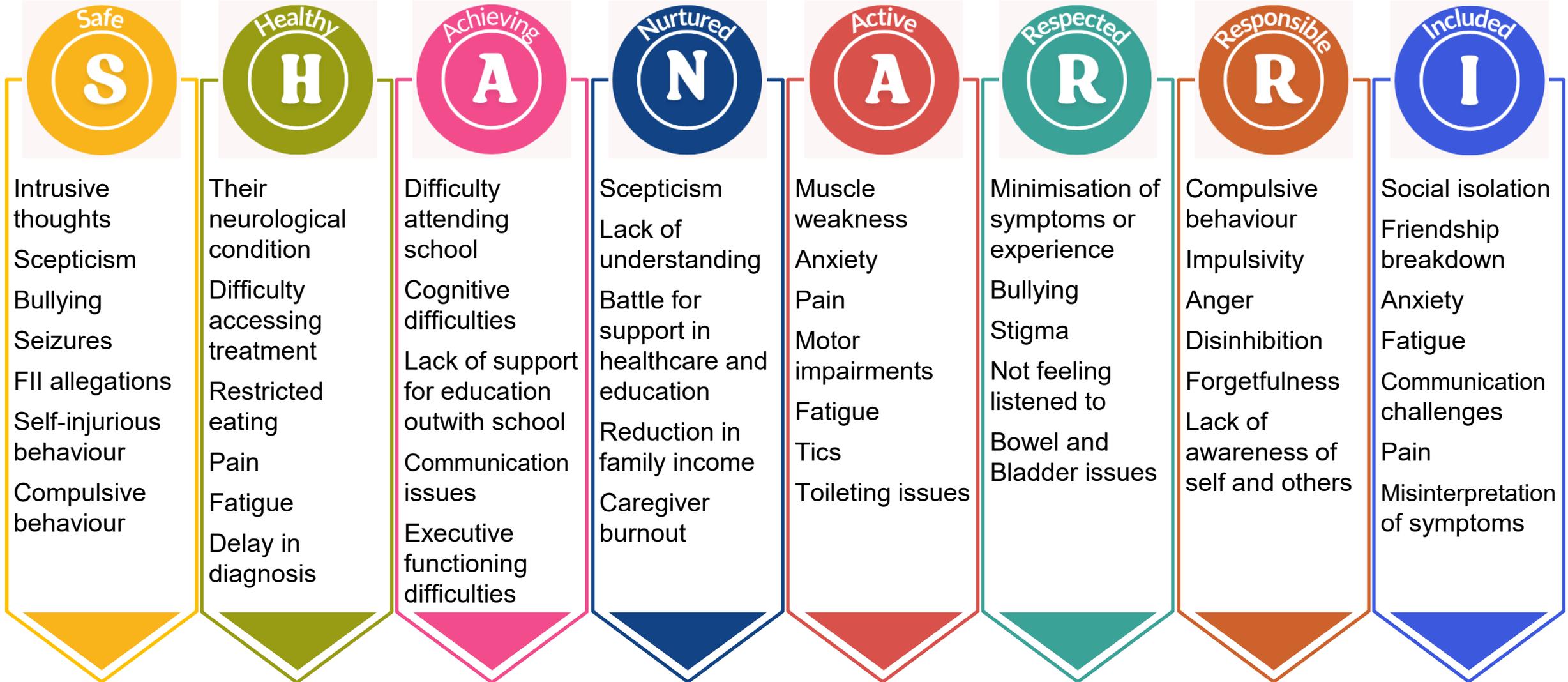
”Recognizing the special needs of a disabled child, assistance shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child’s achieving the fullest possible social integration and individual development.”

Article 23 of the UNCRC¹

The following rights are the most likely impacted in children with neurological conditions:



Neurological conditions can impact children and young people across all SHANARRI indicators



Anxiety over not knowing what's happening

"Give me time to

think and talk to my parents.

Present me with all the

information I need. Let me know
what is going to be discussed

beforehand, so I can be prepared if
a big decision is being taken."

(My Neuro Survey 2024)

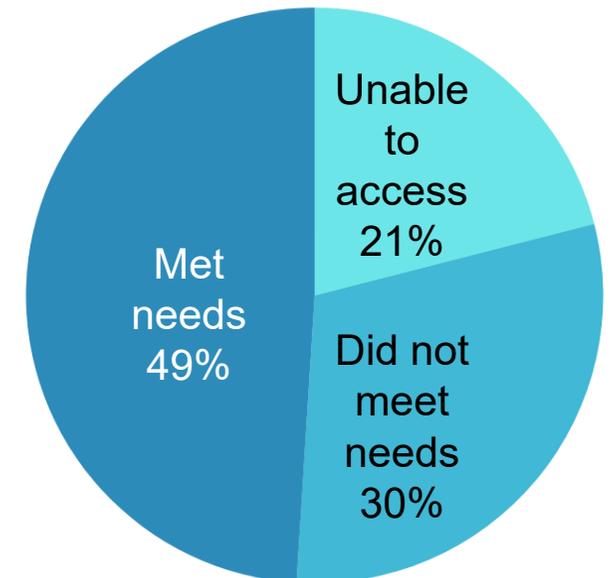
Impact on mental health:

- 84% of respondents said their mood or mental health is impacted by their neurological condition
- 45% of respondents said that care from mental health services did not meet their needs

(source My Neuro Survey 2024)

Care planning:

- Of those who stated it was relevant to them, 21% were unable to access care planning.
- Of those who had access to care planning services 38% said it did not meet their needs.



(source My Neuro Survey 2024)

Care Planning

What do CYP want?

To be believed

"Tell me that my condition is real and that it's not just "all in my head" or that I'm "faking for attention".

"Be more understanding of FND. I've had doctors act like its all in my head and like I can help my symptoms when I can not"

"Be more understanding that young children under 5 do suffer a lot of pain with cerebral palsy and do more to help."



What do CYP want?

To be respected

They need more understanding on FND and shouldn't be so fast to judge."

"A big reason I'm so insecure about my condition is because of doctors and healthcare professionals that make me feel like I'm just being silly and that nothing I'm experiencing is actually real. it makes me feel like I'm going crazy"



What do CYP want?

To be supported

“My GP says there is no suitable specialist service to refer me to and as I am 'managing' there are no suitable support services because they are for people whose condition is worse than mine...”



“The NHS and my GP have only recently started to acknowledge my condition but won't diagnose or support it. They could be more willing to learn about it and try treatment options rather than leave me to suffer.”

Wait times

From My Neuro Survey 2024/5 (UK data): **waits of 2 years +**

- Home adaptations: 8%
- End of life care: 8%
- Orthotics: 9%
- Counselling: 9%
- Speech and language therapy: 10%
- Specialist nurse: 12%

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." - Epilepsy Connections

Key takeaways from My Neuro Survey

- Health and social care services are not meeting people's needs (ADD STATS)
- Carers report that CYP cannot participate in 'normal' day to day activities such as socialising, working, maintaining family relationships is hugely compromised by the presence of a neurological condition
- Respondents agreed that care from mental health services had not improved over the last 12 months (ADD STATS)

"Understand my condition, be able to advise, be able to support and have pathways who will accept me."
(My Neuro Survey 2024)

"Explain in simple terms . Talk to me not just my Mum. Ask me more questions"
(My Neuro Survey 2024)

"More information on FND and how it will affect me There is no support from CAHMS even though I'm on antidepressants I use a wheelchair as I can't walk for long and school can only offer me support to take me from class to class."

(My Neuro Survey 2024)

Recommendations

Recommendations



Understand the challenges of the individual child in front of you



Learn more about their condition through the single condition charities within our network



Work together as a team and share this presentation and other information with your colleagues

Further research and reports on mental health impact

Research and reports

- The Neurological Alliance of Scotland, [Recommendations for better mental health support for people affected by neurological conditions](#) (May 2024).
- The Migraine Trust, [Migraine hurts in many ways beyond the physical pain report](#), (September 2024).
- Epilepsy Scotland, [Epilepsy on the Mind](#) (June 2023)
- MS Trust, [Life changing: mental health and MS](#) (May 2023)
- MS Trust, MS Society, Shift MS, Overcoming MS, MS UK, MS National Therapy Centres, [Mental Health and MS Joint Policy Position](#) (May 2023)
- The Migraine Trust, [“Dismissed for too long: the impact of migraine on children and young people”](#) (September 2022)
- PANS PANDAS UK, [PANS, PANDAS & Fabricated or Induced Illness](#) (May 2023)
CHECK LINK

Third sector services and support

[FINAL Information Unpaid Carers and Professionals](#)

[PANS PANDAS UK GIRFEC resources](#)

References

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<https://www.childrenshealthscotland.org/childrens-healthcare-rights/transitions>

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<https://migrainetrust.org/>

<https://www.longcovid.scot/>

<https://www.longcovidkids.org/>

<https://www.adoptionuk.org/fasd-hub>