“Don’t assume I’m Ok”

A toolkit for parents, teachers, and professionals working with children and young people affected by neurological condition/s.

Out of the children and young people you work with, ***do you know who is affected by a neurological condition?***

What impact might this experience have on the child or young person you are working with?

Are you supporting them effectively?

What is a neurological condition?

A neurological condition is any condition ***affecting the brain, spinal cord, nerves and/or muscles***. There are over 600 known neurological conditions. They happen for lots of different reasons such as illness, injury, or genetics. Many causes are still unknown.

At least 1 in 6 people in the UK live with a neurological condition, including children and young people. Neurological conditions are the leading cause of ill-health worldwide.

Many children and young people will have a loved one with a neurological condition and, in some cases, multiple family members with ***complex and life changing conditions***.

Why is mental health important?

Mental health is as important to physical health when enabling people to live well.

Neurological conditions can co-occur with mental health challenges such as anxiety, depression, behavioural change, attentional challenges, sleep disturbance and more. Access to limited vocabulary can also inhibit expression of feelings.

For children living with neurological conditions in the family, ***many take on caring roles without identifying as a young carer***. Too often, access to mental health support for families impacted by neurological conditions is inadequate.

Every child and young person is different and requires a unique approach to supporting their wellbeing.

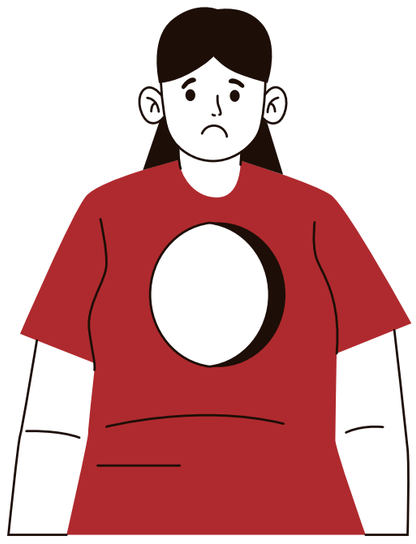
Taking the wrong approach can be potentially harmful to a child or young person or risk missing a key opportunity for intervention.

It is important to make sure:

- you are **informed**;
- you **listen** to the child or young person’s needs; and
- you are **proactive** in your approach.

Don’t assume they’re ok***. It is everyone’s responsibility*** to make sure children and young people are safe and supported.

What can you do to help?



01 Be informed

- ***Understand neurological conditions*** and their impact and know where to look for support. Find out more here: Neurological Conditions - information and resources
- ***Visit our mental health webpage*** for a list of generalist and specialist mental health support services for children and young people: Neurological Alliance of Scotland- Mental Health and Neurological Conditions
- ***Understand the impact of loss.*** Loss can take many forms and grief isn't straightforward—keep returning and gently checking in. Find out more on loss and bereavement here: Cruse Bereavement Support
- ***Be aware of how trauma can impact a child.*** Trauma is the lasting emotional, psychological, physical response to events that overwhelm an individual's ability to cope. Use a trauma-informed approach when working with children and young people. Watch this short clip on Childhood Trauma and the Brain | UK Trauma Council
- ***Understand impact on carers.*** See our resource for supporting unpaid carers of those with neurological conditions: Information for unpaid carers and professionals.

02 Don't assume, ask

- Make sure to have ***routine check-ins*** with the children and young people you encounter.
- Create a ***safe environment*** where conversations are possible.
- ***Model the use of language associated with feelings*** and use aided language displays where appropriate.

03 Listen

- ***Assign meaning to nonverbal communication***. Find out more here: Communication Methods for Non-Verbal Children, FCA and What is AAC? Communication Matters.
- ***Notice the subtle signs.*** All behaviour is a form of communication. Sudden dip in energy, more absences, quiet withdrawal, perfectionism, or irritability can all be signs of not coping or masking. Find our more on masking here: Masking, Kids Charity.

04 Be proactive

- ***Use wellbeing indicators*** such as the SHANARRI indicators to assess a child's wellbeing.
- ***Do not exclude children from big conversations***, talk about or over them, or assume they don't understand. Including children in decision making and conversations about their future will help reduce fear of the unknown and make them feel more in control about their future. Visit: NSPCC How can we hear and facilitate the voice of the child?
- ***Offer private opt-out / timeout options***: quiet spaces, rest breaks, sensory accommodations.

Don’t Assume I’m Ok: My Story

Real people, real stories

In the section below, children, young people, and their carers share their experiences of living with a neurological condition, or growing up with a parent or loved one with a neurological condition, and the impact it has had on their mental wellbeing.

Some names have been changed to protect anonymity.

This is Alex’s story

“My mum was diagnosed with MS long before I was born. **For me, growing up, MS was normal; it was just what my Mum had.**

I could tell you all about MS – and I often did! As a child, I stood up for my Mum when people didn’t understand why she was using a wheelchair, had questions (as children do), or perhaps when she was making noise while trying to get her sweets out of the bag in the cinema because her hands were shaking. **I felt very strongly about looking out for my Mum.**

I could also tell you more advanced things, like whether my mum had drunk enough based on her catheter bag, or whether she was having a relapse and what that was. **But, was I a young carer? No.**

Looking back now, knowing what a young carer is, of course I was. But to me, when I was a child looking out for my Mum, I wasn’t.

To me, I was just looking after my Mum and that was fine. I think, looking back, the label wasn’t important. What was important was support. I knew so much about my Mum, and was also one of the people looking out for her, but in my own way. **However, my ‘expertise’ wasn’t always acknowledged by some family, or even health professionals.**

My advice to family and professionals then, is: Think about the ‘mini-experts’ in someone’s life. Check in with them, ask them what they think – include them. Children pick up on so much without you knowing, make sure they know they are valued, beyond just labelling them as ‘young carers’.

For young people going through a similar experience: We see you. You are doing so well, and are so important to your families’ lives, keep fighting for what you see, know, and feel, and know your voice is important too.”

Don’t Assume I’m Ok: My Story

This is Bruce’s story

“Bruce was a bright, confident six-year-old who loved school, football, and family life. **Two weeks after a respiratory illness swept through the household, he woke up a completely different child**.

Overnight, Bruce developed severe contamination fears and obsessive rituals. He refused to touch everyday objects, demanded multiple baths and showers, and followed rigid bathing routines. He had tics, his legs were stiff and he walked with a limp, and his hand and wrists locked into uncomfortable positions. He also suffered with separation anxiety.

While these are physical symptoms of what was later understood to be PANDAS, they also led to mental health challenges, with **Bruce banging his head off walls, saying that he couldn’t cope, and at his lowest moments said over and over that he wanted to die. He was 6.**

Local NHS services referred Bruce to CAMHS, however with CAMHS suspecting a medical cause, there wasn’t pathway for Bruce to be referred onto. Bruce’s parents took him to see a private doctor. The doctor diagnosed PANDAS and prescribed a short course of antibiotics. By day 10, all of Bruce’s symptoms had gone.

With exposure to another trigger however (this time it was the flu), Bruce’s symptoms re-appeared, and this time he also developed severe eating restrictions. Foods he had always enjoyed became impossible to face, he thought he was choking and was going to die. He stopped eating, and his weight dropped dramatically. Doctors warned that if he didn’t start eating, they would need to intervene. Bruce’s parents returned to the private doctor, who again prescribed antibiotics, and again Bruce recovered.

Bruce’s symptoms continue to fluctuate, most notably when he is fighting an infection, and he continues to find dealing with his symptoms incredibly challenging, **some days he can manage in school no problem, on others he just can’t cope with the environment and becomes completely overwhelmed.** Bruce and his parents are fearful of what the next infection might bring, not only in terms of symptoms, but also in the battle they will face for medical care, as well as health, education and social care support.”

Don't Assume I'm Ok: My Story

This is Sarah's story

"Mum was an extraordinary role model for me as a very young girl. She was a beautiful dancer with an amazing vibration about life. But over time she became moody and unpredictable, and her movements and behaviour changed. Sometimes people thought she was drunk.

As a child of someone with Huntington's disease, I now realise how isolated I was. I was caring for my mum but not coping with what was going on. As a family, we never really discussed what was happening at home and I never told anyone. **Even if I knew who to tell, I didn't have the words to explain.**

We didn't know what was wrong, or even that she was ill at that stage. I just knew my mum was different and our relationship became very difficult when I was a teenager.

Fortunately, young people from Huntington's families now have the specialist support that I needed back then. We now see a generation of children and young people with the confidence, knowledge and vocabulary to talk about what it means to have such a devastating disease in their family, and how it impacts their home, school, work and social lives."

This is Jaz's story

"I was eight or nine when I found out Dad was ill with Huntington's disease and he passed away when I was 12. I wanted to be tested as soon as possible and was 18 when I found out that I've inherited the faulty gene that causes the disease. **I gave up on things after that, withdrew from the world, and didn't have the motivation to get through college, or for anything else really.**

I didn't want to engage with any services or support for quite a long time before Scottish Huntington's Association invited me to volunteer at its youth summer camp. It wasn't typical of me to do something like that especially as I feel awkward in social situations, but I've been back year after year. **It's a great environment for meeting other young people from Huntington's families, supporting one another, learning about the disease and finding out about the help that's available.**

It really inspired me and I realised that I could be doing a lot more. **I've regained a bit of the confidence that I'd lost during those darker years** and have even fundraised for Scottish Huntington's Association to give back.

I didn't tell my friends about my test result until after that first summer camp. They made me wonder why I'd tried so hard to keep it secret for all those years. Although we don't talk about it much, it's not an awkward subject. I know they and Scottish Huntington's Association are there for me when I need them."

Don’t Assume I’m Ok: My Story

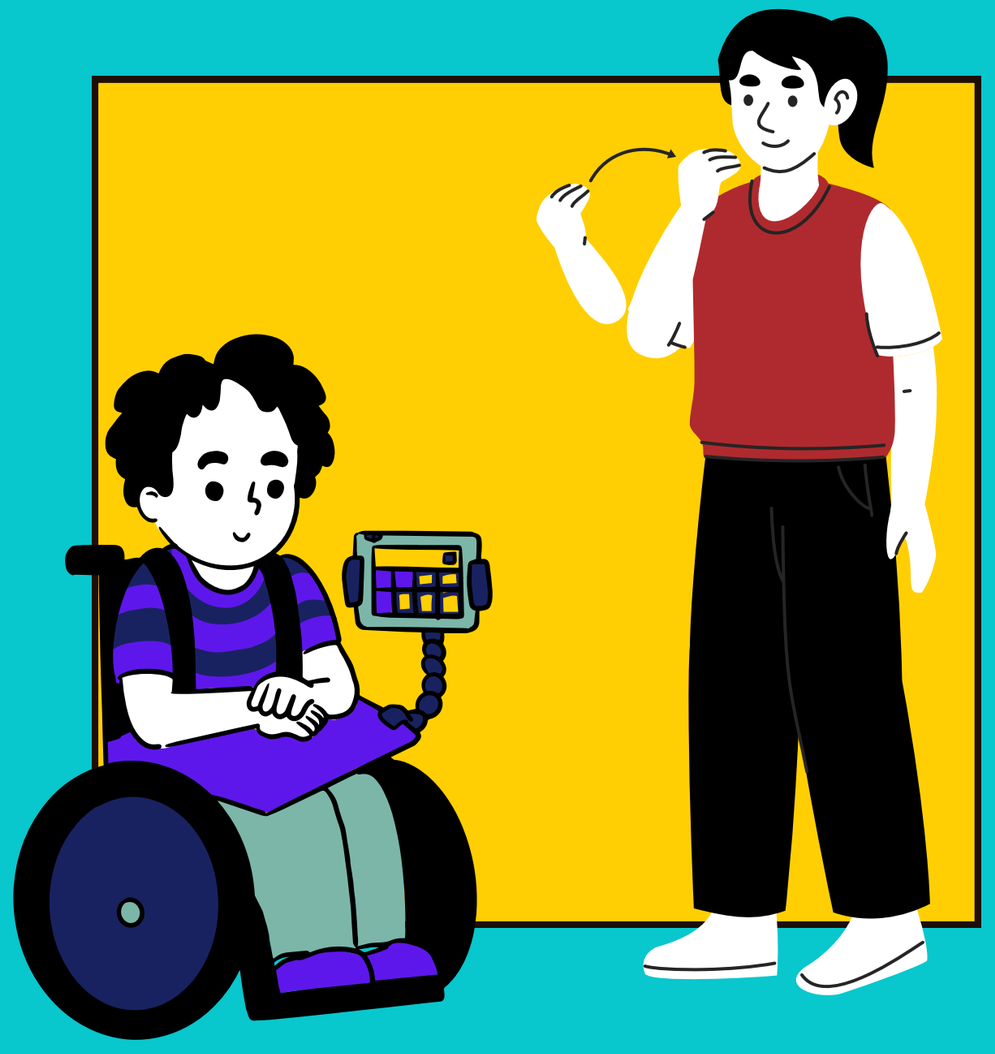
This is Nikolas’ story

“Nikolas is a young boy with a rare neurological condition whose journey has been transformed by being truly listened to.

Previously, **his world was limited by a lack of understanding and appropriate support.** He showed no clear startle response to sensory stimuli and was highly agitated which caused him to overheat and sweat. These behaviours were believed to be a fear response triggered by isolation and having no robust communication strategies in place. He experienced high muscle tone, particularly during movement and personal care, requiring three adults for safety during transitions.

With no consistent communication strategy in place, his cognitive ability and emotional wellbeing could not be assessed, leaving him isolated and largely disengaged from his environment. His parents described him as being ‘depressed’ and rarely smiled or appeared happy. Most of his day was spent positioned in his Acheeva bed, often with his neck extended backwards to maintain his airway, and he was unable to access learning experiences, play and fun. **His interactions with others were minimal, and his feelings, preferences, and needs went unheard.**

Now, by contrast, Nikolas is an active, expressive learner with “a lot to say.” **A consistent communication strategy is embedded, using a high-contrast 12-cell-per-page PODD, alongside a refined affirm and reject response that allows him to make clear choices**. He spends most of his day sitting upright in a supportive seat, giving him a secure base, improved head control, and greater functional movement. He initiates conversations, contributes to learning, and demonstrates understanding through alternative pencils, letter recognition, and self-correction. Switch access has enabled him to control music, games, and eventually the drive deck, giving him choice, independence, and opportunities to play, cook, and explore with peers and family.



He now engages meaningfully with the world around him, seeks out relationships, expresses how he feels, and has his wants, wishes, and needs heard and respected. His parents have commented that his emotional wellbeing has significantly improved and **his personality and character is shining through.** Being heard has brought him safety, confidence, curiosity, and age-appropriate access to learning, play, and joy.”

Don’t Assume I’m Ok: My Story

This is Alex’s story

“Loss is a strange thing. We don’t talk about loss, death, or grief enough. We know it exists, and we support those going through it, but loss is more than death. **‘Loss’ encompasses many things, from a physical sudden loss, to a slow and ongoing loss.** For me, I experienced both through my Mum’s MS.

My Mum was diagnosed with MS at 17, she had me at 26. By the time I was starting high school, my Mum’s MS had progressed, meaning her symptoms were gradually worsening with little improvement. Sadly, her MS progressed to a point where she was unable to live alone, and I moved away to live with my Dad. **This was the first loss I felt, moving away from my Mum** who now lived in a strange (but lovely) place, that was no longer my home, and I couldn’t see her every day.

The next loss I felt was slowly losing more and more of the ‘old Mum’ I had always known. Gradually my Mum stopped being able to communicate verbally, and didn’t always know who I was. However, we adapted and through our connection I began to know what my Mum was trying to say based on her eyes – **communication is not always verbal!**

The final loss I felt was when my Mum sadly passed away in 2020. **Slowly and all too quickly, I had lost pieces of my mum over the course of 8 years. The loss of my mum was neither quick, nor was it simple.** It is therefore important to talk about loss, not only to support those going through it, but to acknowledge the varying types of loss that people go through.

For me, **I held on to the ‘loss’ I was feeling privately for many years, feeling as though no one would understand. Know that we understand, support you, and it is okay to talk should you wish.**”

Read more here: Don’t Assume I’m Ok: My Story - Neurological Alliance of Scotland

Download these stories as infographics to use as posters or share online: Case study and key messages.

Glossary and further resouces

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 affect anyone at any age.

For more information, visit What is a neurological condition? The Neurological Alliance of Scotland.

Mental health

The World Health Organisation defines mental health as: '*Mental health is a state of mental well-being that enables people to cope with the stresses of life, realise their abilities, learn and work well, and contribute to their community. It has intrinsic and instrumental value and is a basic human right. Mental health conditions include mental disorders and psychosocial disabilities as well as other mental states associated with significant distress, impairment in functioning, or risk of self-harm*.'

For more information about mental health and rights under the law see Social care, mental health and your rights, NHS.

Masking

The Kids Charity define masking as '*the conscious or unconscious act of suppressing or mimicking behaviours to appear more "neurotypical". This may be to try to fit in, avoid negative reactions, or meet the expectations of those around them. Long-term masking can be exhausting and harmful to an individual's mental health*.'

United Nations Convention on the Rights of the Child (UNCRC)

The United Nations Convention on the Rights of the Child (UNCRC) is an important, legally binding agreement signed by 196 countries (as of 12 July 2022) which outlines the fundamental rights of every child, regardless of their race, religion or abilities.

Getting it Right for Every Child (GIRFEC) (Scotland)

GIRFEC is based on the United Nations Convention on the Rights of the Child (UNCRC) and seeks to realise children's rights on a day to day basis. It is about enhancing the wellbeing of all children and young people as well as building a flexible scaffold of support: where it is needed, for as long as it is needed. Using the GIRFEC principles, practitioners and organisations should consider each of the eight wellbeing indicators (SHANARRI : safe, healthy, achieving, nurtured, active, respected, responsible, included).

Find out more here: Getting it Right for Every Child (GIRFEC) and Wellbeing SHANARRI

Trauma informed approach

The UK Government defines trauma-informed practice as *'an approach to health and care interventions which is grounded in the understanding that trauma exposure can impact an individual's neurological, biological, psychological and social development*.'

For more information on taking a trauma informed approach see: Keeping Trauma in Mind - Education Scotland and Trauma Informed Practice Toolkit.

Young Carers

A young carer is defined as a child or young person under 18 who provides care, assistance, and support to a family member or friend, typically for a physical/mental health condition, disability, or addiction. They often take on extra jobs in and around the home, such as cooking, cleaning or helping someone get dressed and move around. These extra responsibilities can impact their education and social life. Young carers have certain legal rights to access support.

For more information on carers rights and support for young carers, visit Carers UK: Support for Young Carers. For more information on supporting young carers of people with disabilities visit Sibs - for brothers and sisters of disabled children and adults.

Adverse Childhood Experience (ACE)

An Adverse Childhood Experience (ACE) is a traumatic event or sustained stress occurring before age 18 that disrupts a child's safety, stability, and healthy development.

In some cases, neurological conditions can contribute to ACE-like stress for both the child directly affected and for children living with a parent or sibling with a condition. Sudden or significant changes in behaviour, cognition, or emotional regulation—and the uncertainty that surrounds conditions that are poorly understood or inconsistently supported—can create chronic stress and repeated exposure to frightening or destabilising situations.

For more information on ACE visit: Help Children Live Better- ACE.

Further resources and organisations

Bereavement and loss

- Child Bereavement UK - offer free, confidential, digital bereavement support by telephone, video or instant messenger, to families wherever they are in the UK.
- PAMIS Bereavement and Loss Learning Resource Pack - a resource to support bereaved people with profound learning and multiple disabilities and their parents and carers.

Communication

- TalkingMats - a visual communication framework which supports people with communication difficulties to express their feelings and views.
- AAC Scotland - a website designed to help raise awareness of Augmentative and Alternative Communication and ways of providing communication support, aimed primarily at people who have little or no previous experience of communication disability.

Including children and young people in decision making

- Decision-making: children and young people's participation: Professional advice on how to involve children and young people in decision-making published by the Scottish Government.

Neurological Alliances

The Neurological Alliances of England, Wales, Scotland and Northern Ireland are coalitions of organisations aiming to make sure that the experiences of people with neurological conditions - and those around them - are recognised.

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