

"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.

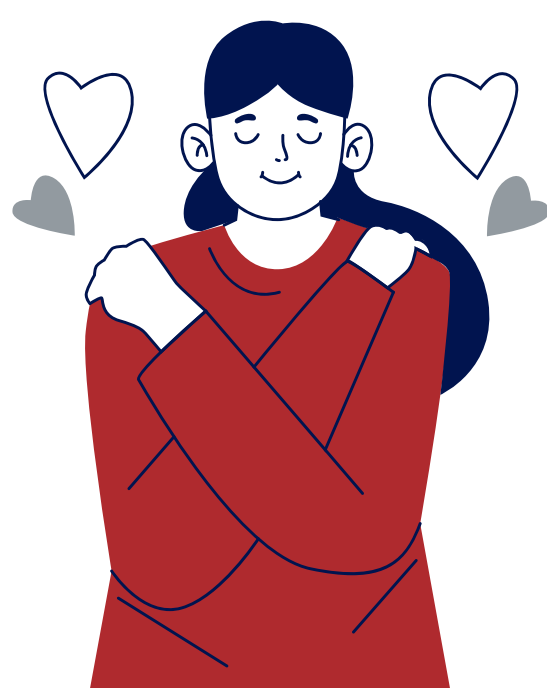
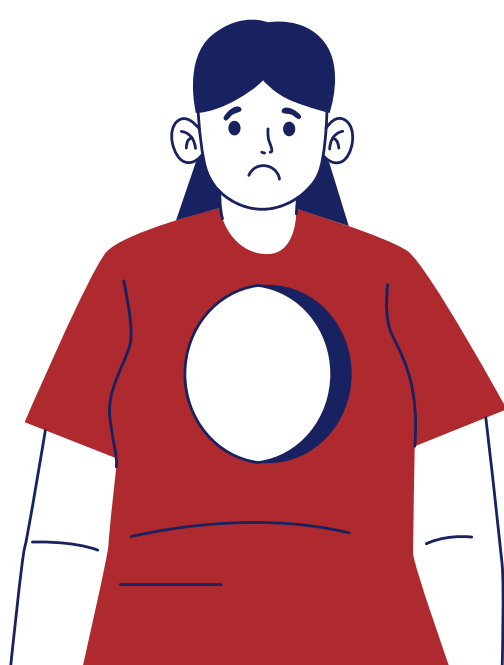
It is important to make sure:

- 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 out 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.

Glossary and further resources

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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