

# “Don’t assume I’m Ok”

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

## What is a Neurological Condition?

A neurological condition impacts the **brain, spinal cord, nerves and/or muscles**.

There are over 600 of these conditions.

They happen for lots of different reasons such as illness, injury, family, or they may be unknown.

**At least 1 in 6** people in the UK live with a neurological condition, including children and young people.

They are the leading cause of ill-health worldwide.

Many children and young people have a loved one with a neurological condition and, in some cases, multiple family members.

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

**What impact might this have on the children you work with?**

**Are you supporting them well?**

## Why is mental health important?

Mental health is just as important as physical health.

**Neurological conditions can happen alongside other mental health challenges** like anxiety and depression. They can also include changes in behaviour and attention. They may cause problems with sleep.

Some children have a limited vocabulary. This can make it hard for them to talk about their feelings.

Some children live in families where someone has a neurological condition. **They may help with caring at home but not realise they are ‘young carers’.**

Mental health support for anyone impacted neurological conditions can be hard to access.

## Every child is different. They need their own way of being supported to protect their wellbeing.

Using the wrong approach can cause harm. It can also mean missing a chance to act early.

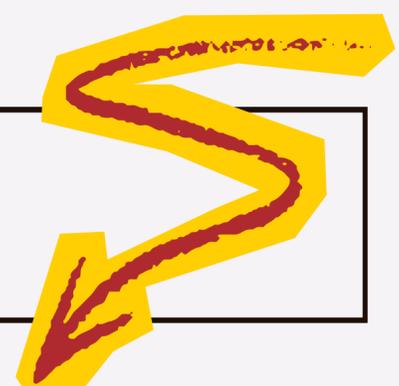
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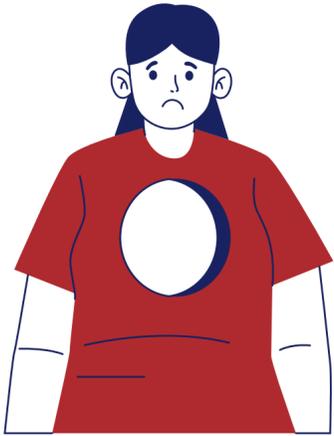
- you are **informed**;
- you **listen** to the young person and their needs;
- you take **action** and do not wait for the problems to grow.

Do not assume they are ok. **Everyone has a responsibility** to help keep children and young people safe and supported.



## What can you do to help?





## 01

### Be informed

- Learn about neurological conditions and find out where to find help and support: [Neurological Conditions - information and resources](#)
- Visit our mental health website page to find support services for children and young people: [Neurological Alliance of Scotland- Mental Health and Neurological Conditions](#)
- Understand the impact of loss and grief. Loss can take many forms. Grief is not simple and does not follow rules. Keep checking in with the child, gently and often. For help visit, [Cruse Bereavement Support](#)
- Look out for trauma. Trauma happens when something is too much to cope with and can impact feelings, thoughts for a long time. 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 unpaid carers. Friends and family count as carers. It can be very hard and tiring, so they also need support. See our resource for supporting unpaid carers of those with neurological conditions: [Information for unpaid carers and professionals.](#)

## 02

### Ask, do not guess

- Make sure to have regular check-ins with the children and young people you meet.
- Create a safe space where conversations are easy to have.
- Show and use words for feelings, using visual helpers where needed, like [PODD](#).

## 03

### Listen

- Not all conversation is said out loud. Give a meaning to any gestures and signs used. Find out more here: [Communication Methods for Non-Verbal Children, FCA](#) and [What is AAC? Communication Matters](#)
- All behaviour is a type of communication. Someone being more tired, quiet, angry, or absent could be telling you they're not doing well. Find out more on what 'masking' means and how to spot it here: [Masking, Kids Charity.](#)



## 04

### Act Early

- Use wellbeing tools like SHANARRI to check a child's wellbeing
- Let children join in "big" conversations. They may understand more than you think. For tips on helping children be part of conversations and decisions 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.

# Definitions and more information

## **Neurological condition**

A neurological condition is any condition that affects the brain, spinal cord and/or nerves. There is a very wide range of neurological conditions, and they can affect people in very different ways.

Neurological conditions can affect the way you think, 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**

Mental health means feeling well enough in your mind to handle everyday stress, you are able to learn and work well, and be part of your community. It's an important part of being human and everyone has a right to good mental wellbeing. Mental health conditions include lots of different conditions which may cause changes in how someone behaves, thinks, and copes with emotions. Some mental health conditions can cause distress, make life harder to manage, or put someone at risk of harming themselves.

For more information about mental health and rights under the law see [Social care, mental health and your rights, NHS](#).

## **Masking**

Masking means hiding or copying certain behaviours to seem more "normal" or like others expect you to be. People might do this to fit in, avoid being judged, or meet other people's expectations. Doing this for a long time can be very tiring and can negatively affect someone's mental health. For more information on how masking can look and its impact, visit [The Kids Charity](#).

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

The [United Nations Convention on the Rights of the Child \(UNCRC\)](#) is an important, legal agreement between 196 countries which clearly outlines the rights of every child, no matter their background, race, religion or abilities.

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

GIRFEC is a set of principles created by the Scottish Government to make sure people working with children and young people are protecting their rights on a day to day basis. It gives guidance on how to support children and young people, and gives eight 'wellbeing indicators' for professionals to use to make sure children are safe and supported. The wellbeing indicators are: safe, healthy, achieving, nurtured, active, respected, responsible, included (SHANARRI).

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

## **Trauma informed approach**

A trauma informed approach means providing health or care in a way that understands that going through trauma can affect how a person's brain, body, emotions, and social skills develop.

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 someone under 18 who looks after a family member or friend who has an illness, disability, mental health problem, or addiction. They may do extra tasks at home, like cooking, cleaning, or helping someone get dressed or move around. These responsibilities can affect their schoolwork and social life. Young carers have legal rights to get 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 something very upsetting or stressful that happens to a child before they turn 18. It can make them feel unsafe, unstable, and can affect their healthy development.

Sometimes neurological conditions can create ACE-like stress. This can affect the child who has the condition, or other children in the family. Big or sudden changes in behaviour, emotions, or thinking—and the confusion that comes with conditions that are not well understood—can cause long-term stress for everyone involved.

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 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 for 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

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.