Working wonders for children with brain conditions

Families where a child has a brain condition face challenges every day. Just to learn, play, make friends and experience the world can feel difficult, even impossible. But we don’t believe there’s any challenge that can’t be overcome.

So we listen to families, we learn from them. We carry out research, we design and innovate, we make and share. From new equipment to new learning resources, to new ways to play and support each other, everything we find out together makes life better. It opens doors to discovering the world.

It’s an incredibly rewarding journey for everyone involved. Why not be a part of it? You never know what we’ll discover together.

www.cerebra.org.uk

Our guides for parents help you find the answers you need. You can view and download the full series of our guides and factsheets completely free from our website www.cerebra.org.uk.

If you would like to make a donation to help cover the cost of producing our guides give us a call on 01267 244216 or donate at https://cerebra.org.uk/get-involved/donate/.

Thank you.
Managing challenging behaviour

Aims

This factsheet gives information on how to manage challenging behaviour (CB). In particular it explains what CB can be and why it might happen. The main aim is to help parent/carers to find high quality sources of information. This factsheet will help parent/carers get started on their information/research journey.

Key points

- What is challenging behaviour?
- Why does challenging behaviour happen?
- Understanding challenging behaviour
- Where do I find professional help?
- What further information is available?

What is challenging behaviour?

Some behaviours are a challenge to professionals, teachers, carers and parents. Behaviour is challenging if it causes harm to the person or others, or if it stops them fulfilling some aspect of their lives, such as when a child cannot go to school because they show some aggressive behaviour. It is the impact of these behaviours that makes them challenging.

Challenging behaviour (CB) can be:

- **Self-injurious**: Head-banging, scratching, pulling, eye poking, picking, grinding teeth, eating things that aren’t food.
- **Aggressive**: Biting and scratching, hitting, pinching, grabbing, hair pulling, throwing objects, verbal abuse, screaming, spitting.
- **Stereotyped**: Repetitive movements, rocking, repetitive speech and repetitive manipulation of objects.
- **Non-person directed**: Damage to property, hyperactivity, stealing, inappropriate sexualised behaviour, destruction of clothing, incontinence, lack of awareness of danger, withdrawal.

To find out more about CB and the types of CB visit: https://www.challengingbehaviour.org.uk/

The Challenging Behaviour Foundation (CBF) offers a wide range of information sheets about CB and related topics. The following information sheets are available to download:

- Pica (Eating inedible objects) - https://www.challengingbehaviour.org.uk/understanding-behaviour/understanding-behaviour.html
Why does challenging behaviour happen?

CB has been found to occur more often in people with more severe disabilities, especially those with a learning disability.

Every behaviour has a function for the person displaying it.

Sometimes this can be a form of communication, a wider mental health problem, biological cause or an environmental cause.

To find out more on why CB occurs visit: https://www.challengingbehaviour.org.uk/understanding-behaviour/understanding-behaviour.html

Factsheets include:


There are also many charities willing to help with challenging behaviour.

Mencap have developed some useful information resources to help families get the right support for people with learning disabilities and behaviour that challenges - https://www.mencap.org.uk/advice-and-support/children-and-young-people https://www.mencap.org.uk/advice-and-support/displaying-challenging-behaviour
Families and carers can contact the Challenging Behaviour Foundation to speak to a Family Support Worker - https://www.challengingbehaviour.org.uk/supporting-you/for-families/family-support-service.html. Also contact your local council to find out what help is available in your area.

Understanding challenging behaviour

Parents and carers can learn to understand and interpret children’s CB.

It is important when faced with CB to think about why is this behaviour being displayed?

By looking at the meaning behind the child’s behaviour, as a parent or carer you can provide support and guidance to your child at this difficult time.

There are questions to think about when looking at why the CB is being displayed.

- Is the behaviour new, or has it been on-going for a while?
- Who does the behaviour occur with?
- Is there a pattern to the behaviour, for example at a certain time of the day?
- Is this a behaviour to avoid doing something, or to escape?
- Is this a behaviour for a need to be met, or for interaction or attention?
- Is this a behaviour for a sensory reward?
- Is the trigger for the behaviour known or unknown?
- Have there been any changes in medical history? For example, illness or medication.
- What changes in the environment have occurred? For example, change in daily routine, activities, peer groups, lack of stimulation, over stimulation, fatigue, pain or discomfort, changes in noise level, or changes to the people around the child, peers or professionals.

Where do I find professional help?

If you’re finding it hard to cope with the behaviour of the person you look after, you can ask your GP to refer you to a specialist with knowledge of challenging behaviour. You will usually be asked to keep a record of the person’s behaviour to see if there are any patterns.

In extreme circumstances – for example, if the person’s behaviour is harmful to themselves or others and all methods of calming them have been tried – a doctor may prescribe medication.

If you’re concerned about the side effects of medication, speak to the person’s GP. There is more information on the use of medication for challenging behaviour and physical interventions on the CBF website:

- https://www.challengingbehaviour.org.uk/understanding-behaviour/physical-interventions-sheet.html

What further information is available?

The National Institute for Clinical Excellence (NICE) have provided quality standards that say what services should be providing for children. NICE also offer evidence-based advice on prevention and interventions for children, young people and adults with a learning disability and behaviour that challenges.

The carer/parent version can be found here: https://www.nice.org.uk/guidance/ng11

NICE has produced an easy read version for people with a learning disability - https://www.nice.org.uk/guidance/ng11/resources/behaviour-that-challenges-and-learning-disabilities-easy-read-version-64199918
The link below explains the advice about behaviour that challenges and learning disabilities in people of all ages that is set out in NICE guideline NG11. This information is for parents, family members or carers of children, young people and adults with a learning disability and behaviour that challenges – https://www.nice.org.uk/guidance/ng11

The PBS Academy has developed an Information Pack for Family Carers (produced jointly with the Challenging Behaviour Foundation), the contents of which are:

- Introduction
- Resource 1 – What is Positive Behavioural Support?
- Resource 2 – What should Positive Behavioural Support look like?
- Resource 3 – Questions to Ask to Check Positive Behavioural Support is being used well
- Resource 4 – Family Carers Using Positive Behavioural Support
- Resource 5 – Practical Tools to Help You

This resource can be found at: http://pbsacademy.org.uk/family-carers/

Find further information and more views from parents on stopping challenging behaviour from other charity websites such as SCIE and family lives:

- http://www.familylives.org.uk/advice/primary/behaviour/challenging-behaviour/
About the author

Elizabeth Halstead is the Lead Research Officer at Cerebra based at the University of Warwick. She has a background in Psychology and her research is specifically focused on learning disabilities and autism.

This factsheet has been peer reviewed by Professor Richard Hastings, Cerebra Chair of Family Research at CEDAR at the University of Warwick.

This edition has been updated by Jane Margetson, Lead Research Officer at Cerebra.

The findings of this report are those of the author, not necessarily those of Cerebra.

First edition: 2015
This edition: 2019
Review date: 2022
Working wonders for children with brain conditions

Postal Address
Cerebra
The MacGregor Office Suite
Jolly Tar Lane
Carmarthen
SA31 3LW
Tel: 01267 244200
FreepHONE: 0800 328 1159

www.cerebra.org.uk