

Emotions and behaviour

Information resources

About this information

This information sheet aims to answer your questions about some of the emotional and behavioural difficulties you may encounter: what they are, why they are associated with hemiplegia and what strategies there are to deal with them. This was written with children in mind, but it is equally relevant to young adults.

Why is this particularly relevant to children with hemiplegia?

All children misbehave on occasions – it is part of growing up and learning about the world. This behaviour can become more concerning when it begins to affect the quality of life of the child and those around them. Studies of groups of British children and teenagers have shown that, at any one time, about 10% are diagnosed with emotional and behavioural difficulties that cause an impairment to their everyday lives. The London Hemiplegia Study (1987), still the biggest of its kind, showed that around half of children with hemiplegia had significant emotional and behavioural difficulties, regardless of their social or economic background.

The research that has been done shows us that having a brain injury, like those

that cause hemiplegia, makes children more vulnerable to displaying challenging behaviour. It is thought that the brain injury that caused the hemiplegia may also be responsible for a difference in temperament; evidence suggests that some children with hemiplegia feel more irritation than their peers.

The brain is very clever and often 'rewires' pathways to work around damaged areas and find a way to get messages through. This is called neuroplasticity. Sometimes, however, this means that information gets sent to parts of the brain it shouldn't. This process means that there are signals flying back and forth in the brain that aren't helpful, they are just 'noise'.

This noise means that there is less room to process the genuine signals which can cause the build up that many parents will be familiar with: a tough day at school leads to an outburst at home over something that seems small to you, like the television or a fork. With less capacity to cope with the stresses of everyday life it's inevitable that children will feel cranky and overwhelmed.

This neuroplasticity can also increase worries and anxieties. It seems that sometimes areas of the brain that detect things that usually don't make us feel anxious can become 'rewired' to the parts of the brain that cause us to feel fear, making children more vulnerable to phobias and anxiety.

Unfortunately, behavioural challenges can easily be overlooked by some health professionals, when their focus is on improving physical skills, but ignoring challenging behaviour can have a significant impact on the young person's quality of life and that of their parents and siblings.

With more and more families affected by hemiplegia seeking support with emotional and behavioural difficulties there is a need for further research specifically in this area so that there is more information and support available to parents and children.

What are emotional and behavioural difficulties?

Children's emotional wellbeing and behaviour lie on a continuum from causing no concern to being challenging (but not enough to warrant a diagnosis),

right through to behaviour indicating a diagnosable psychiatric or psychological condition. Most children fall within the first two categories but for some, the symptoms are persistent and so extreme that they cause considerable distress and have a debilitating effect on daily life or affect the wellbeing of others.

Dr Robert Goodman, Professor of Brain and Behaviour Medicine at King's College London looked at this question in the 1987 London Hemiplegia Study. He found that the three biggest areas of difficulty were:

- **Conduct.** This refers to unacceptable behaviour. About 25% of children in his study were identified as having conduct difficulties that included disobedience, arguing with adults and losing their temper. Interestingly very few of the children with hemiplegia displayed more severe antisocial behaviours such as stealing, fighting or destroying other people's property that might get them into trouble with the authorities.
- **Emotional difficulties.** Persistent fears and moods that interfere with life and cause others to be concerned about the welfare of the child. Again approximately 25% of young people with hemiplegia fit into this category.
- **Activity or hyperactivity.** Approximately 13% of the young people had significant difficulties with over-activity, impulse control and attention at home and at school that affected their learning and relationships. This figure was higher if home and school were looked at separately.

These are some of the issues that you may encounter. Every child and situation is unique so not all of these will be relevant.



“My child is normally sweet-natured but suffers outbursts. The triggers seemed to be tiredness, anxiety, change of routine, too many people in the house, any suspicion of criticism or belittling.”

Common behavioural difficulties:

- irritability and anger
- verbal and physical aggression
- impulsive behaviour
- inflexibility
- overreaction
- disruptiveness
- defiance and opposition
- argumentative
- destructive behaviour

Common emotional difficulties:

- withdrawal
- depression
- anxiety
- shyness or social anxiety
- emotional immaturity
- low self-esteem
- mood swings

These behaviours and emotions are commonly experienced from time to time but become problematic when they begin to negatively affect the child’s wellbeing and engagement in typical activities and learning, or that of people around them.

Understanding triggers

Many parents of children with hemiplegia report feeling responsible for their child’s behaviour, as though they are to blame because of bad parenting. Or it may sometimes feel as though your child is wilfully misbehaving just to be annoying. However, there are many complex reasons why emotional and behavioural difficulties can occur.

Like any other behaviour, challenging behaviour is a type of communication, just in an unwelcome and unpleasant form. It is often motivated by an unconscious need, perhaps to gain attention, exact revenge or exercise power or control. Or it might be a display of frustration or feelings of inadequacy. Inappropriate behaviour usually happens when the young person or child is not able to perform the more appropriate behaviour or finds it more difficult to do so. They might not have the skills to articulate what they want or to describe how they are feeling. They may feel that the good or acceptable behaviour is not as effective as the misbehaviour, perhaps because in the past it has not been successful, as fast or as easy as they would have liked.

“If your child is frustrated because they have difficulties making sense of their environment, they will act up. There are lots of ways to help once you know what you are dealing with.”

It may feel as though the child has made a conscious decision to behave badly, but this is often not the case and it is a response to a situation that is difficult to deal with or accept.

Some events that trigger challenging behaviour are easier to detect than others and so it is potentially easier to intervene when there is no time lag between trigger and behaviour. For example:

Trigger: asking your son or daughter to turn off the television in order to focus on their homework.

Behaviour: argument.

In this case you can easily work out what has caused the argument because there is a very clear cause (the request to turn off the television) and effect (the argument).

Sometimes you might not witness the trigger event, or it might be a series of events. For example, your child:

- may be physically tired after a day at school
- in pain
- feeling frustrated about something that is happening in their life
- may be getting bullied or having troubles at school
- they may be seeking attention or it could be they are experiencing hormonal mood swings

As a general rule triggers are external factors, such as:

- Frustrations relating to cognitive impairments or lack of support in managing these.
- The environment, for example a young person who is sensitive to noise may be more prone to challenging behaviour in crowded places.
- Physical tiredness as a result of the stress on the body, which can generate frustration, outbursts and meltdowns.

Whatever the cause of their behaviour it may be quite clear to you that they are struggling to manage their anger and emotions but it may be hard to think about how to help them.

What can you do?

Firstly, it should be clear that the challenging behaviour is not the fault or responsibility of either you or your child. As we have seen, it is the result of injury to the brain and an unconscious reaction to the environment. It is very easy to feel as though your parenting skills are being judged or questioned, particularly when incidents happen in public – like a tantrum in a shop or playground, but it is really important to acknowledge that this situation is not anyone's fault.

There are strategies that can help deal with challenging behaviour and emotional difficulties. As there is such a strong link between the two types of difficulties many of these tactics may work in coping with a number of causes or types of behaviour. There is no 'one size fits all' solution and you will know best what will be helpful for your child. A strategy may be effective when your child is ten years old but may be less so when they are thirteen and vice versa.



Although there are a great number of books on the market that can be helpful, it is worth thinking about getting a referral to a psychologist or other specialist. Working together with a professional can be very useful because it combines their expertise in behaviour assessment and management with your expertise in your child. They can also help you judge when a strategy has been given enough time to work and you need to move onto another. They can provide support and encouragement. Together you should be able to develop a plan that works and makes everyone feel a lot better.

Behavioural management uses methods to prevent or respond to behavioural difficulties by:

- using safe and effective strategies
- increasing acceptable behaviour
- decreasing challenging behaviour
- building skills in both the child and the parents
- meeting everybody's needs
- making those involved feel good about themselves

Some practical tips

There is no universal solution, all children are unique. Understanding the triggers and the pay offs for misbehaving is likely to produce the best results. To do this we need to examine the young person's behaviour in detail. By identifying recurring themes you can understand potential triggers and work towards a solution. For example, if your child is always bad tempered and argumentative on Tuesdays, and only during termtime when this coincides with PE, then it may be helpful

to speak to the school about adapting PE lessons or providing greater support. Spotting these things can be difficult in the heat of the moment or when you are struggling to remain calm and patient in the face of continuing provocation. You may find it useful to keep a diary so that you can look back and spot any patterns of behaviour or see if events in your family or school calendars are triggering issues.

“We think a lot of it is just down to how tiring school is for him so they do a lot to try and make his day easier and less demanding without compromising his learning. They are also more lenient with his homework.”

Here are some tips to help maintain positive and helpful responses that can help get the most out of a behaviour management plan:

Acknowledge that you can and do affect your child's behaviour. Be

mindful of your own reaction because your behaviour affects the behaviour of others; in this case whether it stops or escalates.

Don't take it personally. This is often easier said than done but we maintain control by not taking negative comments or actions personally. Without this rational detachment we may react instinctively or defensively without thinking, which may make the situation worse.

Be attentive. This is an effective way to counter any anxiety. Pay attention to what your child is saying. Give them plenty of personal space. Show them through your facial expressions and body language that you're listening, and you can understand why he or she is upset.

Use positive self-talk. It is important to remind yourself that when you're the target of an outburst or a negative situation, you're rarely the cause of the behaviour. And just as thinking, "I can't deal with this" might cause you to react one way. Telling yourself, "I know what to do" will cause a more productive response.

Recognise your limits. As parents we often want to make everything alright but this is not always possible. You may need to accept your limits and keep in mind that sometimes the best decision is to let someone else take over. That someone may be a partner, grandparent or a professional.

Be assertive but positive in your parenting style. It is OK to have expectations concerning socially appropriate behaviour and expect your child to adhere to these. It is important to convey conviction in your child's ability to achieve these expectations in a manner that nurtures their self-esteem.

Model and instruct your child on acceptable behaviour. Children learn through their interactions with others. Therefore it is important that they not only hear about how they should behave but they see this too. Parents are best placed to demonstrate effective problem-solving and how to respond to provocation by demonstrating these skills when intervening with their child's challenging behaviour.

Recognise when you need a break. Dealing with challenging behaviour can take its toll on parents. Making sure you have some respite and time away from the situation is important to allow you to reflect and recharge your batteries.

Once you have developed a management plan there are some things that can help you and your child succeed in implementing it.

- Share the plan with your child and the set of rules that help explain what behaviour is expected.
- Keep the number of rules to a minimum, usually no more than four or five. The plan must contain good rules and clear, effective consequences for keeping to the rules (rewards) or breaking (sanctions) them.

Good rules are specific and achievable. 'Your mobile phone should be switched off at 8.30pm' is a good rule if the young person can tell the time. 'Your mobile phone should be switched off in the evening' is not a good rule because there is no shared understanding of evening.

- It is always helpful to have these written down and displayed where you and your child can refer to them when needed.
- Identify rewards for following these rules. Choose ones that are valued by the young person. It is always best to get the young person involved in developing a 'menu' of rewards because what is rewarding for one child might not be for another, and whilst parents often know what motivates their children we don't always get this right.
- Sanctions should be proportionate and applied immediately. Once a sanction has been served, actively look for an opportunity to praise the child for good behaviour. This will help to build self-esteem, preserve relationships and draw a line under the previous incident.

Where to find more support

If you are concerned about difficult behaviour or finding it hard to cope, you should talk to your doctor. They may refer you for further support, such as with the Child and Adolescent Mental Health Services (CAMHS).

Your school may also have access to a number of useful services including educational psychologists, specialist teaching teams and CAMHS.

There are a number of organisations who can signpost support depending on your particular situation. You can call our helpline on 0345 123 2372 for more information or support. You can also join our Facebook group where parents often share their practical tips and provide emotional support on this topic.

Other useful organisations

The Challenging Behaviour Foundation
0300 666 0126 (Family Support Line)
www.challengingbehaviour.org.uk



How can HemiHelp help you?

HemiHelp:

- has a helpline staffed by trained volunteers who all have personal experience of hemiplegia (**0345 123 2372**) – helpline@hemihelp.org.uk
- runs a UK-wide home visiting service
- has an extensive website with news and free information downloads www.hemihelp.org.uk
- has a Facebook group and Twitter feed ([@hemihelp](https://www.facebook.com/hemihelp))
- puts members in touch with others who have faced similar problems (available upon written request) and is developing a network of local groups
- has over 30 information sheets on various aspects of living with hemiplegia
- provides a resource booklet of useful names and addresses for members
- produces a quarterly magazine where members can share information and experiences
- runs regular conferences and workshops around the UK for parents and professionals
- organises sports and activity days for children in different regions
- has a transition support service for young adults including employment workshops, 1:1 support, and work placements
- membership is from £10 a year and benefits include HemiHelp's quarterly magazine, access to our services and schemes, and priority booking at HemiHelp events

We can provide references on the source material we used to write this information product. Please contact us at info@hemihelp.org.uk

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