

Behaviour management in children after encephalitis

By Dr Emily Talbot, Clinical Psychologist, Nottingham University Hospital NHS Trust and reviewed by
Dr Katie Byard, Consultant Clinical Psychologist, Recolo

Content

1. Behavioural changes after encephalitis
2. Referral to a psychologist
3. Antecedent behavioural management
4. Strategies for parents/carers

1. Behavioural changes after encephalitis

After encephalitis, children can be left with various and complex needs (cognitive, emotional, fatigue, epilepsy) which may impact on how they behave. Sometimes, when behaviour changes after encephalitis, it is behaviour that was present before the illness but has become more extreme, making it 'inappropriate', or it has taken an unwanted form. Difficulties at school and with making friends are likely to make unwanted behaviours worse, increasing your child's sense of loss and lowering their self-esteem. Also the behaviour can sometimes 'wind up' in a spiral; it is as if the thermostat is missing. In these situations the behaviour can become extremely challenging and aggressive, and it can be difficult for the children to calm down by themselves.

Following encephalitis, an injury to the brain can affect both your child's ability to control their behaviour and their awareness of what is acceptable or appropriate in the moment. However, speaking to you, in a quiet situation, they may be able to tell you exactly how they should behave, but be incapable of putting that into practice in 'real life' circumstances. After an episode of inappropriate behaviour, they may be upset about what they have done, but they still have difficulty not displaying this behaviour again. This can feel very frustrating for parents.

2. Referral to a psychologist/neuropsychologist

The best basis for helping your child is a loving and caring relationship which is not always easy in the face of very difficult behaviour. Try to see your child as separate from the difficult behaviour: 'I love you, but I don't like what you're doing'. This can help you to work together on the problem behaviour, without your child feeling bad, or unloved.

To help change a child's behaviour it is essential to have an assessment of the difficulties that may lie behind it. Is there a lack of insight, is there disinhibition or poor emotional control, is there a memory problem or a problem with visual or auditory perception (your child's interpretation of what is seen or heard)? For an assessment of your child's difficulties and help with strategies to change them, ask their doctor or GP to refer them to a child psychologist for a neuropsychological assessment and/or advice.

3. Antecedent behaviour management

Most children can learn to behave in an acceptable way because it results in a *rewarding consequence*. Children affected by encephalitis may have lost the cognitive skills needed to respond in this way. They may not be able to:

- Understand cause and effect.
- Always remember what they have to do to avoid punishment or to earn rewards.
- Understand that good behaviour may be rewarded at a later time and be patient.
- Remember the rules and be able to use them in different situations.
- Control their behaviour at will in different situations.

Antecedent behaviour management is a much more appropriate strategy for children affected by encephalitis. It is a positive, proactive approach, based on the idea of preventing inappropriate behaviour as opposed to dealing with behaviour problems after they have happened. The antecedent is what happens before the behaviour occurs or what has provoked it. Antecedents can be things that happen, such as a change in activity, a loud noise or a distraction. They could also be actions such as asking your child to complete a task, giving attention to another child or saying something that they don't like.

4. Strategies for parents/carers

Keep a diary

You should seek help from a suitably qualified and experienced psychologist to address significant behavioural problems and to learn ways to manage the behaviour differently, but it is possible to make some changes yourselves. Problem behaviour can be overwhelming and it can feel as though like all behaviour is a problem, so it can be helpful to keep a diary or draw up a chart and record behaviour for one or two weeks. This will give you information about the patterns of behaviour across the day and week and may help you to identify times of day

(e.g. before school, at bedtime or at the dinner table), or particular triggers (being told 'no', arguments with a sibling, your child being tired) to behavioural outbursts. Suggested information prompts for a behavioural diary include:

1. Date
2. Time
3. Description of previous night's sleep
4. Fatigue levels before the outburst (0 = no fatigue; 10 = very fatigued)
5. Where were you?
6. What was happening beforehand?
7. Description of what happened
8. Intensity of behaviour (0 = lowest; 10 = highest)
9. How long did it last for?
10. What did you do next?
11. What happened afterwards?

An example of antecedent management of the problem behaviour

Your child swears and kicks whilst getting ready for school in the morning. It is a busy time and everyone else is getting ready for school or work. You just want your child to get dressed and have their breakfast but when you tell them to do this the tantrum starts. You tell them that they must be ready by a certain time or they cannot watch their favourite TV programme that evening. Your child takes no notice and does not do what you tell them. You and the rest of the family become exasperated. Then your child has another tantrum when they do not get to watch the TV programme later.

One possible cause of the behaviour above is that children affected by encephalitis are less flexible in their thinking; they may find doing more than one thing at a time impossible; they may not be able to focus and concentrate when the environment is busy. A solution based on antecedent management is to manage the situation by putting something in place before the behaviour occurs. In this example, it could include ensuring you have a structured morning routine. It is important to break down and list the morning activities, making sure all the activities in a routine are listed. It might be helpful to create a visual timetable with pictures and words attached to each activity. You might want to invite your child to take part in creating the visual routine. This might include finding pictures off the internet connected with the activity, or taking pictures of your child undertaking each activity.

It can also be helpful to list each activity in a routine in the order they are done. For example, against '*eat breakfast*' break down the sequence into:

- take bowl from cupboard
- take cornflakes from shelf
- pour cornflakes into bowl
- put packet back on shelf
- take milk from the fridge
- pour onto cornflakes etc.

This is initially very time consuming for you as a parent but soon your child will learn to use the checklist and their morning activities will flow. You may also decide that you need to sequence some activities within a routine and not others. Putting antecedent behaviour strategies in place is not easy for a family. Discuss the possibility of accessing training with your child's GP or any other doctor.

Tips for parents/carers

Be goal-focused and proactive. Choose which behaviour to focus on and make a plan ahead of time about how to manage the targeted behaviours. You might want to use some of the tips below when you make your management plan.

- Whatever strategies you plan to use, be consistent and apply routinely.
- You may need to change your behaviour for your child to change theirs. It can be helpful to use the behavioural diary to reflect on your responses and emotions.
- Keep calm, do not over-react or shout, stay in control of your own feelings, expressing anger or irritability will only make your child more anxious.
- Maintain eye contact at their level and a low tone of voice. Do not ask your child to explain the reasons for his / her inappropriate behaviour, especially at the time of a behavioural outburst as children affected by encephalitis often have limited self-awareness and difficulty analysing their own behaviour.
- It can be helpful to use a 'loud speaker' approach with a child by speaking out thoughts to support orientation, de-escalation, to explain helpful strategies and to forewarn about transition. For example, *'you have 5 more minutes on PS4 before we have lunch'*.
- Children with behavioural problems following encephalitis can reach a 'point of no return'. Recognise and respond to initial signs of agitation or inappropriate behaviour and make a de-escalation plan ahead of time about how to respond in those situations. A de-escalation plan may include distraction, redirection, labelling emotion, cueing them away from an environment that is upsetting them, cueing them into a low stimulation environment to promote calmness.
- Avoid non-specific comments such as *'behave yourself'* or *'try being good for a change'* which give no clues to how your child should behave. Instead, say exactly what you want them to do.
- Keep activities structured and organised.
- Use calendars, visual timetables and clocks to explain what is going to happen before it happens.
- Avoid the word 'no'. Instead use redirection and provide a positive alternative. For example, rather than *'stop climbing on the climbing frame'*, say *'climb down from the climbing frame and let's play on the swing / go and have lunch'*. Also using structured choice to scaffold decision making in advance can prevent you from having to say 'no', which often causes distress and non-compliance. For example, *'do you want ham or cheese in your sandwich?'; 'do you want to go to the park or play a game at home?'*

- It may help to get your child to do something physical to work off emotional tension. Take them for a walk round the block. However, be wary of vigorous exercise if they are ‘*wound up*’ already. A quiet time with music may then be better.
- If your child is getting anxious or agitated, try giving them something to occupy their fingers (plasticine or a squishy ball) or a sweet to suck or a drink with a straw.
- Make sure your child gets plenty of rest. Pace and plan activities accordingly across the day and week; behavioural problems often become more frequent and intensive when a child is tired.
- Use planned ignoring (have a blank non-smiling face, avoid eye contact and turn away/walk away) for negative attention seeking behaviour with quick diversion to a positive activity. As soon as your child stops the behaviour smile and make eye contact, give a hug.
- Focus on strengths, on what your child is able to do.
- Use sincere, meaningful words and actions to show how pleased you are with good behaviour. Tangible rewards (chocolate or other food stuffs) do not help teach the value of social reward.
- Use descriptive praise for positive behaviour, i.e. label clearly your child’s positive behavioural response. It is hugely reinforcing when behaviour that is positive is noticed and praised.
- Give your child a place of refuge, somewhere calm and safe, where they can go when they feel overwhelmed.
- Everyone needs to be in charge of something in their lives. A child with cognitive problems has little control, so behaving badly is one way of gaining some control. Make sure that your child is allowed some control over something appropriate.
- Show your child, by your actions, how to handle difficulties and get along with others.
- Behave in and model the ways you want your child to behave—for example, be caring, show understanding and be respectful of others.
- If your child is older you may want to include them in the discussion and plans about managing difficult behaviours.
- Be kind to yourself, plan in fun stuff and talk to other people – find out what has been helpful for them.
- Communicate with school regarding the behaviour at school/home.

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Thank you!

Encephalitis International, 32 Castlegate, Malton, North Yorkshire, YO17 7DT, UK

Administration: +44 (0) 1653 692583 **Support:** +44 (0) 1653 699599

Email: mail@encephalitis.info **Website:** www.encephalitis.info

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