



Returning to school after encephalitis

Guidance for school staff

Acknowledgements

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Our gratitude also extends to Dr Andrea Pickering, Consultant Clinical Psychologist at Canterbury Christ Church University, UK for her assistance with reviewing this document.

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References

If you would like more information on the source material and references we used to write this guidance, please contact Encephalitis International.

Feedback

We hope you find this guidance useful. However, we advise that schools focus on the specific and unique circumstances experienced by each child because they can vary widely. Teachers need to also balance the priorities of helping fellow students understand the needs of the child with an acquired brain injury (ABI) as well as maintaining the privacy and dignity of the returning child whilst mitigating risk of bullying and social isolation to aid reintegration.

In all circumstances, deciding how best to meet the needs of a child with an ABI is often complex and demanding – information and decision-making need to be very explicit, reviewed, and evaluated regularly and passed on with care.

Your comments/suggestions are very welcome. Please email them to us or fill in the feedback form included with this guidance and send it back to us.



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About this guidance

The long-term prognosis for children after encephalitis varies considerably. In some instances, children come through the illness with little or no consequences. In others, children have considerable life-long difficulties or appear to have recovered well, but their future learning and personal development are affected.

Returning to school after encephalitis is a very important step in the child's recovery from encephalitis, in terms of both their social and educational reintegration. However, sometimes returning to school is a continuous battle to get the right services for the child at the right time. This guidance aims to help school staff understand that encephalitis changes lives and that their support is essential in helping the child and their family have an enjoyable and successful return to school.

The guidance covers information about encephalitis and the difficulties that may result from it. Various specific needs are described individually for clarity but of course their combined effect must be considered with care. There is also advice about how school staff can plan and implement the provision needed to meet the child's needs.

We hope that this guidance is useful, but schools will also require specific and detailed information about the child that is their concern. Teachers need to take great care and consideration in helping fellow pupils understand the child's needs so the risk of bullying and social isolation is minimised. In all circumstances, deciding how best to meet the needs of a child with acquired brain injury (ABI) is often complex and demanding-information and decision-making need to be very explicit, evaluated and passed on with care.



A summary of this guidance (**Returning to school after encephalitis. Guidance for school staff. A summary**) is also available on our website or can be requested from our office. With the ever increasing workload in school, we understand that teachers have limited time, therefore such summary guidance can be useful for an overview on encephalitis and its impact on learning before the more in depth knowledge discussed in the full guidance is required.



Encephalitis the illness. Key facts

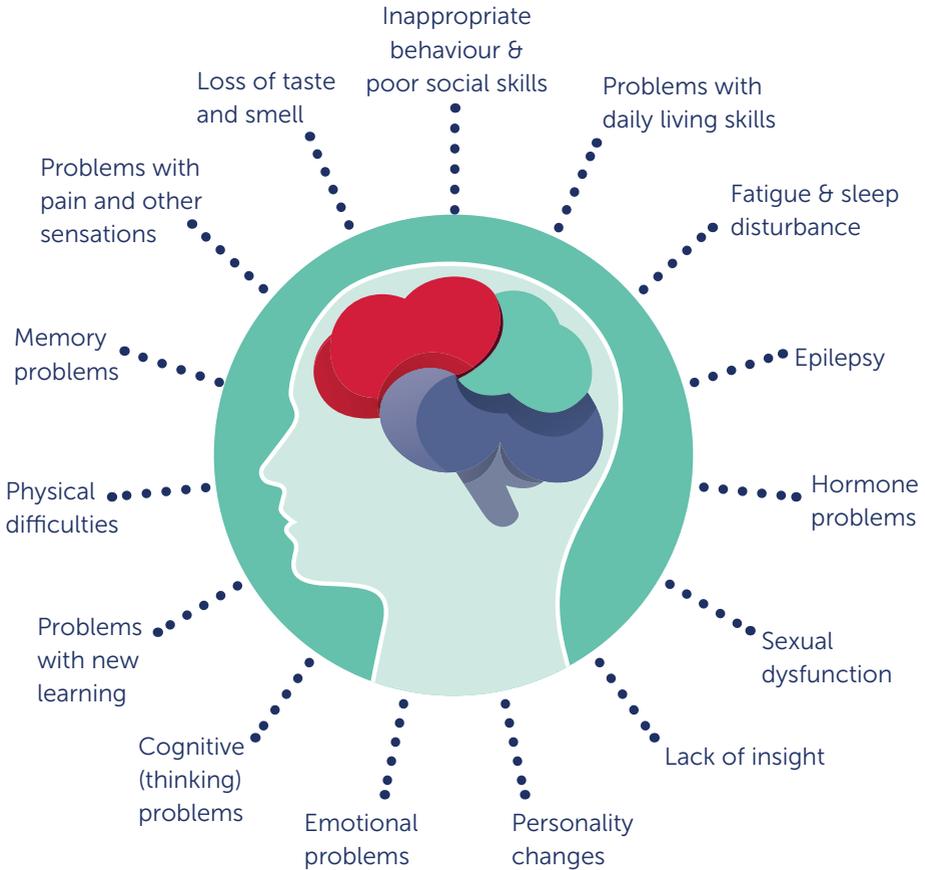
- Encephalitis is an inflammation of the brain. It can be caused either by an infection (any virus or bacteria) invading the brain (infectious encephalitis) or through the immune system attacking the brain (post-infectious or autoimmune encephalitis). In 40-60% of encephalitis cases no cause is identified.¹
- Encephalitis is different from meningitis (inflammation of the meninges, which is the protective membrane that surrounds the brain and the spinal cord).
- Anyone can become ill with encephalitis at any age. Worldwide, up to 1.5 million people are diagnosed each year² with mortality (death) rates up to 40% depending on the cause, even with treatment.³
- Encephalitis can be difficult to manage. The symptoms can be very similar to those for other diseases, so the diagnosis is sometimes delayed. The initial stage of the illness is usually serious and acute and can last anything from a few days to weeks and sometimes months. Prompt diagnosis and treatment including access to appropriate rehabilitation and support can reduce death rates and improve outcomes.
- Children who have been ill with encephalitis are likely to have a brain injury which is termed 'acquired brain injury' (ABI). This injury can result in a wide range of cognitive, physical, emotional, mental health, behavioural and/or social consequences.
- There is no set timescale for recovery. Families may feel that returning to home will make everything 'normal' again. However both the child and the family may find that there is a great deal of adjustment to the new situation required.

1. Granerod J, Ambrose HE, Davies NW, et al. (2010) Causes of encephalitis and differences in their clinical presentations in England: a multicentre, population-based prospective study. *Lancet Infect Dis*;10 (12):835-44.

2. Wang H, Zhao S, Wang S, Zheng Y, Wang S, Chen H, et al. Global magnitude of encephalitis burden and its evolving pattern over the past 30 years. *J Infect*. 2022 Jun;84(6):777–87

3 Günther, A., Schubert, J., Witte, O.W. et al. (2019) *Med Klin Intensivmed Notfmed*
<https://doi.org/10.1007/s00063-019-0604-5>

OUTCOMES AFTER ENCEPHALITIS



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The effects of encephalitis on learning and school life

The ABI may have a significant impact on a child's learning and school life, with the child no longer performing and behaving as before the illness.

It may be difficult for the school staff to identify, 'categorise' and understand the complex and unique nature of the challenges the child is experiencing such as:

- tiredness (cognitive fatigue and/or physical fatigue)
- problems with concentration especially in a noisy classroom
- difficulty working at speed
- difficulty following instructions
- difficulty changing tasks
- difficulty refocusing on a new issue
- auditory and visual memory difficulties
- sensitivity to sound
- difficulty remembering places and directions
- seizures
- inappropriate behaviour
- lack of insight into their difficulties
- not being able to get ready for specific activities
- making misjudgements
- difficulty changing routines
- not understanding jokes
- forgetting what they were doing
- physical restlessness
- disruptiveness
- appearing to be daydreaming
- limited social awareness

Difficulties after encephalitis can lead to isolation because others do not understand the cause of the child's changed ability and behaviour. The child's confidence can be impacted. They may become anxious and withdrawn or they may exhibit challenging behaviour. If the child had any learning difficulties prior to encephalitis, these may become greater as a result of the illness and the child's special educational needs may increase.

A child may return to school and continue learning, but not as before. This will be well understood by staff who have known the child before the illness, but over the years to come, the child may move on to be taught where there is no such personal knowledge and understanding. Moving from primary to secondary school is daunting for many children (new environment, new teachers, new colleagues), but for children with ABI this could be very challenging indeed (higher demands, more responsibilities, some of the effects of ABI just starting to become apparent).

Children's brains develop throughout infancy, childhood, adolescence, and during early adulthood. Some areas are fully developed and functional at an early age (e.g. the occipital lobes responsible for seeing) whilst other areas (e.g. frontal lobes associated with planning and other executive functions) continue to develop well into adolescence and early adulthood. Damage to fully developed areas of the brain may be immediately apparent through loss or impairment of former skills. The effects of damage to parts of the brain yet to be developed fully may not be apparent for some time after injury. This explains the emergence of difficulties with behaviour or subtle cognitive skills later in the child's development, perhaps years later after an injury.

It is important to recognise the impact over time of acquired brain injury and to plan accordingly.





Overall, it is essential to understand that the effects of encephalitis are:

UNIQUE

No two cases of encephalitis have an identical outcome.

HIDDEN (invisible)

The child may look exactly like they did before the illness with the effects being cognitive, behavioural, emotional or social rather than physical.

SLEEPER-EFFECT

The effects can be apparent immediately after the illness (when the part of the brain affected is already developed) or later in life (when the part of the brain affected is not yet developed at the time of the illness).

SUBTLE AND INCONSISTENT

The child can often perform as well as before in many respects, but not all, and better on some days than on others.

INDIVIDUAL

The child may be seen to perform better than other children, but definitely not as well as they did before the illness. They may reach the same achievement level as some of other children, but not their full potential.

LIFE-LONG

The effects of the illness can last for ever. The child needs to learn to live and cope with them.

Above all, it is good to bear in mind that a child who has just come back to school may not be the same as they were before the illness. After an illness such as encephalitis that may result in long-term absence from school, careful planning for the child's return is essential. Their difficulties need to be recognised, planned for and managed with care. Adequate information provided to school staff, active communication among parents, teachers, health care professionals and the child, realistic plans and expectations and a willingness to learn and work together can help children both deal with the difficulties left by encephalitis and have a positive learning experience.

How school staff can help. Ten recommendations

1. Consider a gradual return to school.
2. Learn about encephalitis/ABI and the specific needs of the child.
3. Facilitate understanding and friendship with other children.
4. Communicate well with parents, carers, families and the child.
5. Plan according to the child's needs.
6. Consider specialist help, such as an educational psychologist.
7. Consider requesting help with daily school activities.
8. Maintain an adequate environment and provide necessary resources.
9. Delegate responsibility.
10. Inform all the school staff about the child's difficulties.



1. Consider a gradual return to school.

The timing of a child's return to school after encephalitis is crucial. If the time is not right, there is an increased risk of academic failure and peer rejection. In agreement with the parents, it may be best for the child to return gradually or start with home-schooling. The pace may be extremely slow, but it is better to keep moving forward than to make a mistake by going too fast, and end up going backwards.

The child may also need to be taught and allowed to rehearse the routine of the learning environment before they return to school (e.g. putting on uniform, how to get to school for a certain time, find where all the classes and facilities are, how to get from one to other).

2. Learn about encephalitis, ABI and the specific needs of the child.

General information about encephalitis can be obtained from Encephalitis International, but details specific to the child are essential (from parents and professionals). It is helpful if reports and personal advice provided to the school describe and address in detail any difficulties that the child has and their effects on learning, together with clear, detailed advice on provision required within the classroom and school environment.

School staff need to bear in mind that sometimes, the assessments may not show the full picture. Assessments are normally not carried out in an environment similar to a school, may not be focused on educational needs or include neuropsychological perspective and/or early assessments may not reflect later difficulties. It is good practice for a member of staff to get in touch with hospital/home tutors and/or take part in the Discharge Planning Meeting (when the child is discharged from hospital or rehabilitation setting). In this way staff can learn about the child's specific needs directly from professionals who looked after the child.

Parents and carers are a key source of information about the specific needs of their child because they 'become the experts' - any challenges in school will reflect challenges they have learnt how to deal with all day every day since their child was ill. If the illness has had a significant effect, staff training could be considered. This might be provided locally by education and health services, through staff attendance at specific training events or by the voluntary sector.

3. Facilitate understanding and friendship with other children.

Contact with friends and classmates is important for many children who cannot go to school because of an illness. With parental consent, schools may be able to facilitate this via home visits, phone or video calls. Prior to meeting the child, prepare fellow pupils as appropriate for their age and understanding. The child may behave in ways that are unexpected and unfamiliar to their peer group. Consider planning and supporting a friendship group or a buddy system to enable transition back into school and ensure companionship. Plan to avoid the child feeling 'left out', while always bearing in mind that the child can't just 'catch up' and join in everything as they will get tired. Overtiredness can lead to the child feeling negatively about their experience, so a focus on pacing and gradual adjustment is important to sustain long-term success.



Schools have a legal duty of care towards their pupils, and must act as any reasonable parent would to keep them safe. All staff need to be aware of the risk of bullying and thoroughly implement the anti-bullying policy of the school.

4. Communicate well with parents, carers, families and the child.

Parents and school staff need each other's support and understanding. They need to work together and share information, good practice or concerns about the child. If the child is doing well at school, but very tired and angry in the evening at home, it may be that the child is overdoing things at school.

Sensitivity in communication with parents is needed. They have lost the child they once had and this is a very traumatic experience for them. Relationships and roles within the family are likely to have changed and they are unsure about what the future brings. Encephalitis affects the whole family, not only the child. Ask for parental consent for access to information and liaison with others, except in very specific circumstances.

5. Plan according to the child's needs.

Distinguish between any learning needs before having encephalitis and any acquired since the illness. Consider with care current difficulties on a day-to-day basis in school. Be aware of changes to the levels of attainment and rates of progress which may or may not be affected by the illness and subsequent recovery. Significant problems can develop in years to come.

Be prepared to be flexible. The child may have bad days and good days. Some of the difficulties do not appear straight away. Some of them are hidden. It is easy to forget about them in the busy classroom and assume that the child is functioning like the rest of the class.

Teachers may need to consider:

- different options for schooling (e.g. part time, home-schooling)
- lesson plans and homework customised to fit the child's current needs
- modification to the existent materials (e.g. large print, audio books, dictionaries, certain amount of content on a page/screen, different colour/details, lower volume)
- alterations of the expectations for the child's participation (e.g. giving the child more time to complete the task. reducing unnecessary tasks. focusing on the quality of the results rather than the number of tasks)
- changing aims depending on the child's response.
- using multi-sensory and contextualised learning strategies to expand potential for learning and comprehension.
- setting specific learning goals of each lesson, starting with a focus on building success and avoiding failures and mistakes to sustain progress.



6. Consider specialist help.

With parental consent, comprehensive psychological assessment is essential when problems with cognitive functioning or social, emotional and behavioural difficulties become apparent in school. As recovery takes time, and the effects of damage may not be apparent for some time, it is recommended that reassessments be planned and followed through. Educational psychologists and clinical psychologists, some of whom may specialise in neuropsychology, undertake psychological assessments of children who have had encephalitis.

7. Consider requesting help with daily school activities.

Consider asking for a special needs assessment if the child is finding learning, communication, or daily activities more difficult than others their age. This kind of assessment helps the school understand what support the child may need to feel comfortable, confident, and able to learn in their own way. It is about making sure they get the right help – whether at school, at home, or in their community – so they can grow, participate, and reach their full potential just like every other child.

8. Maintain an adequate environment and provide necessary resources.

School needs to ensure that all the support and equipment needed are specified, available and maintained, that the environment is well-organised and consistent, and that potential risks are understood and well managed by all parties.

9. Delegate responsibility.

Name a key worker at the school responsible for communicating with staff/parents. Work out a way to report problems or positive examples of things that are working. Keep reassessing.

10. Inform all the school staff about the child's difficulties.

All staff (e.g. teachers, teacher assistants, meal supervisors, secretaries) who work with the child need to be fully informed about ABI in general and the child's current needs and potential problems in particular. It is helpful to create a one-page Student Passport, including a photo, to share with school staff – providing specific information about the child in order to help them prepare and to provide specific adaptations in settings across the school environment (please see Student Passport form in Appendix 2).

When the child moves class or there are new staff, school needs to provide full reports about the child. Remember that some of the effects of encephalitis do not appear straight away, but emerge years later when the child starts using new skills. While trying to be as positive as possible after the child has returned to school, it is important to give clear and accurate information in reports and records. 'Doing well' in a report following illness, while true in respect of being back after missing several weeks, might be misinterpreted in later years. On transfer to secondary school, it is essential to make possible future needs clear. If the child has a complex pattern of impaired learning and very specific needs for intervention, it is important to explain this in detail.



Specific areas of difficulty and their impact on learning

Memory

As memory processes are complex, a pattern of memory difficulties may be very specific after encephalitis:

- difficulties remembering things seen compared to those heard, or the other way round
- difficulties remembering things that happened some time ago, but not activities that happened recently
- difficulties remembering instructions for a task whilst doing it
- difficulties remembering names, faces, places or directions

“Julia has problems with her memory (about what happened recently and in the past). She often can’t remember what happened at school that day. We don’t know why, but sometimes she does remember. It’s the same about things that happened a long time ago. She knows what she wants to say, but it takes her longer to find the words to say it than other children do.”

(Parent’s experience of a child’s memory problems)

“Home/school liaison over homework has helped. Using the internet has helped clarify things for many parents, and we check they’ve got access”.

(Teacher’s experience)

What can help?

The ideas below are not exhaustive or age/stage specific and above all, it is important to use the child's strengths and maintain their confidence.

- Use reminders, checklists, labels and color codes.
- Establish a routine and build good habits.
- Use repetition and reinforcement of information and cues to aid their recall.
- Use mind maps or spider diagrams to help the child link their memories together to support recall of related information,
- Use multiple choice testing, rather than tests involving free recall.
- Allow them more time to access memories as they may have to use a more complex brain pathway than before.
- Keep the environment well organised.
- Say one thing at a time and always be very explicit.
- Record the lessons and make recordings available to the child.
- Be clear about rules and expectations.
- Monitor attentiveness and minimise distractions.
- Avoid asking children to guess the answer, as there is a risk that if they give the wrong answer, they will always remember the wrong answer. For example, if a child who has had encephalitis cannot read a word and is asked to 'have a guess' and then gives the wrong answer, they may 'over-learn' that response at that point and always make the same mistake again. Instead of guessing, use 'errorless learning' which means exposing children to the answer a number of times before they are asked to remember it.

It can be difficult to grasp this fully and to act accordingly in school, **but memory loss from ABI does not 'getter if you try harder'.**

The focus is to try and help the child using their remaining memory abilities more effectively.

Planning and organisational skills (executive functions)

“Planning is the process of thinking about the activities required to reach a desired goal. Organisation refers to the ability to direct and bring order to the task at hand.”

Difficulties in this area can range from being subtle to being so extreme that the child may appear unable to tackle even the simplest of tasks, more impulsive or totally disorganised. This may sometimes be interpreted wrongly as ‘lack of effort’. These difficulties may continue throughout schooling and into adulthood, increasing as daily life becomes more complex and greater independence is expected.

Examples of problems with planning and organisation in school include:

- not having the right thing in the right place at the right time
- delays in getting to the right place at the right time
- being unprepared for specific events and/or tasks
- poor organisation when carrying out tasks
- considerable difficulties with following, keeping to and integrating aspects of the topic of the moment
- making misjudgments
- losing things
- a risk of being ‘all over the place’ in many aspects of school life

What can help?

The list of general examples below is by no means complete, and child-specific solutions are essential.

- Adhere to regular routines as much as possible.
- Establish the system of prompts and/or structure for planning and implementation that work best for this child; try to ensure the system is in place, and stays in place (e.g. school and homework timetables and/or equipment checklists).
- Give the child time to 'get ready' for any change in activity and for the next lesson.
- Be simple and clear about what needs to be done; repeat it as necessary.
- Check out the child's plan of action verbally and then monitor implementation.
- When appropriate, be explicit with the child about how staff are assisting, and that it is because they 'care', not because they are 'cross'.
- Support the child to develop a routine of Planning, Doing, Reviewing in order to learn a pattern of preparing for a task before doing and reviewing progress to learn from mistakes.
- Help the child prioritise work by adopting a traffic light system. The child can be supported to prioritise tasks into categories of Red (to do now), Amber (to do next), Green (to be done later).

"He has a checklist in his school diary, but a list's no use when he's in a muddle. We try to give him a few extra minutes to get ready and then briefly talk things through with him while the others are packing up".

(Teacher's experience)

"She's really thrown by any change in routine. We try to explain in advance, and this helps, but that isn't always possible. We do arrange for an assistant to be with her in advance of fire drill though".

(Teacher's experience)

Attention and concentration

Children who have had encephalitis may have long-term difficulties with attention and concentration. This requires in-depth understanding of their needs and consistent management throughout their schooling. It can be easy to think they are 'just not paying attention' and to forget that attention and concentration may have been permanently impaired.

I try to speak to the class and then to him, using his name and ensuring eye contact. That's helping".

(Teacher's experience)

"We thought he just couldn't do the work anymore, but when he was in a one-to-one, he could. This explains it".

(Teacher's experience)



Attention and concentration are more difficult when:

- the child is tired or distressed in any way
- the room is noisy with people moving around and various distractions
- the child finds tasks difficult to grasp
- there is lack of continuity when topics or activities change
- the child is affected by seizures and/or other health problems

What can help?

Support in school means understanding, minimising distractions and teaching at the child's pace.

- Keep the environment as quiet and calm as possible.
- Enable the child to be comfortable, but away from distractions.
- Ensure that the child is attending to, has understood or can ask for clarification about what is being said.
- Avoid any information overload or complexity.
- Develop a pattern of prompts and reminders that works for this child now (e.g. provide a stopwatch).
- When the child is to be working unaided, only set work that is fully achievable.
- Provide individual attention for new steps in learning.
- Break up activities in small steps.
- Always keep an eye on issues such as fatigue, distress. seizures and changes in routine-attention and concentration are likely to be seriously affected in these circumstances.
- Be positive with the child about the completed tasks.
- Ensure the child listens to the lesson rather than note-taking and provide the notes for the lesson, from another pupil.

Speech, language and communication

The potential impact of speech, language and communication problems on provision of education may be very considerable, with teachers needing detailed information, understanding, and the skills, equipment and resources to meet the child's needs. Provision of direct help from a speech, language & communication specialist is essential.

Difficulties from impairment of parts of the brain that control different aspects of speech, language and communication may arise in areas such as:

- accessing information at the moment required
- the speed of information processing
- attention and concentration span
- vocabulary knowledge, access and usage
- quantity of information taken in at a time
- understanding 'jokes' and alternative meanings
- flexible rather than 'concrete' thinking
- sentence formation
- timing the speech and the emphasis on words
- physical movements that enable clear speech (and also eating, chewing, drinking, swallowing)

"He has a lot to say, but we often can't quite understand – it's distressing – and at lunchtime he doesn't seem to chew anything. We're worried he might choke..."

(Teacher's experience)

"He never seems to take any notice of us – just says what he wants, doesn't seem interested in us anymore."

(A friend's experience)

What can help?

A detailed programme for action in school needs to be in place and meet the child's needs. Aspects of speech, language and communication which need to be considered when creating an action plan include word-finding, understanding meaning, phrasing, dealing with complexity, articulation, personal communication (facial expression, gesturing, listening and responding) and general communications (attention and understanding).

- Always check that the child understands what they are asked to do.
- Plan to have the time to deal with a child with speech and language difficulties.
- Consider a Specialised Communication Assessment to identify any necessary augmented and assistive technology to support the child's acquired language and communication needs.
- Be aware of how best to communicate with the child. Use language and presentation appropriate to child's needs. Remember to consider whether auditory or visual communication will be better suited to the child.
- Make sure that speech, language & communication therapy is provided if needed.



Hearing loss, processing auditory information and sensitivity to sound

A child affected by encephalitis may be left with specific impairment of hearing such as:

- hearing loss
- sensitivity, sometimes extreme, to particular types of sound
- difficulty with processing auditory information

Children may not be able to pick up, process and act on information when they are tired or in a noisy environment. In a busy classroom or after a period of concentration, a child may become overloaded and unable to take in what is said to an unexpected extent. Hearing loss is not always obvious. School may need to consult with parents and specialists for full assessment and strategies to help children coping with the learning environment. If visual or hearing difficulties are not identified, the resultant failure to respond to the information the child would be expected to see or hear may be misinterpreted as learning or behavioural problems.

What can help?

- Avoid the background noise and/or disturbing sound as much as possible.
- Make sure fatigue is well managed.
- Use multi-sensory teaching methods to support learning.
- Access Specialist support to advise on adjusting for hearing/visual impairment.
- Look at the child when you talk to them and use cues (gestures) if needed.
- Encourage and help the child to use the aids if these are recommended.
- Get familiar with assisted technology (hearing aids, implants, or FM system). If the child uses an aid, it does not mean that they no longer have hearing impairment.
- Ensure that key information has been absorbed.
- Ensure the child's need for 'time out' in a quiet and supervised place is met.

Visual perception and sensitivity to light

When specific neural pathways have been affected, an ABI can affect a child's ability to see and/or interpret what has been seen. Example of difficulties:

- omits lines or words when reading or copying
- runs into people or objects
- cannot see words in a text or material objects displayed
- difficulties with perception of visual information (colour, shape, size, depth, distance)

What can help?

- Staff are fully informed and specific advice/ strategies from professionals are available.
- Allow support for reading such as an assistant to help with reading and reduce the need to read aloud in front of the class.
- Keep the environment well-organised and consistent.
- Provide help with orientation in the environment.
- Allow extra time the child needs to move around.

"He was in a class for children with considerable learning needs, working well at his ability level. Staff were concerned that he kept missing bits of his work. Often, when prompted to pick up something he'd dropped on the floor, he just said he couldn't see it. It was found he had problems with sight in a particular visual field and needed to learn to move his head to make sure he saw everything."

(Parent's experience)

Physical skills

Some physical disabilities such as hemiplegia or hemiparesis (weakness on one side of the body) or ataxia (unsteadiness or tremor) are more visibly apparent. This can help to highlight adjustments that need to be made on the demands and expectations of a child. Other physical changes, however, may be less apparent:

- a general problem with co-ordination and balance
- difficulty putting a sequence of movements together even if the child knows what they want to do
- slowed physical actions compared with previous abilities
- difficulty controlling their bladder or bowels and sometimes they may need to learn how to do that again
- fatigue may become apparent following encephalitis, with the child tiring more easily in activities such as physical activities or games, as well as in lessons where concentration is required

What can help?

- Detailed information, advice and monitoring have been obtained from specialists such as physiotherapist and/or occupational therapist to assist the school's detailed planning.
- Time is given for the child to move from place to place.
- Staff are fully aware of the child's difficulties and what to do in an emergency.
- Technical equipment is provided and the use supported.
- Transport needs are reviewed routinely and arranged as necessary.
- Support staff are trained specifically to meet the child's needs.
- Staff are aware of situations to avoid, where possible.
- The child has access to a suitable rest area, if necessary.



It is very important that environmental demands on the child in school are manageable. The following need to be considered in the context of all the child's other needs:

- access to, in and around school
- health and safety in and around school
- suitability of toilet and changing facilities
- participation in physical activities

Children should participate in activities as much as they are able to. It is not OK for schools to sit children out of activities "just in case".

They should do a full risk assessment and make every effort to manage those risks so the child can join in. It is also the school's responsibility to make reasonable adjustments, including providing appropriate staffing rather than ask parents to step in.

"Her assistant sees when she is too tired to hold her pencil, use her arm - her hand shakes. Her writing becomes just a wavy line. Her coordination has gone. The assistant quietly takes her pencil and writes what she wants to say on a post-it and puts it on the page".

(Parent's experience)

"His basketball coach was the best. He let our son come back and play right away. He helped him by using basketball as his physical therapy. When my son was still very weak, the coach would always put him in each game for a minute or two at a time, then he would rest and go back in for another minute. It was an amazing way to help my son. He wasn't playing well at the time but his coach knew it was the right thing to do and it made all the difference in our son's recovery. Because of basketball he had something to look forward to that made him stronger".

(Parent's experience)

Seizures/epilepsy

Epilepsy may occur immediately after the initial illness, or may develop some time later. Seizures (previously called fits) may be classified into different types, according to the pattern of the abnormal electrical activity in the brain. Epilepsy following encephalitis can sometimes be particularly difficult to treat, becoming in some children 'intractable' (seizures that do not respond to medication). Children with epilepsy may take anticonvulsant drugs, of which there are several.

"Epilepsy is a very individual condition, so how it affects someone's education can vary. Knowing as much as possible about your child's epilepsy can help you to make decisions with them about their education".

(Epilepsy Society, UK (<https://epilepsysociety.org.uk/>))

What can help?

- Have a written health care plan, agreed and regularly reviewed by parents, school staff and a relevant health professional such as school nurse or epilepsy nurse.
- Communicate with staff regarding specific risks and/or needs for health care as per care plan.
- Consider the implications for day-to-day schooling.
- Train (epilepsy training) all school staff so they know what to look out for and how to respond, in case they are the first adult on the scene.
- Ensure that any necessary arrangements for medication and 'emergency' are in place, tried and tested.
- Educating children on epilepsy to help them understand their peers.



Fatigue

Children may experience fatigue as a result of having encephalitis. Over the months of early recovery, this fatigue is likely to reduce, but a significant level of fatigue may continue throughout schooling and into adult life.

- ‘Physical fatigue’ can usually be observed, understood and the resulting needs met. It can place additional demands on the child’s personal efforts and coping skills.
- ‘Cognitive fatigue’ may be less apparent to staff. It is a major issue that requires awareness, understanding, attention and facilities for being ‘away from it all’ for a while. It can pose significant challenges in managing curriculum over time.

Cognitive fatigue

After encephalitis, the brain has to work harder to overcome the difficulties left by the illness. Taking in information and thinking may become much more work than before and take longer. The process of shutting out what isn’t relevant (e.g. background noise, instructions to others, talk amongst peers, personal thoughts) may be more difficult than before. These processes burn up the child’s resources and they suddenly reach a threshold when they cannot take any more in. Then they may ‘switch off’. In these circumstances, they often lose personal controls and present behaviour difficulties.

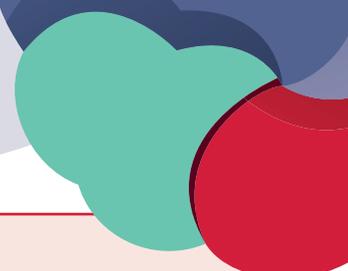
“This pupil settled back into school without difficulty and worked hard. However, we are concerned that she often seems exhausted and not entirely ‘with it’. We understand this may be caused by fatigue, but have raised the needs for further medical advice with her mother. We wonder if she might be having a type of less obvious seizure, and need advice”.

(Teacher’s experience)

Signs of cognitive fatigue in school

- The child presents differently at different times of the day, often not so well in the afternoon, or after break, or during a long session.
- The child presents differently on different days of the week, such as not so well on the third day when attending part time two or three days running, or not so well towards the end of the week when in full time.
- The child no longer pays attention (e.g. seems to 'switch off' or fiddle with something or become physically restless, disruptive).
- The child seems unable to work through tasks they should normally be able to do.
- The child loses concentration and forgets what they are doing.
- The child may keep losing things.
- The child may suddenly not remember what to do or where to go.
- The child may behave inappropriately. The child's ability for self-control has ebbed—they often become rude and difficult. It is important to keep detailed records of problem behaviours and social difficulties in these circumstances so that in the future staff, who have not known the child previously, are able to understand the extent to which behaviour problems are the effects of the outcomes of ABI and need to be managed accordingly.

The effects of fatigue may come on very suddenly. It is difficult even for adults to monitor and respond appropriately to their own fatigue after encephalitis, never mind a child or young person. When fatigue is also linked with the effects of epilepsy, this and the overall effects need to be considered with care. Teachers' observation and intervention are invaluable. Information about the effects of encephalitis is important so that staff in school understand that fatigue is extremely common after initial recovery from encephalitis, and not an 'avoidance' strategy.



What can help?

It will take time to establish what works best. Guidance should be obtained from a local psychology service if needed.

- Be aware of how the imminent onset of fatigue may be noticed and what action to take.
- You may need to direct/take the child to the resting place as the child may not know they need a rest.
- Facilitate the class/friendship group's understanding.
- Plan for interpersonal activities and core skills and academic subjects to take place at times of least fatigue such as in the morning and early in the week.
- Minimise the amount of 'optional' work required.
- Plan tasks for a length of time that suits the child, with definite breaks in activity between 'work' sessions (this is known as pacing).
- At a time when no close supervision and support is available, only work within the child's competence levels.
- Be flexible and responsive to the child's immediate needs (e.g. if the child is fatigued they can sit out).
- Understand that catching up at home after school is most unlikely to be appropriate, because of the fatigue.
- Provide access to a calm, quiet rest area in school, away from other children and under adult supervision.

A comprehensive plan should be drawn up in conjunction with parents based on information from parents and specific teachers/assistants about the effect of fatigue on this child. The plan/programme of work should include:

- a timetable including all the child's regular activities in and out of school (e.g. if the child goes to an after-school activity on a Tuesday evening they may be more fatigued than usual at school on a Wednesday)
- examples of what works well at home alongside difficulties that parents have experienced in respect of the fatigue
- clarity about any risks in school that might arise from fatigue
- consideration of whether the child should attend school full or part time, in the context of fatigue
- agreement about arrangements for homework in the context of fatigue (e.g. if the child soon sleeps on arrival home from school, which is often the case)
- consideration of the situation and needs in respect of examination entry (e.g. arranging for only one exam on one day; supervised rest periods during an exam, as required)
- detailed guidance to staff on the amount of information the child is probably able to take in and guidance on managing this, as required
- the potential impact of fatigue on social behaviour and maintaining friendships
- medium and long-term planning for the child's access to the curriculum (e.g. reduction in subjects studied; extension of post-16 timetable)





Behaviour

Our brains control the way we behave and therefore changes in a child's behaviour may be a consequence of the brain injury itself. An injury to the brain can affect a child's ability to control their behaviour and their awareness of what is acceptable or appropriate at any given time.

"His friends have been good to him. He wants to be with them, but keeps saying things that are rude I might call them 'blunt truths' – and that's putting them off".

(Parent's experience)

Behaviour may 'wind up' in a spiral, out of the child's control.

"She may be upset and genuinely apologetic after an episode of inappropriate behaviour, but unable to prevent it happening again".

(Parent's experience)

Sometimes, it is behaviour that was present before the illness that has become more extreme or has taken an unacceptable form after encephalitis. At other times, behaviour post-encephalitis is quite different from that before the illness. Difficulties in any aspect of schooling-moving around, schoolwork, free time or friendships-are likely to increase the child's sense of loss, and unwanted or 'inappropriate' behaviours.



Assessment of the behaviour difficulties

To help change a child's behaviour it is essential to have an assessment of the difficulties that may lie behind this behaviour. Detailed observation and records of what may be stimulating this behaviour are essential.

- Does the child have a lack of age-appropriate insight?
- Is there any failure to take responsibility or poor emotional control?
- Are there memory problems?
- If there are problems, when-and perhaps why-do these occur?
- When are problems least likely?
- Is there evidence of any specific environmental effects?
- Are there any problems with visual or auditory perception - the child's interpretation of what is seen or heard?

"She's been banned from school transport. This is because she keeps getting in a state and shouting and refusing to move and hitting out at everyone. It happens a lot at the end of school when she's tired and she finds getting to her feet difficult. Of course it gets a bit crowded and she's so slow they have to keep hurrying her".

(Parent's experience)



Behavioural management strategies (consequential and antecedent)

Most children can learn to behave in an acceptable way because it results in a rewarding consequence and prevents the reverse (consequential management strategies). 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
- consistently remember what they have to do to avoid punishment or to earn reward
- understand that good behaviour may be rewarded at a later time, and be patient
- remember rules and be able to use them in different situations
- control their behaviour at will in different situations

Antecedent behaviour management (positive behaviour support) is a much more appropriate strategy for children affected by encephalitis. This approach is based on the idea of preventing inappropriate behaviour as opposed to dealing with behaviour problems after they have happened. Antecedents that trigger inappropriate behaviour include:

- fatigue, which frequently results in unexpected outbursts; a child is no longer being able to control their reactions
- disturbance in routine, such as change in activity or being in a different room
- distractions such as a loud noise or different activities taking place in the same time
- demands that the child finds difficult, such as completing a task. approaching work that feels beyond them or being faced with complexity
- lack of attention from staff
- upsetting interactions, or lack of interactions, with other children

What can help?

Strategies therefore need to focus on identification and prevention of the triggers. General strategies are listed below, but a programme specific to the child will be required in consultation with parents and professionals. Management of behaviour difficulties following an ABI is complex; the advice of an educational or clinical psychologist specialised in neuropsychology is strongly recommended.

- Avoid non-specific comments such as 'behave yourself'. Instead, say exactly what they should do.
- Be clear, calm and use a low tone of voice.
- Try to understand the reasons behind the behaviour.
- Keep activities structured and organised.
- Manage demands on the child.
- Focus on their strengths, on what the child is able to do.
- Try to avoid 'No' when the child is asking for something or doing something that is inappropriate at that time; try using something along the lines of: 'Yes, but later', 'Yes, but on (time or a date)'.
- Plan to have activities ready to help the child work off emotional tension, such as a gentle physical activity, artwork or a quiet time.
- Some children find having something to occupy their fingers (plasticine or a squishy ball) helpful to reduce restlessness and disruption.
- Give the child opportunities to regularly get up and move around.
- Keep an eye on fatigue-behavioural problems are more frequent and intensive when a child is tired.
- As far as possible, avoid using behavioural interventions such as 'punishments'.
- Use meaningful verbal and non-verbal means of rewarding good behaviours that are appropriate to the child, the time and place.

- Ensure the child has a safe place of refuge, where they can go when they feel overwhelmed.
- Try to arrange for the child to have some responsibilities that they can cope with well, as a child with cognitive problems may find behaving badly is their only way of gaining some control.
- Present model behaviour: show the child, by your actions, how to handle difficulties and get along with others - i.e: behave in the ways you want the child to behave.

"We've said whenever you start to feel cross, just go over to the quiet corner and do nothing, or draw, or look at a book, we won't interrupt you, and come back when you're ready. This seems to be working well".
(Teacher's experience)

As children become older and enter adolescence, specific advice on management of adolescent behaviours may be required. Local services may offer provision to assist with specific behaviour difficulties.

It cannot be stressed enough that the way a brain injury makes itself known will depend on the individual child!



Social skills

Social skills are the skills used to interact and communicate with each other. Social communication is through verbal language and body language (gestures). The 'socialisation' of children as they mature is well understood in schools, but difficulties with social skills caused by encephalitis can be hard to understand in depth and to manage. These difficulties may result in children not maturing socially and not behaving as would be expected over the following years. Problems with social skills can interact with all other areas of physical, emotional, behavioural and cognitive difficulties following encephalitis.

There is no set time for the emergence of these difficulties. They may be apparent while ill at home, on returning to school as the child tries to settle in or even years later when changing class or school.

It is important to record in detail all changes in the child's social skills following illness, as well as both the effective and the less effective management of this aspect in school. If the origin, nature and best approaches to the child's difficulties are not set out clearly, there is a risk that the situation may be misinterpreted in the future, and the child's needs less well met.

Supporting the child's recovery and development of social skills is essential, and often challenging. Approaches based on evidence of the extent of the child's impairment from encephalitis and knowledge of their previous 'self' need to be planned in detail, and delivered with steady care.

Good models of social behaviour are essential alongside kind but firm clarity about what is and isn't acceptable. Fatigue has a marked effect. Support from local specialist services is recommended.

"...talks with his family and friends without difficulty, but seems to be coming out with inappropriate things without thinking, and this is only since having encephalitis. It is as though a control has gone".

(Parent's experience)



Social difficulties that often occur after encephalitis include:

Lack of appropriate verbal communication

- not listening to what others are saying
- poor turn-taking
- not focusing on the topic in discussion
- making comments that come over as rudeness
- speaking too loudly
- inability to follow what is said (please see the section on 'Speech, Language & Communication')

Lack of appropriate non-verbal communication

- not reading the posture or gesture of others
- not responding to facial expressions
- standing in an inappropriate position, such as much too close to someone
- not understanding how to approach a group

Inability to understand meanings that are not explicit

- not being able to follow jokes or humour
- taking sarcastic remarks literally
- dealing absolutely concretely with everything that is said

What can help?

The support listed below is frequently needed, but it is important that professional advice on the needs of the individual child be available to school staff.

1. Ensure a return to school relationships as smooth as possible

- Prepare fellow pupils as appropriate for their age and understanding for the child's return to school.
- Consider planning and supporting a friendship group or a buddy system to enable transition back into school and ensure companionship.
- Plan to avoid the child feeling 'left out' a lot, but always remembering that the child can't just 'catch up' and join in everything as they will get tired.
- Communicate regularly with parents to understand what helps the child's behaviour in other settings, such as home and in the community. This can also inform behaviour management strategy.
- Give guidance on management of social issues to staff who supervise break times, library access and so forth.
- Remember the adverse effects of fatigue that have a marked effect on interpersonal behaviours.

"A large secondary school has a centre for students who need a quiet place, understanding and attention. It is a haven for a young person who has lost previous social skills and all their friendships. It provides an opportunity for new learning and preparation for the social world post 16/18".

(Parent's experience)

"To help her fit in, my child's school arranged for a social skills group to meet each week. After only 3 weeks it made a difference".

(Parent's experience)

2. Teach appropriate interpersonal behaviour

- Always be clear about the behaviours expected, speaking to the child personally, kindly and firmly.
- When appropriate, teach situation-specific behaviours in one-to-one and small group sessions.

3. Manage situations

- Plan to avoid situations in which social difficulties will occur and/or be difficult to manage.
- Ensure supervision wherever necessary. Teach the supervisor how to deal with the child's strong emotions.
- At all times, be calm, reassuring and use simple language that the child is well able to take in and understand.
- Plan and ensure rapid intervention when interpersonal difficulties may be underway-both to preserve possible peer-group relationships and to help the child learn to avoid this sort of problem. This may well be rest time/time-out.
- Children with ABI are extremely vulnerable to being bullied and often even less well able to deal with it than other children; great care is needed in this respect.

4. Provide direct help

- Group work to develop skills in interpersonal behaviour may be considered; this needs to be delivered with a full understanding of the effects of encephalitis on this child.
- Supported 'partnerships' within school might be considered also; specialist advice, careful monitoring and long-term maintenance would be essential.
- Seeking outside help (psychology service, mental health team or other local social group) (with parental consent).

Bullying

Bullying is when one person or several people deliberately hurt someone else physically, emotionally, verbally or psychologically. Bullying is serious. It can happen anywhere. Children with an ABI are particularly vulnerable to being bullied, and may be even less able to deal with the effects. Schools have policies and aim to reduce bullying. Ideally, all staff are aware of the risk of bullying and thoroughly implement the anti-bullying policy. Parents are often in the best position to observe their child's response to going to and from school and to being among other children. As children grow up, they often become less likely to 'tell everything' to parents and there is also pressure, and indeed threats, from other children not to tell tales.

What can help?

- Ensure the school feels a warm, friendly, safe and supportive place to the child and that the child knows a safe way to tell someone when something bad is happening.
- Make the child and their family aware of anti-bullying policy, posters and information sheets.
- Ensure that supervision during movement about the school and during breaks is well managed.
- Listen to the child and take action if needed.
- Routinely monitor whether there is bullying on this child.
- Encourage their parents to notice and to speak with you if ever there may be a problem, even if this matter is very emotional for them.



Repeating a school year

It is unusual for a child to repeat a school year, but this may be considered in exceptional circumstances such as after very long absence from school following encephalitis. A repeat year may be just right for the occasional child, but if it is being considered, issues to think through include:

- the exact purpose of repeating the school year
- whether the situation could be managed differently
- whether being a year behind will disrupt friendship groups
- whether repeating a year is simply delaying the kind of support that the child really needs
- the implications of a child being a year behind the age-group over the following years
- the extent to which the arrangement could be kept going throughout the future stages of schooling such as transfer to secondary school, post 16 education and so forth
- the risk that a year may be missed out completely
- the possible implications of reaching school leaving age before reaching the last class
- above all, the extent to which a repeat year will resolve learning difficulties arising from this child's ABI

In discussion with parents, it is best that specific advice from a psychologist be obtained if a repeat year is being considered.

Brothers and sisters of children affected by encephalitis

The wide-ranging impact of encephalitis has a profound effect on other family members and especially on siblings. When a brother or sister is very ill, their parents have to be with their sick child as much as possible. Day-to-day routines are changed. They often have to rely on others to look after their other children. When a child who has been in hospital comes home, they may need much care for a long time, and be the focus of everyone who telephones, writes or visits their home.

A brother or sister who has been very ill may not seem the same as before, and their parents' behaviour with them may have had to change. Some children are born into a family where they already have a sibling who has had encephalitis. For these children, the impact of their sibling's needs may develop over the years, particularly as they go through school.

Strong feelings

The siblings may be affected in many ways depending on their age, family's dynamics and resilience and the effects of encephalitis on their brother/sister. It is good if school staff can be aware of feelings that naturally result from both major change at home, and with living alongside siblings with various special needs. Strong reactions are understandable.

Children need their feelings to be recognised, and understood. Siblings may feel:

- loss and feelings of bereavement they cannot understand
- jealousy at the attention their sibling receives
- anger about the attention their sibling gets
- guilty that it may be all their fault
- anxiety that the illness may happen to them
- left out, that they are missing things
- confused because of the changes in their social lives
- frustration when having to play/interact with a child with a brain injury who cannot remember, is tired or displays disinhibited behaviour
- responsibility for their siblings

What can help?

- Recognise their feelings and the effects.
- Reassure that is not the sibling's fault.
- Provide opportunities to talk things through, as and when appropriate; having someone to turn to can make a big difference.
- Nurture an atmosphere in which the care of others is respected and no adverse remarks from other pupils are tolerated.
- Facilitate access to a support group for brothers and sisters, such as Young Carers.
- Talk with parents if needed.

Encephalitis International developed a series of short animations that explain encephalitis and its after-effects in different languages.

One of these animations features Tilly who talks about her experience of having a sibling affected by encephalitis.

Access the animations, including the sibling animation on the Encephalitis International YouTube Channel.

www.youtube.com/@encephalitisinternational

Appendix 1

Difficulties checklist

This checklist can be used by any educational professional in respect of a child's particular needs.

Area of Difficulty	All information and plans are in place	Further information is needed	Further actions are required
Memory			
Planning and organisational skills			
Attention and concentration			
Speech, language and communication			
Physical skills			
Hearing perception and sensitivity to sound			
Visual perception			
Epilepsy			
Fatigue			
Behaviour			
Social skills			
Other			

Appendix 2

Student passport

This form outlines key facts about the child and their needs in order to inform the school staff about the specific needs of the child. It aims to help the child and their families not having to repeat the same information to different people.

This template can be used in this format or adapted to own school practices or pupil's needs. Ideally it should be completed together by the child and parent/ carer and given to the teacher who can also make notes regarding their day-to-day management in class.

Insert photo here	Name
	Class
	I had encephalitis on (add date)
I need help with	
My medication	
What helps me?	
What doesn't help me?	
My interests	
My School Staff contact is	

Appendix 3

Teacher's notes (Practical steps)

What supports the student in the Classroom/School grounds?

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What doesn't support the student in the Classroom/School grounds?

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Encephalitis International

Encephalitis International is an international charity and the only organisation of its kind in the world dedicated to supporting adults and children affected by encephalitis. Encephalitis International provides support and information to all people affected by encephalitis across the globe, and to a variety of professionals and organisations from health, social care and education. Encephalitis International works in conjunction with academic and clinical partners to promote and conduct high quality research into encephalitis and its consequences and promote high standards for patient diagnosis, management and care.

Key services

- Encephalitis International website which contains information about encephalitis and its consequences www.encephalitis.info
- Telephone, online chat and email Support Line giving advice, support and information about encephalitis [+44\(0\)1653 699599](tel:+44(0)1653699599) or support@encephalitis.info
- Team Encephalitis Volunteer Scheme - an expanding network of global volunteers
- Residential weekends, meetings and events for all the family
- Connections Scheme which puts people affected by encephalitis in touch with each other
- Seminars, training and education about encephalitis to health, social care, legal and education professionals
- World Encephalitis Day (22nd February each year)





Encephalitis International

The brain inflammation non-profit

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Registered company number: 04189027

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