



# Returning to school after encephalitis

Guidance for school staff. A summary

## About this guidance

This summary guidance aims to assist school staff when pupils return to school after having had encephalitis and have been left with difficulties. It covers key information about this illness, its effects on health and learning, and also how school can help a child's recovery. For detailed information on specific areas of difficulty (e.g. memory, fatigue, behaviour, social skills) and their impact on learning please see the full guide '**Returning to school after encephalitis. Guidance for school staff**', which is available as a PDF from our website ([www.encephalitis.info](http://www.encephalitis.info)) and as a printed copy from our office.

Should any of the information contained in this Summary raise concerns or if you would like information on the source material, please don't hesitate to contact Encephalitis International.

"Oliver was very ill with autoimmune encephalitis just before starting school. The Special Educational Needs Coordinator made sure she met with us well in advance, came to meetings to discuss Oliver and planned carefully for his joining the Reception class.

Training and guidance were provided to all the school staff by Encephalitis International. An Education Health & Care plan was asked for urgently. School staff were very well prepared indeed. Very detailed advice was provided in person and in writing by all the therapists involved. Their understanding of needs following acquired brain injury and commitment to welcoming into their school resulted in staff setting out and following detailed plans to be able to meet Oliver's needs. Oliver loved going to school. In many ways, his needs were very well met. Staff cover was managed to ensure learning, health and safety. Sadly, the school's attractive, stimulating and welcoming open-plan environment could not provide the quiet, less stimulating areas that children who have had encephalitis so often need, both indoors and outdoors."  
(Parents' experience)

Returning to School After Encephalitis.  
Guidance for School Staff. A Summary  
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## Encephalitis the illness.

- 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 in error (post-infectious or autoimmune encephalitis).<sup>1</sup>
- Anyone can become ill with encephalitis at any age. Worldwide, up to 1.5 million people are diagnosed each year<sup>2</sup> with mortality (death) rates up to 40% depending on the cause, even with treatment.<sup>3</sup>
- 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 followed by access to appropriate rehabilitation and support can reduce death rates and improve outcomes.
- Children who have been ill with encephalitis are likely to have an injury to their brain which is termed 'acquired brain injury' (ABI). This injury can result in a wide range of cognitive, physical, emotional, behavioural and/or social difficulties.
- There is no set timescale for recovery. Families may feel that returning home will make everything 'normal' again. However, both the child and the family may find that the new situation requires a great deal of adjustment.

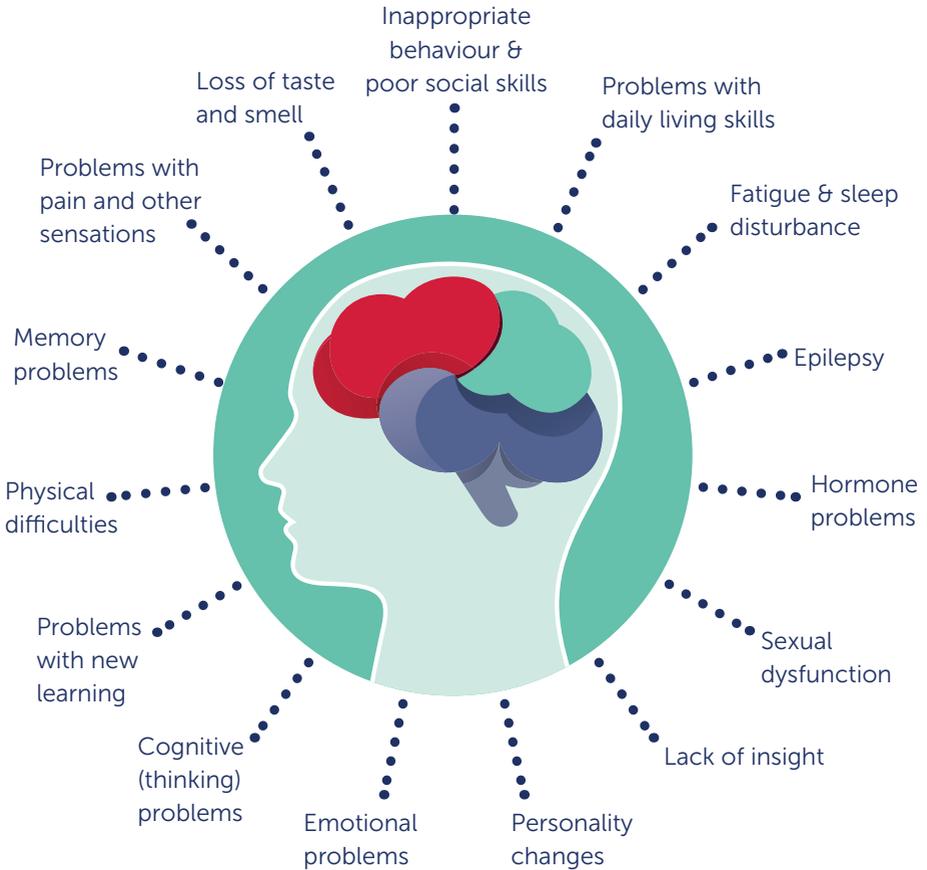
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1. Granerod J, Ambrose HE, Davies NW, et al. (2010) Causes of encephalitis and differences in their clinical presentations in England: a multicentre, population-based prospective study. *Lancet Infect Dis*;10 (12):835-44.

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. The child may experience:

- tiredness (cognitive fatigue rather than 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
- difficulty changing routines
- not understanding jokes
- forgetting what they were doing
- physical restlessness
- disruptiveness
- appearing to be daydreaming
- poor memory
- difficulty remembering places and directions
- inappropriate behaviour
- lack of insight into their difficulties
- not being able to get ready for specific activities
- making misjudgements
- poor social awareness
- sensitivity to sound
- seizures

Difficulties after encephalitis can lead to isolation, as others do not understand the cause of the child's changed ability and behaviour. The child's confidence diminishes. They may become **anxious and withdrawn** or they may exhibit **challenging behaviour**.

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

- **UNIQUE** No two cases of encephalitis will have an identical outcome.
- **HIDDEN (INVISIBLE)** The child may look exactly like they did before the illness, with effects being cognitive, behavioural, emotional and/or social rather than physical.
- **LIFE-LONG** The effects of the illness can last for ever. The child needs to learn to live and cope with them.
- **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 still seem 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 other children, but they do not reach their full potential.



## How can school staff help?

Returning to school is a very important step in the child's recovery from encephalitis, in terms of both their social and educational reintegration, so careful planning for the child's return is essential. Deciding how best to meet the needs of a child with ABI is often complex and demanding. Information and decision-making need to be very explicit, evaluated and passed on with care.

### Consider returning to school gradually.

- In agreement with the parents, it may be best for the child to return to school gradually or start with home-schooling.
- The child may need to be taught and allowed to rehearse the routine of the learning environment before they return to school (e.g. putting on uniform, where all the classes and facilities are, how to get from one to other).

### Learn about encephalitis/ABI and the specific needs of the child.

- General information about encephalitis and its consequences can be provided by Encephalitis International.
- Training for educational professionals working with children with ABI may be provided by local brain injury organisations.
- Information about the child's specific needs and their effects on learning can be obtained both from parents and, with parental consent, from professionals. Parents/ carers are a key source of information about the specific current needs of their child.
- It is good practice for a member of staff to get in touch with hospital/home tutors and take part in the meetings. In this way staff can learn directly from professionals who looked after the child about the child's specific needs.
- Encourage children and their family to fill in the **My journey through encephalitis** form on page 12.

### **Keep communicating with parents/carers and the child.**

- Parents and school staff need to 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. They are unsure about what the future will bring. The impact of encephalitis affects the whole family, not only the child.

### **Plan according to the child's needs. 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:

- lesson plans and homework customised to fit the child's current needs.
- modification to existing materials (e.g. large print, audio books, dictionaries).
- alterations of the expectations for 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.

### **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.



### Consider requesting a special needs assessment of the child's needs from the local authority.

- If a child has considerable difficulty in learning compared to others in the class, or if the child is not able to make use of facilities in school, the child may have special educational needs for which a formal needs assessment is necessary.
- Schools should consider making a request for a needs assessment if it needs to make educational provision for a child that is different from the provision it makes other children of the same age who do not have learning difficulties.
- Getting an assessment in place can be a lengthy process, so if an assessment is needed, it is important to request this as soon as possible.

### Maintain an adequate environment and provide necessary resources.

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

### Facilitate understanding and friendship with other children.

- With parental consent, schools may be able to facilitate contact with children who cannot go to school because of an illness, via home visits, calls, messages 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' a lot, while always bearing in mind **that the child can't just 'catch up' and join in everything as they will get tired.**
- All staff need to be aware of the risk of bullying and thoroughly implement the anti-bullying policy.

### 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 the child's current needs and potential problems.
- 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.**





## Practical strategies for day-to-day management in school.

- Have routines.
- Have a system of prompts, reminders and checklists.
- Keep the environment well organised.
- Keep everything simple and clear.
- Minimise noise and distractions.
- Be very explicit about rules and expectations.
- Provide written and verbal instructions.
- Allow the use of learning aids (e.g. dictionary, calculator).
- Keep an eye on issues such as fatigue, seizures and bullying.
- Break up activities into small steps.
- Prioritise and avoid unnecessary activities and tasks.
- Ensure the child listens and understands what they are required to do.
- Provide access to a quiet area if needed.
- Provide preferential seating to the front of the class if needed.
- Provide additional time to complete a task.
- Provide enough instructions and support when introducing new tasks or activities.
- Provide extra or longer breaks.
- Avoid negative feedback.
- Establish the best time of the day for more difficult tasks, tests or new learning.
- **BE FLEXIBLE.**

**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. 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 overcome the difficulties left by encephalitis and have a positive learning experience.**

## My journey through encephalitis

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 family 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 the 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.

Name .....

Class .....

### History of the illness

My difficulties .....

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My medication .....

What helps me? .....

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What doesn't help me? .....

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# Teacher's notes (Practical steps)

## Do's

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## Don't's

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## 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			



## About Encephalitis International

Encephalitis International is an international charity and the only organisation of our 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](http://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](mailto: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



# Encephalitis International

The brain inflammation non-profit

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