



**ENCEPHALITIS**  
**SOCIETY**

*The brain inflammation charity*

# **ENCEPHALITIS IN CHILDREN. A GUIDE**

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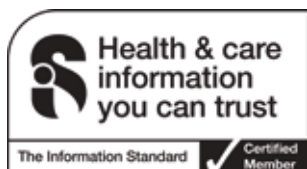
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# ACKNOWLEDGEMENTS

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We would like to give our thanks to all Professionals, Volunteers and Supporters who have helped develop this guide. Your input has been invaluable and has enabled us to produce a very useful resource for families of children affected by encephalitis.



## ENCEPHALITIS IN CHILDREN. A GUIDE

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*The brain inflammation charity*

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# ABOUT THIS GUIDE

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This guide provides information about encephalitis in children from types of encephalitis, symptoms, diagnosis and treatment to recovery, rehabilitation and returning to school.

The guide is a very comprehensive resource which follows the child's journey from the hospital ward to the rehabilitation setting, school and home. However, it is designed in a format in which families can dip into as and when they need it to avoid being overwhelmed by the information.

The aim of this guide is to enable families and children to understand what has happened to them, make informed decisions regarding their child's care, treatment and recovery, and also find ways of coping with the life changes brought by this illness.

We hope you find this guide useful. If you have any questions or any feedback please get in touch with us: **support@encephalitis.info** or **+44 (0)1653 699599**.

***"It is the only written documentation we can find that explains the problems that come after having encephalitis, issues that my son faces every day."***

(Mother's feedback)

***"Comprehensive, well written and covers everything that we needed guidance with in our personal circumstances."***

(Parent's feedback)



## Disclaimer

No two people have the same course of the illness or the same after-effects. The information in this guide is not reflective of every situation where encephalitis is involved and/or may not be relevant to your child.

We have tried to ensure that the information presented here is accurate and reflects best practice at the time of publication. However, the information provided in this guide is designed to support, not replace, the relationship that exists between a patient and medical professionals. You must obtain specialist advice before taking, or refraining from, any action on the basis of the content in this guide.

Should any of the information raise issues or give you reason for concern we would ask that you contact your health care professional and/or our office on **+44 (0)1653 699599** or **support@encephalitis.info**

Some information in this guide, such as details of organisations and legislation, apply only to the UK or some parts of the UK. If you live outside these areas you are encouraged to find similar organisations to those referenced and consult the legislation which is applicable to the area you live in. Get in touch with our Support Service if needed.

We used both professional experience and academic sources in writing this guide. If you would like information about the references used please email **support@encephalitis.info**



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# SECTION 1

## WHAT IS ENCEPHALITIS?

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1



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# WHAT IS ENCEPHALITIS?

This section provides information about encephalitis – the illness: types, causes, diagnosis and treatment. We have tried to make this information as extensive as possible in order to cover a wide range of scenarios. However, you need to consider that each child is different and so is their illness. In addition, facilities for diagnosis, treatment and recovery vary greatly depending on geographical location.

## KEY FACTS



Encephalitis is an inflammation (swelling) of the brain. Anyone can get encephalitis irrespective of age, gender, nationality or culture.



**There are up to 6,000 new cases each year in the UK and many more thousands worldwide.**



Encephalitis can be caused by an infection (e.g. virus, bacteria, fungus) or by the autoimmune system attacking the brain in error. In some cases, a specific cause is not found despite extensive testing.



**The variety of causes and presentations, along with the rapid onset (often dramatic) may make the management of this condition a challenge for clinicians.**



Early and adequate diagnosis and treatment improve the outcomes.



**The length of time spent in hospital (acute illness) can vary from days and weeks in some cases to months in others.**



Children may recover after the illness with little or no effects or they may be left with an acquired brain injury (ABI) that can result in various difficulties.





# TYPES OF ENCEPHALITIS

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Encephalitis is caused either by an infection invading the brain (infectious encephalitis) or by the child's immune system attacking the brain in error (post-infectious or autoimmune encephalitis).

## INFECTIOUS ENCEPHALITIS

- ▶ Viruses are the most common cause of infectious encephalitis (e.g. herpes viruses, enteroviruses, West Nile, Japanese encephalitis, La Crosse, St. Louis, Western equine, Eastern equine and tick-borne viruses). Any virus has the potential to produce encephalitis, but not everybody who is infected with these viruses will develop encephalitis.
- ▶ Bacteria (e.g. *Streptococcus Pneumoniae* or *Mycoplasma Pneumoniae*) is another common cause.
- ▶ Occasionally other infections such as fungus and parasites can cause encephalitis.

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## AUTOIMMUNE ENCEPHALITIS

- ▶ Some types of autoimmune encephalitis, such as acute disseminated encephalomyelitis (ADEM), happen following an infection or after an immunisation, in which case the term 'post-infectious encephalitis' is used.
- ▶ Other forms of autoimmune encephalitis are associated with finding specific levels of antibodies in blood such as VGKC complex (anti-LGII and Caspr2), NMDA receptor, GAD, AMPAR and GABA antibodies. It is not clear why people with autoimmune encephalitis produce these antibodies.



Sometimes a tumour (benign or cancerous) may generate the antibody. Antibodies, also called immunoglobulins, are produced by the immune system to identify and help remove foreign antigens such as viruses and bacteria.

- ➔ Factsheets on different types of encephalitis can be requested from our Support Service – **support@encephalitis.info** – or downloaded from our website – **www.encephalitis.info**

## SYMPTOMS OF ENCEPHALITIS

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**Infectious encephalitis** frequently begins with a flu-like illness (e.g. headache, high temperature). Typically, more serious symptoms follow hours to days, or sometimes weeks, later. The most serious finding is an alteration in the level of consciousness. This can range from mild confusion, a change in behaviour or drowsiness, to loss of consciousness and, in some cases, coma. Other symptoms include seizures (fits), aversion to bright lights, inability to speak or control movement, sensory changes, neck stiffness, or uncharacteristic behaviour.

**Autoimmune encephalitis** often has a longer onset. Symptoms will vary depending on the cause but may include: confusion, altered personality or behaviour, severe psychiatric symptoms including psychosis, movements the child cannot control, clumsiness, difficulty walking, seizures, hallucinations, memory loss or sleep disturbances. In babies, the symptoms may be non-specific at the beginning and include poor feeding and lethargy.



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# DIAGNOSIS OF ENCEPHALITIS

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The range of possible symptoms and their rate of development vary widely, and are not just found in encephalitis, so making the diagnosis can be difficult. A diagnosis of encephalitis is made following various tests.

- ▶ A **lumbar puncture (LP)** or spinal tap is a test which allows a doctor to sample the cerebrospinal fluid (CSF) that surrounds the brain and spinal cord and test for the presence of viruses or antibodies. All patients suspected of encephalitis should have an LP as soon as possible unless there is a clear contraindication. The test involves passing a needle, under local anaesthetic, into the base of the spine to collect CSF. This test can be life-saving.
- ▶ **Brain scans**, such as computerised tomography (CT), which uses X-rays or magnetic resonance imaging (MRI) based on magnetic fields, scan the brain in cross section to show the extent of any inflammation and help exclude other neurological disorders, for example brain tumours and strokes (medical condition where the blood supply to part of the brain is cut off).
- ▶ **Blood tests** are used to check for the presence of antibodies and any signs of infection. These tests can also help exclude a metabolic encephalopathy (neurological disorders caused by systemic illnesses such as diabetes, renal failure, heart failure or some rare inherited genetic conditions).
- ▶ An **electroencephalogram (EEG)** may help confirm a diagnosis of encephalitis by recording the slowing of usual electrical activity in the brain. It can also pick up seizure activity.

It should be noted that it is not unusual for the results of some tests to be 'normal'. However, these tests are very helpful in excluding some more common diseases that may need different management, like those mentioned above.

Sometimes, some of the tests cannot be taken immediately because of the patient's medical state (e.g. patient is agitated). Nevertheless, it is important that investigations are carried out as soon as possible as prompt diagnosis reduces mortality and improves the outcomes.

## TREATMENT OF ENCEPHALITIS

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Treatment of patients with encephalitis has two aims.

**THE FIRST AIM** is to ensure that the child receives specific treatment for the cause of their encephalitis.

Where encephalitis is thought to be infectious, patients are treated with antiviral (against viruses), antibiotic (against bacteria) or antifungal drugs (against fungus). It is important that these drugs are started promptly. They will often be started before a definite cause is found. Several different drugs may be given at once. Acyclovir is the most frequently used antiviral drug.

It is effective against the herpes simplex virus. Acyclovir is usually given three times a day by direct infusion into the veins. The treatment with Acyclovir is usually continued for 14-21 days and stopped after a negative result from the LP. Unfortunately, for many viral infections there are no specific treatments at present.



Where encephalitis is thought to be autoimmune, treatments aim to modify the immune system's function. These include drugs such as:

- ▶ **Corticosteroids** (drugs to relieve inflammation) such as prednisolone.
- ▶ **Intravenous immunoglobulin (IVIG)** which is a blood product given into the vein in a drip.
- ▶ **Plasma Exchange (plasmapheresis)**, which means that some of a person's blood is taken out from a vein, the plasma part of the blood – which contains antibodies – is separated and replaced with new plasma and this is put back into the vein in a drip.

Prompt therapies offer a good chance of substantial recovery in the majority of children. As they improve there is often a reduction in the amount of antibodies in their blood when the test is repeated.

Some of the drugs have potential side effects but also important benefits as they reduce the inflammation of the brain. The risks of harm from any of these side effects are minor compared to the good that they do in patients with autoimmune encephalitis. However, in each patient the risk-benefit balance may vary.

Some children taking corticosteroids or other immune treatments will be immunosuppressed. Your doctor will explain what to do if your child becomes ill at home and they are taking any of these medications. Children taking corticosteroids cannot have some types of immunisation. Please make sure any other health care professional involved with your child knows they are taking corticosteroids.

**THE SECOND AIM** is to treat the complications arising from encephalitis and to support the child whilst they are not able to perform their usual bodily functions.

Often, treatment with anticonvulsants to control seizures, or sedatives to reduce agitation, is required. Occasionally, the patient may need to be placed in an intensive care unit (ICU) so that the doctors can monitor them closely and treat any complications. Ventilation (mechanical help with breathing) may be needed.

Sometimes feeding has to be stopped for a while; it can be restarted using a nasogastric (nose to stomach) or orogastric (mouth to stomach) tube.

Guidelines for management of viral encephalitis have been developed by the National Encephalitis Guidelines Development Group and the Encephalitis Society. These guidelines are intended to be a ready reference for doctors when they have suspected cases of encephalitis. The guidelines (a copy for medical professionals and a copy for parents and families) are available from the Encephalitis Society's website at **[www.encephalitis.info](http://www.encephalitis.info)**

## PROGNOSIS

The effects of encephalitis in children vary greatly from one child to another. Some children will come through the illness with few or no difficulties at all. In others, there may be considerable problems (cognitive, emotional, behavioural, physical and social). The pattern of difficulties varies according to the severity and duration of the inflammation, part of the brain affected, the child's age, as well as the promptness of the diagnosis and treatment.



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# RELAPSES

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Infectious types of encephalitis tend to occur only once. It is rare for infectious types of encephalitis to recur later in life. However, in the cases where there is worsening despite ongoing treatment (Acyclovir), it may be due to insufficient doses (often based on the patient's body weight) or other complications of encephalitis may have developed, such as seizures.

In some patients (although this is rare) in whom there is a recurrence of infectious encephalitis early after stopping treatment (Acyclovir), it may be because the treatment was not given for a sufficient length of time. In these cases, it is often appropriate to restart treatment promptly. Nevertheless, rarely in some patients, there may be an early recurrence of encephalitis after stopping treatment that is due to inflammation even after the virus has cleared.

In some types of autoimmune encephalitis there is a recognised risk of recurrence. It is difficult to predict accurately who will relapse but if the risk of relapse is considered to be significant, treatment is often offered over a longer period of time. Despite treatment a number of patients will still relapse.

Recognition of potential relapses requires ongoing vigilance from the patient and their relatives and should be quickly reported to the patient's neurologist. Some forms of autoimmune encephalitis may in some cases follow a viral encephalitis.

# DEATH FROM ENCEPHALITIS

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Unfortunately, despite improvements in diagnosis and specific and more supportive treatments (i.e. intensive care management), encephalitis still has a high mortality (death) rate depending on the cause of encephalitis and the disease course.

When death happens it is usually because of severe brain inflammation. The brain is wrapped in a bony shell (the skull) and when it swells it pushes downwards onto the brainstem. The brainstem is the part of the brain that controls the vital functions of breathing and circulation. When the brainstem is under this type of pressure it stops functioning.

The rapid course of encephalitis can be overwhelming. The realisation that today's drugs, medical management and sophisticated equipment are sometimes unable to treat the disease successfully is frightening. Families who suffer a bereavement are often left feeling shocked and traumatised. Support from family, friends, a counsellor, a doctor or voluntary organisations may be needed.

- ➔ The Encephalitis Society has produced a factsheet 'Bereavement' which features various resources which may be helpful.

The factsheet can be downloaded from our website – **[www.encephalitis.info](http://www.encephalitis.info)** or requested from our Support Service on **+44 (0)1653 699599** or **[support@encephalitis.info](mailto:support@encephalitis.info)**



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# SECTION 2

## BEING IN HOSPITAL

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Being in hospital can be a confusing and stressful time for everybody: the children affected and their family. This section gives an overview of the medical management on the ward, how to look after yourself while caring for your ill child, how to prepare for discharge from hospital and who to contact if things go wrong.

## KEY FACTS



Your child may be suddenly seriously ill and surrounded by machines and doctors.



**Seeing your child so ill can be a very traumatic experience for the whole family.**



An acquired brain injury can be a consequence of encephalitis; it is difficult to estimate the extent of this in the early stages.



**When the inflammation begins to resolve the child may not remember anything about being ill and they may be confused and anxious.**



Remember your own needs when looking after your child; you can't help them if you don't take care of yourself.



**It is good practice to have everything in place at home before discharge from hospital (e.g. care, adaptive equipment).**



Any concerns you have about the hospital stay need to be raised with the hospital staff in the first instance.



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# MEDICAL MANAGEMENT

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On admission to hospital and regularly throughout the patient's stay, nursing staff will conduct careful and repeated observations of your child. These include recordings of temperature, pulse, level of awareness, respiration rates, blood tests, input and output of any fluids.

If your child cannot be treated on a normal ward due to the highly specialised level of care needed (e.g. respiratory difficulties, changes in levels of consciousness, seizures or agitation) they may be placed in the Intensive Care Unit (ICU). The length of stay in the ICU depends on your child's condition and progress.

## **YOUR CHILD MAY NEED:**

- ▶ A catheter inserting in place of using the toilet.
- ▶ A tube into the nose (nasogastric tube) in order to provide essential nutrients and fluids if they are unable to swallow or are at risk of choking on food or drink.
- ▶ A percutaneous endoscopic gastrostomy (PEG) tube into their stomach ensuring that sufficient levels of nutrition and fluid are received if long-term artificial feeding is required.
- ▶ An intravenous line inserted into a vein enabling essential drugs to be administered as and when necessary.
- ▶ A ventilator to help with their breathing.
- ▶ Bedrails to prevent injury.

**The Glasgow Coma Scale (GCS)** is a way of recording the conscious state of a child, assessing their ability to open their eyes, move and speak. The score ranges from a minimum of 3 to a maximum of 15, with 3 having no eye opening, no verbal response and no motor response, and 15 representing full responses. The Glasgow Coma Scale is used to help predict the progression of your child's condition. There is a Paediatric Glasgow Coma Scale applicable to infants too young to speak.

Doctors and nurses need to obtain your consent before any procedure, investigation or treatment is undertaken if your child is below 16. Prior to requesting consent they need to explain to you in detail what, why and how they are going to manage your child. If your child is between 16 and 18 (and sometimes before 16 if they understand what is going on) they are asked for consent.

During and after the acute phase of encephalitis (when there is the swelling of the brain) your child may be uncharacteristically uncooperative and even aggressive. This is due to the impact of swelling in the brain on emotion and behaviour both during the illness and soon after. This state can persist in the early stages of recovery. During this time, the child may not be aware of their behaviour or able to control it. They can also be oblivious to the impact their behaviour is having on those around them.

Observing your child in this state is distressing for family members and can make it difficult for those trying to care for them.



# COPING WITH THE HOSPITAL STAY

Seeing your child seriously ill in hospital is a very distressing experience for any parent. Most of you may not have heard of encephalitis before. Trying to communicate with the hospital doctors and nurses can sometimes seem difficult.

Lack of information or too much specialised information can also be very daunting. You may not understand medical terminology.

Practical issues, such as lack of sleep or time to eat, no appetite, losing touch with family and friends, and/or financial difficulties can all add to the huge impact this illness has. You may at times feel helpless, isolated and confused.

## BELOW THERE IS A LIST OF THINGS WHICH MAY HELP

- ▶ Create a quiet and familiar environment around your child. Hospital can be a busy and noisy place; you don't want to add to it by having many visitors, TV, telephone conversations or other stimuli. Your child will probably benefit from having lots of rest.
- ▶ Try to talk to your child and explain what has happened if and when possible. They may have no recollection of why they are in hospital or for how long they have been there. They may feel upset and scared. Reassure your child that you are there for them and being in hospital is not their fault.
- ▶ Get to know the key staff involved in your child's care.

- ▶ Communicate with health care staff: write down what you want to ask and take any opportunity to ask questions.
- ▶ Acknowledge your emotions and be aware that other family members may deal with this situation differently than you. Some hospitals provide family therapy which may help you deal with the stress and emotions at this difficult time. Ask a member of staff about it.
- ▶ Contact the Encephalitis Society's Support Service **+44 (0)1653 699599** or **support@encephalitis.info**
- ▶ Get your family and friends to do some research for you and bring in some information about the illness and its consequences.
- ▶ Involve your friends and family in doing some chores for you: ask them to bring some food, do some washing, shopping or look after your other children. They probably want to help but don't know how.
- ▶ Parking costs at hospitals can be expensive. Many hospitals make special provision for families with children in the ICU or receiving long-term support. So, it is advisable to ask.



# DISCHARGE FROM HOSPITAL

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Each hospital will have its own policy and arrangements for discharging patients, but ideally, planning for discharge should start from the moment your child is admitted to hospital. You should be able to discuss arrangements for the discharge of your child with the staff.

Before discharge, children should be assessed according to their needs. This may include assessments by a neurologist, neuropsychologist, physiotherapist, occupational therapist, speech and language therapist, dietician, etc. Following those assessments, plans and referrals for after discharge should be in place to meet the child's needs. Parents may find it useful to invite someone from their child's school (e.g. Special Educational Needs Coordinator) to the discharge meeting. You can also ask for a copy of the notes from the discharge meeting.

**Full information and explanation about the illness and after-effects should be given to the child's family and carers.**

Sometimes, the difficulties children are left with, may not appear to be significant and it may simply be assumed that the return to former life will not be problematic. However, problems can become more apparent when they are returning home and to school. It is therefore important to secure some method of follow-up after discharge and/or have the contact details of someone (e.g. neurologist) who can help in case there are problems.

Where the needs of your child are more complex, detailed planning may be required, for example, for equipment or to ensure that rehabilitation programmes can be continued at home, or that social care needs are addressed.

A social worker may also be involved. If your child will soon become an adult, special attention and a plan to manage transition to adulthood services are required. As parents, you are likely to be seen as the primary carers of your child.

You should be happy with and understand the plans that are put in place. If you are not, you need to say so and explain why. You should be convinced that all placements and plans are in place before your child returns home. Your child's GP should receive a discharge letter from the hospital. However, it may be useful to inform the GP about the discharge in case the letter has not yet arrived and discuss any immediate needs if required.

## MAKING A COMPLAINT

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If you are unhappy with the hospital service or any other NHS service you can make a complaint to the hospital or that service. Each hospital/service has a policy regarding the complaints procedure. Alternatively, you can complain directly to the commissioner of the specific service: NHS England for GPs and the Care Quality Commission (CQC) for hospitals or community services.

The time limit for complaints is usually 12 months from the date this happened, or 12 months from the date that you first became aware of it. They can extend the time limit where it would be unreasonable to expect you to have complained in time, for example, because of grief or trauma.





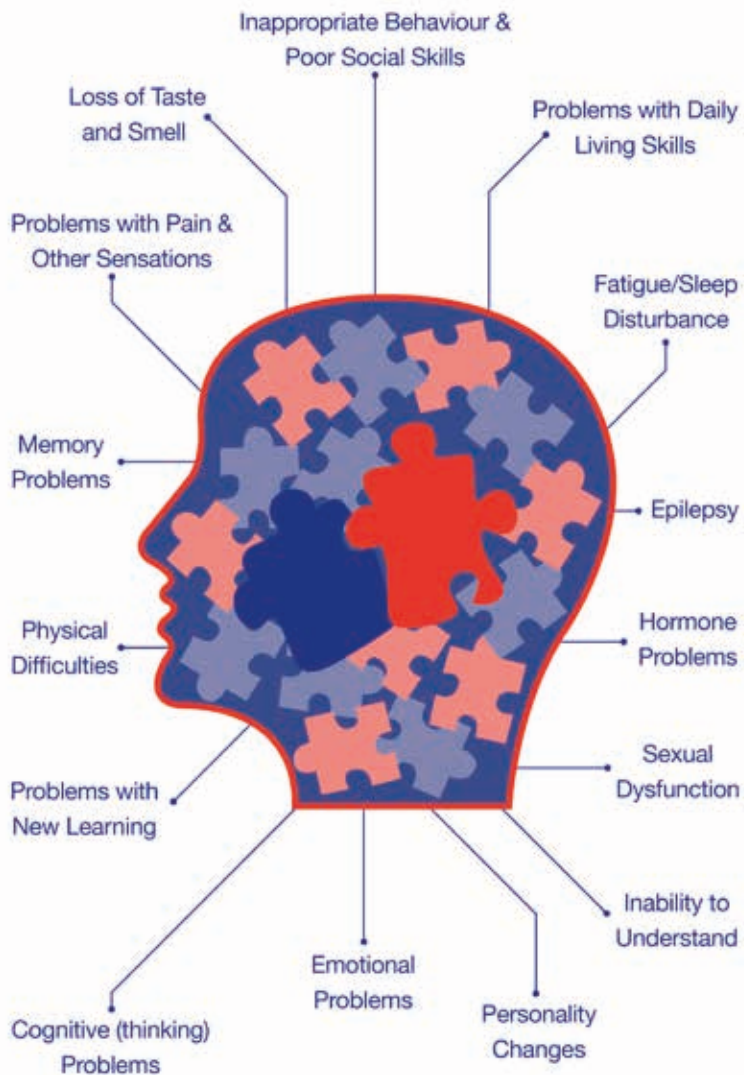
Sometimes, it is quicker and worthwhile to discuss the issue directly with the provider of the service before you make an official complaint. The complaints procedure could be quite overwhelming. You may need to ask for help from somebody who understands the procedure, such as PALS (please see below) or someone from an independent NHS Complaints Advocacy service, details of which you can find through your local council website.

**There are a few organisations which may help if you experience problems or need advice while in hospital.**

- ➔ **The Encephalitis Society** can provide you with support and direct you to those best placed to address your concerns. Get in touch with our Support Service on [support@encephalitis.info](mailto:support@encephalitis.info) | +44 (0)1653 699599.
- ➔ **Patient Advice and Liaison Service (PALS)** can provide confidential information and support on health related matters while you or your loved one are in hospital. You can find PALS officers at the local hospital.
- ➔ **The Patients Association** provides information to patients and their families about the health care system. [www.patients-association.org.uk](http://www.patients-association.org.uk) | +44 (0)20 8423 8999.
- ➔ **Local Healthwatch** provides general advice and support regarding complaints about the NHS and social care. Each local Healthwatch is part of the local community and works in partnership with other local organisations. An online search facility for your local Healthwatch is available on their website at [www.healthwatch.co.uk](http://www.healthwatch.co.uk)



# POST-ENCEPHALITIS CONSEQUENCES



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# SECTION 3

## THE EFFECTS OF ENCEPHALITIS

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3

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This section covers a broad range of situations but not all will relate to your child. Various specific needs are described individually for clarity but of course their combined effects must be considered with care.

## KEY FACTS

**Overall, it is essential to understand that the effects of encephalitis can be:**



### **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.



### **Lifelong**

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 may not be progressing towards their full potential.



# HOW THE BRAIN WORKS

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In order to understand the effects of encephalitis on the brain, it can be helpful to understand how the brain works.

## THE BRAIN

The brain is an amazing organ – it controls everything you think, feel and do. The brain is made up of billions of nerve cells (neurons). A neuron has a cell body containing a nucleus and an axon which carries the impulse away from the cell body. Each neuron makes thousands of connections to other neurons. This ‘neural network’ is similar to the way roads connect to make road networks.

At birth, all the neurons you will ever have are present but there are very few connections. During early development, the neurons form trillions of connections. These connections are fine-tuned by the neurons’ electrical activity: useful connections are maintained or added, while others often disappear.



Axons that become regularly used, are gradually covered by a protective coating (the myelin sheath). A good analogy is the covering of a main road with tarmac allowing traffic to flow more freely. Neurons communicate with one another via specialised chemicals called neurotransmitters, of which there are several. Neurons transmit electrical and chemical signals, and this transmission of signals between neurons is how the brain functions.

## THE BRAIN AND INFECTION

The brain is protected by a blood-brain barrier which prevents any large molecules passing from the blood into the brain. The blood-brain barrier acts very effectively to protect the brain from many common infections. Thus, infections of the brain are very rare.

The outcome of any infection is dependent upon the ability of the infection to cause disease and the response of the immune system. The immune response protects organisms against injury and infection by delivering white blood cells to sites of injury to kill potential pathogens and promote tissue repair. However, the powerful inflammatory response also has the capacity to cause damage to normal tissue. Unfortunately, the immune response to an infection of the brain can contribute more to the disease process than the infection itself.

## THE BRAIN AND ENCEPHALITIS

In infectious encephalitis, viruses entering neurons utilise components of the cell in order to replicate (make copies of themselves). This uses up energy stores and oxygen, damaging the cell. In post-infectious/autoimmune encephalitis, it is the immune system that causes damage to neurons or other brain cells.



In both types of encephalitis, by-products of the immune system's actions (fluid, white blood cells, the contents of dead nerve cells and disabled viruses) can significantly alter the fluid surrounding neurons and affect their functioning. For instance, the characteristics of the cell membrane may be altered, disturbing the electrical properties of the neuron. Swelling resulting from additional fluid entering the brain can interfere with blood supply causing anoxic (lack of oxygen) damage.

The extra unwanted fluids build up rapidly, and glial cells (cells that support neurons) try to absorb the unwanted chemicals and fluids in order to protect neurons from harm, and in the process they swell up too. Glial cells act as sponges and scavengers of toxic by-products, caused by the inflammation, but when they become overloaded, they die and then re-release the toxic chemicals back into the fluid, where they kill additional neurons. The extremely high levels of these substances are sufficient to kill vulnerable and weakened neurons by damaging their membranes or by exciting them to a point where they 'burn out' and die.

At the site of inflammation and in nearby tissue, there is biological chaos, as the brain tries to adjust and fight the consequences of the damage. The dying cells give off chemicals that activate macrophages (white blood cells), which move from the bloodstream into the injury area, to absorb and eliminate debris. Glial cells and their helpers, which have gathered at the site to clean it up, now begin to form the scar tissue that will remain a part of the brain's new architecture. Sometimes, the glial barriers prevent healthy, remaining neurons from restoring axonal connections. In other cases, nerve terminals cannot pass the scar, and abnormal activity is then generated that can lead to epileptic seizures.

# AGE AT DIAGNOSIS

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The brain develops throughout infancy, childhood and adolescence. The process of neural development is not uniform throughout the brain at any one point in childhood, with some areas 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 areas of the brain which are already fully developed and functional may become immediately obvious through temporary, or perhaps long-term, loss or impairment of skills.
- ▶ Damage to an area of the brain which is in the process of development, can result in temporary loss of emerging skills, or the development of skills may take longer and not occur as expected.
- ▶ Damage may occur to parts of the brain which have yet to develop fully. This is particularly true of the pre-frontal cortex which continues to develop through adolescence and early adulthood. Consequently, damage to such areas may appear to have little functional effect soon after injury, but over the years difficulties (e.g. behavioural problems and subtle cognitive difficulties) may begin to emerge.

These difficulties may not appear to have a direct relationship to the earlier encephalitis. A good analogy for damage affecting skills which have not yet developed, or 'come online', is a faulty light bulb – you do not know that it is not working until you turn on the switch.





# COGNITIVE DIFFICULTIES

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## MEMORY PROBLEMS

Your child's ability to remember may be affected. It is important to note, however, that there are different processes involved with memory and different aspects of this (such as visual and verbal memory, and short and long-term memory). Not all may be affected or impacted on to the same degree. For instance, your child may be able to remember things that they see, but not those which they hear, or the other way round. They may be able to remember things that happened some time ago, but not activities that have happened recently. They may have difficulties remembering instructions for a task whilst they are actually doing it. Or they may find it difficult remembering names, faces, places or directions. It is very useful, therefore, to understand your child's specific difficulties in order to help them.

## ATTENTION AND CONCENTRATION

Your child's ability to concentrate may be reduced or they may be very distractible, compared with other children of the same age. They may not be able to divide their attention in order to do more than one thing at once (e.g. have difficulty writing and listening or walking and talking at the same time). They may not be able to shift their attention easily from one thing to another (e.g. from watching a demonstration to writing some notes or from playing with Lego to listening to an instruction). They may take a long time to be able to focus their attention properly on a new activity (e.g. change of a lesson). These difficulties can be hard to spot and are often mistakenly interpreted as bad behaviour.

## **INFORMATION PROCESSING**

Your child may not be able to process information (think) as quickly as they could previously or as quickly as their peers. In school, this means that they may get 'lost' within lessons as these have moved on before they have understood each piece of information.

## **EXECUTIVE FUNCTION**

Executive function refers to skills that may be linked to the sort of supervisory 'jobs' that an executive may do for a company to ensure that it works efficiently. These include the ability to plan and to reason; to set goals; to organise an activity or a task, to complete it in the right sequence and to monitor the way that we do this (e.g. realise if we are not doing it in the best way and revise our plans); to initiate an activity and to know when to stop doing it; to monitor our behaviour and to know what behaviour is appropriate in different situations.

Difficulties in this area may present as subtle or extreme so that your child may appear unable to tackle even the simplest of tasks, seem more impulsive or appear totally disorganised. These difficulties may become increasingly obvious or only begin to be apparent as your child gets older.

If your child is a teenager, it is easy to confuse this behaviour with 'typical' teenage behaviour. Executive function problems may also create challenges for young people entering adolescence when developing relationships and exploring their sexuality.

Your child may become aware of their difficulties, which could lead to a reduction in motivation and possibly other emotional and behavioural consequences, including lowered self-esteem.



# SPEECH, LANGUAGE AND COMMUNICATION DIFFICULTIES

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Your child may lose the ability to communicate through speech and may need a system of alternative or augmented communication. They may have problems with their speech and not be able to articulate words clearly or to string words together correctly into sentences. Or they may recover the ability to speak well, but this may mask more subtle language difficulties underneath. Some language difficulties may not be apparent until your child is older, when more sophisticated use of language would normally be developed.

Although your child may be able to speak normally, they may have difficulty formulating and expressing what they want to say or they may have difficulty finding the right words. This can affect their written work as well as their speech. Conversely, they may have difficulty understanding or making sense of what they hear or read (although their ability to read words may be good). Some of these difficulties may not be apparent in general conversation, but may have significant effects on your child's ability in school.

Your child may not develop the ability to understand, for instance, humour, sarcasm or figures of speech. They may interpret some things very literally. They may not be able to pick up on a key point of a story.

Your child may have difficulty 'reading' non-verbal communication (e.g. understanding from the expression on someone's face that they are bored, irritated or joking).

If your child's speed of information processing is reduced this may affect their language skills. If they have problems with attention, this may affect their ability to understand language and will affect their social skills (e.g. not being able to keep track of a conversation).

## EMOTIONAL AND BEHAVIOURAL PROBLEMS

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Encephalitis may impact on your child's emotions with the child having difficulty controlling their emotions or experiencing uncharacteristic extremes of emotion. 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. Behaviour may build up and spiral out of the child's control.

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 other aspects of life – school or friendships – are likely to increase the child's sense of loss and unwanted or 'inappropriate' behaviours.

Some children may have reduced awareness of their difficulties as a direct result of the brain systems affected. It may be hard for them to recognise changes in their thinking, personality or behaviour and the effects they have. Other children may find it difficult to accept the impact of encephalitis and may deny that they have any problems and/or become anxious, frustrated and even depressed.



# PHYSICAL DIFFICULTIES

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Some physical difficulties, 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 your child. Other physical changes, however, may be less apparent. Your child may have a general problem with coordination and balance or know what they want to do but have difficulty putting a sequence of movements together. Your child may, therefore, appear to be more clumsy or careless.

Sometimes all physical actions are slowed compared with previous abilities. In some rare instances, a child might experience difficulties in controlling their bladder and/or bowel functioning. The child may need support in trying to regain those functions.



# FATIGUE

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Both physical and mental fatigue may become apparent following encephalitis, with your child tiring more easily in physical activities or games, as well as in lessons where concentration is required. Although this is more readily recognised in the early stages of recovery, it can frequently present as a long-term difficulty.

Whereas children may normally tire gradually, your child may suddenly reach a threshold where they are overtired or 'overloaded' with information and unable to continue.

This sudden onset is difficult to predict and control and the only remedy may be to rest or have a break from that activity. Fatigue may present as a difficulty in itself but the combined effect of cognitive, behavioural, fatigue and sleep problems needs to be considered.

# SLEEP PROBLEMS

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Sleep problems may be partly due to the disruption of your child's normal routine while in hospital and partly due to the effect of the inflammation on the brain. Sleeplessness often causes most problems for parents, especially if your child is also overactive in the daytime. Drugs that are sometimes prescribed for anxiety or sleep problems following encephalitis may have the opposite effect in some susceptible children. This is not to say that they must never be used, merely that it may take time to find the most appropriate treatment that suits your child.



# **SENSORY (VISION, HEARING, SMELL, TASTE AND TACTILE SENSATION) CHANGES AND PAIN**

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Your child may have specific impairments of vision or hearing. There may be problems with visual acuity (clearness of vision), or your child's ability to see may be unimpaired but there may be a difficulty with the brain's interpretation of the visual information that it has received.

The child may be left with hearing loss or sensitivity, sometimes extreme, to particular types of sound. It may also be that your child has difficulty interpreting or processing information that they see or hear if there are additional noises in the background, or items within their field of vision which are distracting them.

If these difficulties are not identified, the child's failure to respond to information that they would be expected to see or hear may be misinterpreted as learning or behavioural problems.

Where sensation is concerned the child may experience 'pins and needles', or difficulty gauging 'hot' and 'cold'. They may also experience pain.

# EPILEPSY / SEIZURES

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Seizures can be both a symptom of encephalitis and an effect of encephalitis. Some children have seizures only at the beginning of their illness, when they are very seriously ill. However, some children continue to have seizures or begin having seizures after they are discharged from hospital. This may be apparent immediately after their initial illness, or develop some time later. There is a recognised increased risk of developing epilepsy later in life after having had encephalitis. Unfortunately, nobody can predict if this happens and it is not always linked with having seizures in the acute phase (when the illness started).

Seizures (previously called ‘fits’) may be classified into different types, according to the pattern of the abnormal electrical activity in the brain. The classification of seizures is important for their future management. In generalised seizures, essentially the whole of the brain is rapidly involved right from the beginning. In focal seizures, the abnormal electrical activity begins in one localised area of the brain. As the seizure evolves, it may either remain in that area or spread to involve other nearby areas on the same side of the brain (regional spread), or it may spread more widely to involve both sides of the brain (secondarily generalised seizure).

Some types of seizure cause brief spells of apparent inattention (they are called absences) or strange behaviours.

Epilepsy following encephalitis can be particularly difficult to treat. In some instances the seizures may become ‘intractable’ (which means that medical treatment can’t completely eliminate all seizures).





# DIFFICULTIES WITH SEXUAL FUNCTIONING & HORMONES

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Following encephalitis, some children may have specific problems which will impact on their sexuality and developing relationships.

- ▶ A physical disability can have a direct impact on the child's ability to engage in sexual activity or an indirect impact through low self-esteem and self-confidence brought up by their disability.
- ▶ A disinhibited or sexually inappropriate behaviour, with or without poor awareness and impaired social skills, can impact on the child's relationships.
- ▶ Sometimes, encephalitis can affect the part of the brain that looks after our hormones: pituitary gland or hypothalamus. Sex hormonal imbalance may affect: puberty – yearly or delayed (where a young person doesn't reach physical maturity at the usual age range); growth – most commonly short stature; periods – may stop in young girls; libido – a young person's sex drive might be reduced.
- ▶ There are many other symptoms that may be experienced by changes in hormone levels such as depression, fatigue, headache, visual disturbances, weight gain, changes in skin texture, difficulty regulating body temperature, sleep disturbance and thirst. Sometimes, it can be difficult to recognise that these symptoms are caused by a hormonal imbalance.

# DIFFICULTIES WITH SOCIAL SKILLS

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The potential impact on social relationships should not be underestimated. Your child has suffered a serious illness, which has possibly required a considerable amount of time in hospital and convalescence at home before returning to school.

This extended absence means loss of contact with other family members and peer groups at school. In turn, once your child returns home and to school, friendships may be more difficult to develop with peer groups.

Problems with fatigue, attention, reduced verbal communication ability etc. can all impact on social interaction and peer relationships. Your child may have a tendency to be impulsive, irritable, even aggressive, and this can affect friendships.

If they have problems with memory or with focusing attention, it can be more difficult to understand what is being said and follow a conversation. Thinking skills also play a large part in getting along with others. Your child may have difficulty learning social 'codes of behaviour', such as respect for others, empathy, and a mature understanding of 'right and wrong'.

These difficulties may be apparent on returning home and to school as the child tries to settle in or develop over the following years.



# SECTION 4

## RECOVERY AND REHABILITATION AFTER ENCEPHALITIS

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4








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A child's recovery depends on the degree of the brain injury, the type of after-effects, the support from services, professionals and school, and the involvement of family in their recovery. Nevertheless, we are aware of amazing stories of recovery despite an unfavourable prognosis given at the start of the recovery process.

This section provides an overview of what can help your child's recovery, options for rehabilitation and services and specialists you may encounter during your child's recovery journey.

## KEY FACTS

-  The brain takes much longer to recover from an injury than other parts of the body, such as muscles, bones or skin.
-  Unlike other body parts, you cannot see the brain repairing and may assume all is back to normal when this is not the case.
-  Recovery after encephalitis involves lots of rest and a gradual return to school.
-  Your child may need different assessments and interventions at different stages in their recovery.
-  Rehabilitation does not cure your child, however, it helps them to develop new skills and strategies for coping with their difficulties.
-  A neuropsychological assessment is essential in understanding the child's changes in their thinking, behaviour and feelings.
-  In some cases, the assessments need to be undertaken several times across a child's developmental lifespan.



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# GUIDELINES FOR RECOVERY

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Families may feel that returning home will make everything 'normal' again. However, both the child and the family may find there is a great deal of adjusting required.

The brain takes much longer to recover from an injury than other parts of the body. This is because new nerve cells do not generate easily and renewed neural networks may not function in the same way. Unlike other parts of the body, you cannot see your child's brain repairing and may assume all is back to normal, when in fact some areas are still in recovery. There is no set timetable for recovery – every experience is different – nor a sure answer from specialists of the level of recovery. This uncertainty can make parents feel frustrated and stressed. Dramatic improvements can happen. But it is very important to be patient and aware of what is needed from your child and yourself as part of the rehabilitation process.



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## PACING

A lengthy period of rest and quiet will aid your child's recovery. Try avoiding information overload which could set back the process. Fatigue after a brain injury may be misunderstood, so full information for all those involved is necessary. Pacing (alternating the activity period with rest) needs to be introduced in all day-to-day activities, both at school and at home.

Try to explain to your child about fatigue and the need for rest. Learn to recognise the signs of your child's fatigue. Finding out their limits (how much they can do before they are tired) may be hard but well worth it in the long term. The sooner the family, school and the child begin to manage fatigue, the better they cope with all other consequences of encephalitis.

## GOOD NUTRITION

Good nutrition is important for brain repair. Nutrients that are especially important are antioxidants (found in fresh fruit and vegetables) and omega-3 (fish or flaxseed oils).

The recommendation to eat five portions of fruit and vegetables each day should be taken seriously. Omega-3 is an essential ingredient of myelin, the covering of nerves in the brain. Covering nerves with myelin can be likened to covering a road with tarmac – traffic flows much easier and quicker down a tarmac-covered road.



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## **GRADUAL RETURN TO SCHOOL OR NURSERY**

Plan a gradual return to school/nursery. Don't worry about your child getting behind at school. They will catch up far quicker when they are further recovered. Try to schedule rest periods into your child's day; tiredness is the brain's way of shutting down to continue with repair. Becoming overtired may slow down the repair process and can be the reason for difficult behaviour. When discussing a return to school, allow for flexibility as plans may change depending on the needs of your child.

## **ASK FOR HELP FROM PROFESSIONALS**

The long-term effects of encephalitis may not be evident for some time. Some may show only years later, when your child needs to learn more complex skills or to deal with more complex situations. Whether the problems are immediate or emerge much later, you will need to access the services that can help your child and your family.

As a parent you will know a lot about your child. However, a range of experts from health, social services and education, as well as voluntary agencies, will be important partners for you over the coming months and years. They will help you get the best support for your child. You should always feel able to ask questions or seek other opinions if you feel uncertain or unhappy with what they say. The provision of appropriate services is not the same in all areas and not enough in most, so be prepared to be persistent in asking for input from professionals if you think they can help.

# EXPLAIN TO YOUR CHILD WHAT HAS HAPPENED TO THEM

Your child may benefit from knowing as much as possible for their age and level of understanding about what happened to them, what to expect in the future and what they can do to help themselves.

- ➔ **The Encephalitis Society** has produced two books for children: **'Gilley the Giraffe... who changed'** and **'Medikidz'**, which may be very useful in explaining encephalitis and its after-effects to children.

You can order these books from our website:  
**[www.encephalitis.info](http://www.encephalitis.info)**

- ➔ **Child Brain Injury Trust** has produced **'Rearrange your brain'**, a book aiming to teach any young child about coping with adversities in life and how to adopt a healthy approach when the times are tough.

You can order this book from: **[childbraininjurytrust.org.uk](http://childbraininjurytrust.org.uk)**



Find us online at **[www.encephalitis.info](http://www.encephalitis.info)**



# WHAT IS REHABILITATION?

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The main aim of rehabilitation is to help your child develop new skills, habits and strategies for coping with their remaining difficulties and provide them with as much independence as possible. It may be hard for parents to understand this, but rehabilitation does not cure your child and/or return them to how they were before the illness.

The type of therapy and the setting for rehabilitation needed will depend on the individual needs of the child. It may be part of the hospital, a specialist rehabilitation centre or a community service. At times, the child may need help from only a few key professionals and at other times they may require help from a multidisciplinary team. All activities are specific to your child, depending on their type of difficulties, their emotional state, their age and where they are in their recovery.

Family members are often heavily involved in rehabilitation and are integral to the success of interventions. Being there for your child is very important. Taking part in sessions may help alleviate anxiety. It is important to be patient. Don't be discouraged by the slow pace of recovery. Focus on positives and be supportive. Praise your child for their efforts. Talk to the professionals involved and provide them with information about your child – you know your child best.

In fact, it is also important to note that a certain amount of rehabilitation takes place at home, without the formal involvement of professionals. This kind of rehabilitation involves children/young people and their families using 'self-management' strategies, examples of which are discussed later.

# KEY PROFESSIONALS AND SERVICES

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## THE ROLE OF PSYCHOLOGY

There are two main psychology services available. One is educational psychology and the other is clinical psychology. Both services can plan strategies to help your child overcome or move forward from a particular problem, they can also help parents gain a much better insight into why their child is behaving as they do.

**Educational psychologists** Your local authority will have a team of educational psychologists who support schools and families. There are also private educational psychologists who can provide additional services. Educational psychologists specialise in working with children and young people aged 0 to 25, helping to find ways of improving behaviour, social and emotional development. They assess children in a variety of ways including observations, interviews and tests, and offer consultation, advice, support and training to staff and parents as well as the young people concerned.

Usually, your first contact with an educational psychologist will be when you and the school decide to seek additional advice about meeting your child's educational needs. The school will usually arrange for an educational psychologist to become involved, but they must seek your permission first.



If the local authority carry out a statutory assessment of your child's needs, to see if an education, health and care plan is needed, they must have an educational psychologist's written advice and will arrange for this assessment if it is not already in place.

**Clinical psychology** Clinical psychologists work to increase understanding of how the child's medical condition and acquired brain injuries impact on learning, behaviour, social and emotional functioning. Through one-to-one assessments, observations and group working, information and advice are given to parents, carers, teachers and professionals working with the child. The aim is to support the child and to teach them new approaches and ways of overcoming difficulties. Children may also receive individual psychotherapy and counselling to help them to understand what has happened to them and the way it makes them feel. Clinical psychologists usually work as part of CAMHS (Child and Adolescent Mental Health Service).

Both clinical and educational psychologists can specialise in neuropsychology. **Neuropsychologists** look at how a brain injury may have affected your child's thinking skills and behaviour.

The neuropsychologist can identify where your child's strengths lie – what they can do well – and which functions your child is having problems with via a neuropsychological assessment; and can advise on ways to manage those difficulties.

## KEY PROFESSIONALS AND THEIR EXPERTISE IN MANAGING THE AFTER-EFFECTS OF ENCEPHALITIS

Various professionals often work together in multidisciplinary teams to provide support following ABI, both in the community and in outpatient settings. However, in some regions the health professionals work independently of each other. Depending on where you live, help may be available from local NHS services (e.g. statutory services) and/or there may be other services available that you can access for free.

The best thing to do is speak with your child's GP or neurologist in order to obtain a referral to these services. They are best placed to know what kind of support is available in your local area and how to get access to this support.

- ▶ Educational psychologist, psychologist or neuropsychologist for cognitive, emotional and behavioural difficulties; difficulties with schoolwork and school life.
- ▶ Physiotherapist (physio) for problems with movement, coordination and/or sensory changes (i.e. numbness, pins and needles).
- ▶ Occupational therapists (OT) for fatigue, difficulties with activities of everyday living and engaging in play-based activities and returning to school.
- ▶ Paediatric neurologists for medical problems such as epilepsy, headaches and other neurophysiological problems and referral to other specialist services.
- ▶ Child and adolescent psychiatrist for behavioural issues and difficulties with social relationships and emotional adjustment.



- ▶ School nurse for difficulties that may affect children's ability to learn in school.
- ▶ Epilepsy nurse specialists for epilepsy such as medication review and clinical assessment, as well as providing counselling and social support to patients and their families.
- ▶ Pain management services/pain clinics for pain management via physiotherapy, psychological support and/or medication.
- ▶ Continence services for difficulties with bladder and bowel control.
- ▶ Ear, nose and throat specialists for problems with ears, nose, throat and related structures of the head and neck.
- ▶ Audiologists for problems with hearing, balance and tinnitus.
- ▶ Ophthalmologists for medical and surgical eye conditions.
- ▶ Endocrinologists for conditions related to hormonal dysfunctions.
- ▶ Immunologists for problems related to the functioning of the body's immune system.



## **COMMUNITY SERVICES**

### **Child development centres**

They usually provide assessment and continuing treatment and support for children who have developmental delay.

The team may consist of various professionals such as therapists, paediatric doctors and nursing specialists. Referral is usually by a child's GP, special educational needs coordinator, health visitor or social worker. Please note that these centres are not available in all areas.

### **Child and Adolescent Mental Health Service (CAMHS)**

Specialist Child and Adolescent Mental Health Services are part of the NHS. They provide assessment and treatment to young people and their families where there is concern about emotional, behavioural or mental health problems.

CAMHS usually consists of a multidisciplinary team, including some or all of the following: child and adolescent psychiatrists, child clinical psychologists, child psychotherapists, social workers and community psychiatric nurses.

The referral and assessment process may vary according to area. A referral to CAMHS can be made by a variety of professionals and organisations: GP, paediatrician, social worker, educational psychologist, voluntary organisation, etc. Some services also accept referrals from parents and from young people themselves.

CAMHS provide services to children up to their 18th birthday, but some of them stop after their 16th birthday and the young people move on to the adult mental health services. Parents and young people should be supported through this transition.



## Portage

Portage is a home-visiting educational service for pre-school children with additional support needs and their families. Portage offers regular home visits, generally weekly or fortnightly, by a trained Portage home visitor. The aim of each home visit is to decide on an activity which the family can practise and enjoy together. The activities are based on play and grounded in everyday situations to provide fun and success for the child.

Portage supports families from the time that the additional needs are first apparent – this can be soon after birth or at any time in the pre-school period. You can approach your local Portage directly or you can be referred by any other authority. The service is free of charge. Unfortunately, Portage is not available in all areas.

→ Website [www.portage.org.uk](http://www.portage.org.uk) | Tel 0121 244 1807



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## Getting the most out of your meetings with professionals

Below are some tips that will help you have a successful meeting.

- ▶ Go through all your paperwork beforehand and ensure that you have copies of everything that might be useful for the meeting.
- ▶ Ensure that you know where you are going for the appointment so that you can arrive in plenty of time without being anxious.
- ▶ Make sure that you have completed and returned any forms that have been asked for prior to the meeting. Keep a copy for yourself.
- ▶ Think about what the meeting is for – did you ask for it or has it been arranged to discuss a particular issue? This will help you to determine what you want to achieve from it.
- ▶ Think about what you want out of the meeting and what you are prepared to compromise on.
- ▶ Make a list of questions that you want to ask and points that you wish to raise. Once you are in the meeting make sure that you refer to your list.
- ▶ Try to answer their questions without diverting from the subject.
- ▶ Don't be afraid to question anything you don't understand, disagree with or have a concern about.
- ▶ Try to get someone, for example a friend or a relative, to accompany you and take notes during the meeting.
- ▶ Ask for copies of written reports and assessments.





Meeting professionals can be quite daunting and emotional especially if you are anxious or upset. Remember, good preparation will help you feel calmer and more confident about the meeting.

## Asking for a second opinion

Your child's GP or any health care doctor can refer your child to a different doctor for another opinion but they don't have to do this if they don't agree that it is necessary. Before asking for a second opinion, if you are unhappy with the diagnosis or the treatment, you may want to discuss this with the doctor.

If you would like a second opinion after receiving advice from the GP, you can ask them to refer your child to another GP. If you would like a second opinion after seeing a consultant, or any other health professional, you need to go back to your GP and ask them to refer your child again to an alternative consultant. If your GP agrees to refer to a new consultant, this consultant will be told that you are seeking a second opinion.

Sometimes a GP or consultant may ask colleagues to provide a second opinion on their own initiative. This might happen when the issue is complex or if they feel they are being asked to comment on issues outside of their area of expertise.



# **PRACTICAL STRATEGIES FOR MANAGING THE AFTER-EFFECTS OF ENCEPHALITIS:**

## **Cognitive Difficulties, Fatigue and Behavioural Changes**

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The list of general examples below is by no means complete, and child-specific solutions are essential. Management of some of the difficulties is complex. The advice of an educational or clinical psychologist specialised in neuropsychology is strongly recommended.

### **MANAGING COGNITIVE DIFFICULTIES**

Memory loss from ABI does not 'get better if you try harder'. The focus is to help your child to use their remaining memory abilities more effectively. Try to avoid asking children to guess an 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 'overlearn' 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.

Children with attention problems as a result of encephalitis cannot improve their attention at will. They need extra help in school to ensure that their learning is not impaired as a result of this difficulty.



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## Other practical strategies include:

- ▶ Use reminders, checklists, labels and colour codes.
- ▶ Use repetition and reinforcement of information and cues to aid their recall.
- ▶ Say one thing at a time and always be very explicit.
- ▶ Allow them more time to access memories as they may have to use a more complex brain pathway than before.
- ▶ Allow them more time to get ready for any change in plans.
- ▶ Establish a routine.
- ▶ Keep the environment well organised, quiet and calm.
- ▶ Help them prioritise activities.
- ▶ Break up activities into small steps.

## MANAGING FATIGUE

It can take time to establish what works best for your child. Remember that fatigue does not mean that the child should be excluded from activities, rather they should be supported to achieve these activities.

- ▶ Try to get your child to rest before they get tired, rather than having a rest after they are overtired, as this will take much longer to recover.
- ▶ Be aware of the imminent onset of the fatigue and try to learn the signs of it.
- ▶ Keep a fatigue diary.
- ▶ You may need to suggest that the child has a rest as the child may not know they need a rest.

- ▶ Facilitate the family members' and friendship group's understanding of the fatigue and its effects.
- ▶ Plan for energy-consuming activities (e.g. homework, gym class) at times of least fatigue, such as in the morning and early in the week.
- ▶ Minimise the amount of activities on a day, even if they are only recreational.
- ▶ Plan activities for a length of time that suits your child, with definite breaks in the activity between 'work' sessions (this is known as pacing).
- ▶ Be flexible and responsive to your child's immediate needs (e.g. if the child is fatigued they can miss an activity).
- ▶ Understand that catching up at home after school is most unlikely to be appropriate, because of the fatigue.
- ▶ Be aware that rest does not mean watching television or playing computer games.

## **MANAGING BEHAVIOUR CHANGES**

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 not be able to:

- ▶ understand cause and effect.
- ▶ consistently remember what they have to do to avoid punishment or to earn a 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 with the child no longer being able to control their reactions.
- ▶ Disturbance in routine, such as change in activity or time of activity.
- ▶ Distractions such as a loud noise or different activities taking place at the same time.
- ▶ Demands that the child finds difficult, such as completing a certain task, approaching work that feels beyond them or being faced with complexity.
- ▶ Lack of attention from parents.
- ▶ Upsetting interactions or lack of interactions with siblings and friends.

You may want to try the following strategies.

- ▶ 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 (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.
- ▶ 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'.



# FURTHER SUPPORT AND INFORMATION

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Below there is a list of organisations (UK-based) that may be able to help with information and support.

## EPILEPSY

- ➔ **Epilepsy Action** has many information resources for parents/carers of children with epilepsy. They also have a network of volunteers all over the UK.  
**[www.epilepsy.org.uk](http://www.epilepsy.org.uk) | 0808 800 5050**
  - ➔ **Epilepsy Society** provides information and support to people with epilepsy; they also have a unit providing specialised assessment and treatments.  
**[www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk) | 01494 601 400**
  - ➔ **Young Epilepsy** provides information and support for both parents/carers and young people.  
**[www.youngepilepsy.org.uk](http://www.youngepilepsy.org.uk) | 01342 832243**
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## SLEEP DIFFICULTIES

- ➔ **Sleep Unlimited** provides specialist assessment and treatment for sleep-related problems.  
**[www.sleepunlimited.co.uk](http://www.sleepunlimited.co.uk) | 0191 580 0008**
- ➔ **Cerebra** runs sleep workshops for parents.  
**[www.cerebra.org.uk](http://www.cerebra.org.uk) | 0800 328 1159**
- ➔ **Contact** has developed a booklet for parents of disabled children called '*Helping your child's sleep*'.  
**[www.contact.org.uk](http://www.contact.org.uk) | 0808 808 3555**

## **SPEECH, LANGUAGE AND COMMUNICATION DIFFICULTIES**

➔ **I Can**, a charity helping children develop language, speech and communication skills, has a dedicated website (Talking Point) for children's speech, language and communication. They can provide an assessment from a multidisciplinary team and have an enquiry service with a speech and language therapist.  
**[www.ican.org.uk](http://www.ican.org.uk) | 020 7843 2544**

➔ **AFASIC** supports parents and represents children and young people with speech, language and communication needs.  
**[www.afasic.org.uk](http://www.afasic.org.uk) | Helpline: 0300 666 9410**

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## **EMOTIONAL AND BEHAVIOURAL DIFFICULTIES**

➔ **Young Minds**, a charity committed to improving the emotional wellbeing and mental health of children and young people, provides information and support regarding transition to adult mental health services.  
**[www.youngminds.org.uk](http://www.youngminds.org.uk) | Parents helpline: 0808 802 5544**

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## **HORMONAL CHANGES AND SEXUALITY**

➔ **The Pituitary Foundation** provides information and support on conditions related to a dysfunction of the pituitary gland.  
**[www.pituitary.org.uk](http://www.pituitary.org.uk) | 0845 450 0375**

➔ **Child Brain Injury Trust** produces a factsheet on 'Hormones and Acquired Brain Injury'.  
**[www.childbraininjurytrust.org.uk](http://www.childbraininjurytrust.org.uk) | 0303 303 2248**





# SECTION 5

## THE IMPACT OF ENCEPHALITIS ON THE FAMILY



5








Support line +44 (0)1653 699599



This section focuses on the different ways encephalitis may affect families and highlights the main issues for the family with different options for support. The way a family deals with the difficulties brought about by this condition is very personal.

We do not want to impose on you how to deal with your emotions, but rather give you examples of coping strategies and signpost to organisations that may be able to support you.

## KEY FACTS

-  Encephalitis may affect family relationships.
-  Families often go through a process of coming to terms with the consequences and then finding ways of coping.
-  Family members deal with emotions in different ways; strong feelings are understandable.
-  Disability following encephalitis can be hidden and those around you may not be aware of how your everyday life has changed.
-  Being a carer has a big impact on everyday life, friendships, work and education.
-  Siblings in the family need their feelings and needs acknowledged.
-  Carers need their own needs to be addressed.



# THE EMOTIONAL IMPACT

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Encephalitis can be a bewildering experience for the whole family. Your child has at one moment been a healthy developing individual and then suddenly is struck by a serious and often life-threatening illness that you have never heard of. There may be delay and uncertainty with the diagnosis. Many tests are 'normal' and yet your child is desperately ill. Treatments, particularly of seizures, may be initially ineffective. You become concerned for the child's survival, whilst brothers and sisters see a sudden and prolonged focusing of attention on the sick child.

Emotions may come and go suddenly and unpredictably. The initial reaction to your child's diagnosis can be shock, disbelief and then denial. It may be confusing, chaotic and difficult at times to work out exactly what you are feeling.



## VERY ISOLATING EXPERIENCE

Encephalitis can be a very isolating experience. People may not have heard about encephalitis and see your child recovered well physically. They think that everything is back to normal and do not understand your concerns and difficulties.

Sometimes there may be feelings of shame brought on by the illness and the behaviour after the illness. Your child may behave inappropriately with your friends and family and may say things that upset them or their action/inactions are socially inappropriate. They and you as a parent may be misunderstood or judged.

## EXPERIENCING STRESS

Stress can be brought about by the day-to-day pressures of bringing up any child. For you there may be additional pressures such as coming to terms with a child who has changed and the constant battle for services. Experiencing stress in short bursts is a healthy way to respond to difficult situations but excessive or prolonged stress can cause illness. You might experience physical symptoms such as headaches, nausea, indigestion, palpitations, and/or perspire more.

Prolonged stress might lead to feelings of anxiety, fear, anger, frustration and depression. You may find your behaviour changes too in that you are more irritable or tearful. It can affect how you interact with others (including your partner and your child's siblings), and it may interfere with your sleep patterns or sex life.



# WAYS FORWARD

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There are different ways of coping and below are some of the things we have learnt from supporting people over the years.

## TRYING TO ADJUST TO YOUR NEW SITUATION

Try to acknowledge what has happened and find ways of coping that work for you and your family in your own time. You may need to modify your hopes and expectations which could be really hard. However, this may help you to adjust the changes and realise that although everything won't return to the way it was, things can get better. Your child may not return to how they were before their illness but they can be happy and achieve in other ways.

Try to find a positive thing in what they do/how they are and focus on it. Get involved in their recovery and find out as much as you can about medication, treatment, prognosis and people's similar experiences. Learn to take one day at a time. If you are having a bad day, remember: this is just a phase and it can get better.

If you are the main person providing care, you may suddenly find that people are calling you the 'carer' whereas before you were the parent. You have a new and highly responsible role, but it can take a long time to find out what that role means for you and for your family. It is important to acknowledge that this is likely to have a significant effect on you, and you too will need support.



## EMOTIONAL SUPPORT AND COUNSELLING

Being supported emotionally is very important to all of us. Having someone who shares our concerns makes it easier to cope. For some people having a supportive family and friends will be enough. Or keeping a diary may help.

Some people find that the support of some of their social circle (friends, relatives) may, occasionally, be overwhelming and this can have a negative impact on their emotional wellbeing. Don't be afraid to tell 'no' sometimes and avoid people who raise your level of stress.

Other people may need professional help. There are various kinds of counselling services available to enable you to speak openly about how having a child with special needs is affecting you. Their help may be short or long-term and it may be free or involve payment. Counselling is not offered routinely and you will have to ask for it. Often the first person to ask is your GP or someone involved in your child's welfare.

Some family members develop a severe emotional response and depression may begin to dominate their lives. If you or a member of your family is struggling with these emotions, consult your GP about appropriate treatment and support.

## THE BENEFIT OF SHARING EXPERIENCES

Some people may find joining a support group helpful. Peer support through talking to others who have been through similar experiences can be a positive way of making sense of feelings and life changes.



Reading the narratives of other people who have experienced encephalitis is also often useful. Other people's narratives can provide hope that there is life after encephalitis, by providing tips about different ways of coping and finding meaning in the experience.

Some people prefer not to read narratives. There is always a risk that the story may not be what people expect or that people may experience negative feelings about their own experience as a consequence. Before reading, it is important to consider whether the time is right. Narratives are more likely to be of benefit at a later stage in the recovery than in the immediate aftermath of diagnosis with encephalitis.

➔ Our website – **[www.encephalitis.info](http://www.encephalitis.info)** recommends and reviews a wide range of books in which people have written about their personal experience of encephalitis or ABI more generally.

## **KEEPING ACTIVE AND HEALTHY**

Try to keep active, even if it is just a simple walk. Exercise is proven to improve mental wellbeing. Eating healthily also helps.

Try to do at least one thing a week that is just for you – coffee with friends, gardening, a movie, a walk in the park. Leisure interests are also important in balancing things out. It could be a sport, salsa dancing, a night class or just a night out with friends.

If your child sees you having fun and getting satisfaction out of life, they will tend to see this as a good model to follow and a good way to be. Build new memories to forget the stressful experiences.

## GETTING PRACTICAL HELP

Ask for help and learn to accept help from others such as family, friends or statutory organisations. Remember: acquired brain injury is a hidden disability, so unless you provide them with all the information, it is unlikely people know about your needs or how to support you. Many parents only ask for help when they are desperate and feel they can't cope anymore. If you need help now, say so, or try to ask for help before you reach crisis point.

If your child has a disability, you may be entitled to financial help such as benefits and tax credits. There may also be help available for practical things such as mobility aids, adaptations to your home or travel costs. If you are a carer for your child you may be entitled to support such as financial help from the local authority following a carer's assessment or flexible working arrangements if you are an employee.

### Tips for working with social workers:

- ▶ Don't take 'no' as their final answer.
- ▶ Request written confirmation of a 'no' response as it can prove helpful in appealing against decisions.
- ▶ Find out what other parents have got and what pathway they used.
- ▶ Get your GP, consultant or health visitor on your side – get them to write letters for you explaining what you need and how much you need it.



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## SHORT BREAKS

We all need a break and that's nothing to feel guilty about. Don't be afraid to be honest with those you can trust about the support you need. A 'break' is all about giving you and the rest of the household some time off by allowing someone you trust to look after your child while you go out or spend time with other family members. While you can arrange care with family members or friends or pay for it privately, most formal short breaks are coordinated by social services. It's always worth checking what kind of short-term care is available in your area should the need arise. A word of warning however, there is always a heavy demand and you will have to jump through hurdles and probably have to wait.

Sometimes it's not easy to admit you need a break. You struggle so hard to keep going, the thought of having to make any extra arrangements for your child's care hardly seems worth the effort. But once you've got over the hard work, you may find the break a lifesaver and well worth the effort spent on getting it right.

Parents often worry that their child is vulnerable and don't know exactly when and how much independence should be allowed. Having short breaks can help you discover that it is possible to let your child go and allow them to discover that they can enjoy life away from the family. It can help them learn to adapt to new situations and experiences much better than they might have done otherwise.

Breaks can include care in the home, day care away from the home, residential breaks, family link schemes and holidays. Your local social services department can tell you about the range of short breaks available, eligibility and how to apply.

## **FURTHER INFORMATION AND ADVICE:**

- ➔ **Encephalitis Society** runs the Connections Scheme, through which you can be put in touch with other people going through a similar experience.  
**[www.encephalitis.info](http://www.encephalitis.info) | +44 (0)1653 699599**
- ➔ **Contact** provides advice on how to get your child assessed by the local authority. They also have local support groups for parents.  
**[www.contact.org.uk](http://www.contact.org.uk) | 0808 808 3555**
- ➔ **Carers UK** has information about the practicalities of caring and ways in which you can ask for help.  
**[www.carersuk.org](http://www.carersuk.org)**
- ➔ **Carers Trust** provides access to desperately needed breaks, information and advice, education, training and employment opportunities.  
**[www.carers.org](http://www.carers.org)**
- ➔ **MIND** provides support, information and tips for everyday living for people who find it difficult dealing with the stress.  
**[www.mind.org.uk](http://www.mind.org.uk) | 0300 123 3393**
- ➔ **Working Families** provides information on rights at work, benefits and childcare for carers of disabled children.  
**[www.workingfamilies.org.uk](http://www.workingfamilies.org.uk) | 0300 012 0312**



Find us online at **[www.encephalitis.info](http://www.encephalitis.info)**

# FAMILY DYNAMICS

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The wide-ranging impact of encephalitis has a knock-on effect on other family members. Siblings, parents and grandparents are also affected by the stressful nature of the problems following encephalitis.

Relationships within the family may change; you may have adopted multiple new roles following your child's illness. You may have found yourself becoming an advocate for your child, a caregiver, a coordinator of services and an educator of others. This burden of care severely restricts the time you have for yourself and the time you have for other family members.

## PARTNER RELATIONSHIPS

You may find that your child's difficulties are putting an enormous strain on your relationship with your partner. You and your partner may have different views on how family life should change in response to your child or differences of opinion about how to handle specific issues. There may be a sense that one or other of you is to blame.

There will be external factors too, such as a lack of time for all the jobs that need to be done, tiredness, worries about money, anxiety over the future, feelings of guilt or frustration, or just not getting any time alone together.

Your relationship as a couple sets the emotional environment for your whole family and keeping it strong and healthy will benefit the whole family. Your relationship may become stronger, but some couples may drift apart. Couples, able to talk to – and cry with – each other in safe, confidential surroundings, make it easier to cope.

- ➔ **Relate** specialises in providing relationship support.  
**[www.relate.org.uk](http://www.relate.org.uk) | 0300 100 1234**
- ➔ **Contact**, the charity for families with disabled children, has produced a very useful guide, '***Relationships and caring for disabled children***'.  
**[www.contact.org.uk](http://www.contact.org.uk) | 0808 808 3555**

## **SINGLE PARENTS**

One of the greatest advantages that parents with partners have is that they have someone with whom they are happy to leave their child, enabling them to have a break. For single parents, the practical burdens can seem overwhelming, and there's usually less opportunity for emotional support. Unless other family members or friends live nearby, finding a childminder can be very difficult and evenings out, or other breaks from caring, hard to arrange.

Assistance from local carers groups can be vital – don't feel guilty about asking for and accepting help.

- ➔ **Gingerbread** provides advice and practical support for single parents.  
**[www.gingerbread.org.uk](http://www.gingerbread.org.uk) | 0808 802 0925**



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## SIBLINGS

Depending on their age, they may be aware of how seriously ill their sibling has been. They may be afraid that they too will become ill or that they are in some way to blame for their sibling's illness.

There's a real danger that your child's siblings may lose out because of all the extra attention your child affected by encephalitis needs.

Your other children may have very mixed feelings, alternating between love, protectiveness and jealousy, and resentment and irritation. For your other children, playing with a brother or sister affected by a brain injury can be frustrating as they may not remember rules of games, their behaviour may be disinhibited and 'silly', they may soon lose interest or become tired.

Adolescents may be embarrassed about their sibling's behaviour.

You may be concerned that your other children are missing out because you don't meet their needs or that you don't give them enough time. Dealing with sibling rivalry can be very challenging.

## WHAT YOU CAN DO

- ▶ You will need to address their concerns and answer their questions. If they do not want to talk to you, find somebody else who they can confide in. Or find another way they can express their feelings, such as keeping a diary.
- ▶ Lead by example. Let them know how you feel and that it is okay to feel that way. This will encourage them to express their feelings.
- ▶ Let the teachers at school know what they are going through, so they may be able to help.
- ▶ In some areas there are groups for brothers and sisters (sibling groups) that provide emotional support and social activities. Ask your local social services about them.

## FURTHER INFORMATION AND ADVICE:

- ➔ **The Encephalitis Society** has produced two information resources – ***‘Gilley the Giraffe who changed’*** (book, DVD and games) and ***‘Medikidz’*** which may help siblings understand what their loved one is going through. The books are available to order from our website, **[www.encephalitis.info](http://www.encephalitis.info)** or from our office, mail@encephalitis.info or +44 (0)1653 692853.
- ➔ **Sibs**, the siblings charity may be able to provide useful information and support.  
**[www.sibs.org.uk](http://www.sibs.org.uk) | 01535 645453**
- ➔ **Child Brain Injury Trust** has produced a book, ***‘Rearrange your brain’*** to support siblings of children and young people affected by childhood acquired brain injury.  
**[www.childbraininjurytrust.org.uk](http://www.childbraininjurytrust.org.uk) | 0303 303 2248**

## GRANDPARENTS AND THE WIDER FAMILY

Whether help and support is available to you from your own family depends on many things, such as whether or not they live close by, whether they feel confident about taking responsibility for your child, their own family situation or their own health. For some families, grandparents can be a great help, especially in practical ways, such as helping with childminding or household chores.

Accepting help from grandparents or other members of the family can, however, cause more difficulties in some instances. It can be very frustrating if other people make allowances for your child in a way that conflicts with the way you care for them.



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Inevitably not all families have good relationships and sometimes the sudden impact of encephalitis adds to already strained relations. It has been reported that grandparents go through the same anger, grief and denial emotions that affect parents, but some find it hard to move on to acceptance of the situation.

Equally some grandparents may be overwhelming in their offers of support and advice, not knowing when to back off.



# SOCIAL OPPORTUNITIES FOR FAMILIES

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You may feel that getting out and about is hardly worth the effort.

***“How will I get there?”, “Will my child embarrass anyone?”, “Will they be accepted?”, “What will access be like?” etc.***

However, finding social activities and things that you can enjoy together can go some way towards restoring normality.

All children and young people want to have a social life and take part in activities they enjoy, but there can be barriers if your child has behaviour problems or special needs. You want to know that your child will be welcome, safe and supported, especially if your child needs constant supervision.

When you are considering new activities you may have lots of questions.



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***“What will happen if my child is upset or has a tantrum?  
Is there a safe place to let off steam? What are the rules?  
Are they simple, fair and make sense to the children?  
What’s in place to help a child deal with disappointment?  
Will my child be encouraged to do as much as they can for  
themselves but not be left to struggle with things they  
can’t manage, or allowed to take unreasonable risks?”***

If you ask all your questions at the same time, it may feel like it will be too hard to include your child. So sometimes it’s useful to sit and see how a session runs before introducing your child.

Look around at what other children are doing in your local community, or your child’s school. If you experience difficulties with a particular organisation, it may help to have someone talk to the organisation (e.g. a youth group, camp) to help them understand and cater for your child’s needs. If necessary, consider recourse within the Disability Discrimination Act. You may be fortunate to have local play schemes and clubs with trained and experienced support staff. Usually these are provided by local voluntary organisations. Contact your local social services for details.

The Encephalitis Society organises social events for families, where parents and children get together, share experiences and have fun in a comfortable and understanding environment. Become a member of the Society and we will keep you up to date with the calendar of events.

➔ For membership please visit our website,  
**[www.encephalitis.info](http://www.encephalitis.info)** or phone us on **+44 (0)1653 692583**.

## FURTHER SUPPORT AND INFORMATION

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- ➔ **KIDS** provides play and leisure services with fully trained, safeguarding checked staff in specific settings.  
**[www.kids.org.uk](http://www.kids.org.uk)**
- ➔ **Whizz-Kidz** provides disabled children with the essential wheelchairs and other mobility equipment they need to lead fun and active childhoods.  
**[www.whizz-kidz.org.uk](http://www.whizz-kidz.org.uk)**
- ➔ **Calvert Trust** provides activity holidays specifically for children with a disability, their family and friends.  
**[www.calvert-trust.org.uk](http://www.calvert-trust.org.uk)**
- ➔ **Child Brain Injury Trust** awards grants to a child with an acquired brain injury and their brothers and sisters, enabling them to take part in social activities.  
**[www.childbraininjurytrust.org.uk](http://www.childbraininjurytrust.org.uk)**
- ➔ **Family Holiday Association** provides short breaks in the UK for children and their families.  
**[www.familyholidayassociation.org.uk](http://www.familyholidayassociation.org.uk)**
- ➔ **Family Fund** provides grants to low-income families raising disabled and seriously ill children and young people.  
**[www.familyfund.org.uk](http://www.familyfund.org.uk)**
- ➔ **Roald Dahl's Marvellous Children's Charity** awards grants for families facing financial hardship while caring for a child with a serious illness. They provide support to help families cope.  
**[www.roalddahl.com/charity](http://www.roalddahl.com/charity)**



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# SECTION 6








## RETURNING TO SCHOOL



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, if your child has been left with an acquired brain injury (ABI), returning to school can sometimes be a continuous battle to get the right services for your child at the right time.

The Encephalitis Society has developed an information resource for teachers – 'Returning to school after encephalitis. Guidance for school staff', available as hardcopy from our office or pdf from our website: **[www.encephalitis.info](http://www.encephalitis.info)**. This guidance is a very useful resource for educational professionals, so please make sure your school has a copy. A summary of this guidance is also available.

## KEY FACTS

-  Consider a gradual return to school.
-  Be prepared to be flexible; plans for returning to learning and arrangements in school may change to accommodate your child's needs, which may fluctuate.
-  Inform the school about the effects of encephalitis on your child and about all your child's needs as a result of these effects.
-  Be involved in assessing and planning for your child's needs (e.g. learning, school life, and friendships).
-  Communicate regularly with the school.
-  Ask for specialist help and advice if it is needed.
-  Consider requesting an education, health and care (EHC) assessment of your child's needs if your child needs more support than the school can provide.



# GUIDELINES FOR RETURNING TO SCHOOL

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## TOO ILL TO GO TO SCHOOL

When children are in hospital, parents/medical professionals should tell their school. When a child is away for more than 15 days because of an illness (including time in hospital), the school should inform the local authority (LA).

The LA would then need to make sure the child has full access to education in a hospital school and/or at home. However, it can be a long time before a child who has had encephalitis can do any schoolwork at all.

On returning home, you will be keen for your child to return to school and for family life to get back to normal. At the same time, many children are far from ready in the first weeks after they come out of hospital. The child may need a great deal of care and rest, and should not be overloaded with activities.

- ➔ For more information on what happens if your child is too ill to go to school, visit: **[www.gov.uk/illness-child-education](http://www.gov.uk/illness-child-education)**



## KEEPING IN CONTACT WITH THE SCHOOL

As far as possible, you need to keep in contact with the school, and let them know how your child's recovery is progressing. Teachers working with your child in hospital and/or at home should be in close contact with your child's school about schoolwork, but should:

- ▶ only do as much as your child can cope with.
- ▶ be clear about what your child can and can't do with both you and the school.

You are in the best position to know when your child is well enough for contact with their friends and classmates via home visits, phone or video link (e.g. Skype or Facetime). When contacts are arranged, make sure that:

- ▶ friends and colleagues have knowledge about their friend, the illness and its effects.
- ▶ you request the contact to be short because of the fatigue.

## WILL THEIR SCHOOL STILL BE THE RIGHT PLACE?

Many children go back to the school they were at before they were ill (or the school they were about to move to). Sometimes it is clear that this is the right thing to do, or it may take some time to be sure. When it is very clear that they will need a specialist school or specialist unit straight away, their needs must be assessed by the local authority; this process is described below in this section under 'Education, health and care needs assessment and plan'.



## PLAN FOR A GRADUAL RETURN

After having had encephalitis, many children look physically as though they have fully recovered, but not all will be able to manage a whole school day, do the homework or do the work they used to do for quite some time. You, the school and the LA need to be aware of this and plan accordingly, making sure that any special arrangements needed to support your child going back to school are in place.

Plan for your child to go back to school part-time to avoid fatigue as much as possible by:

- ▶ attending school for a few hours, either morning or afternoon.
- ▶ starting full days towards the end of the week, with time for rest over the weekend.

Remember, return to school plans must be flexible.

Make sure the school are aware that requirements might change.

## REPEATING A SCHOOL YEAR

It is unusual for a pupil/student to repeat a school year, but this may be considered in exceptional circumstances, such as after a very long absence from school following illness. A repeat year may be just right for the occasional pupil. It is important to consider:

- ▶ the exact purpose of repeating the school year and whether the situation could be managed differently.
- ▶ whether being a year behind will disrupt friendship groups.
- ▶ the implications of your child being a year behind the age group over the following years.

- ▶ The extent to which the arrangement could be kept going throughout the rest of schooling, such as transfer to secondary, post 16 and so forth.
- ▶ The possible implications of reaching school leaving age before reaching the last class.
- ▶ Above all, the extent to which a repeat year might resolve your child's learning difficulties.

If a repeat school year is being considered for your child, it is important to get specific advice from a psychologist.

## KEEPING RECORDS

When a child has been ill with encephalitis, families can be inundated with paperwork. If possible, it is good to keep all records that have information about your child before, during and after the illness – up to the present date. Not only will this enable you to give schools clear information they need now, but you will have them to refer to later on. For example, if a child is very ill while at primary school, all members of staff will be aware of the illness and its effects. In future years and in a large establishment like a secondary school, continuing difficulties may not be fully understood and information about your child's illness and recovery may be very useful.





# PROVIDE INFORMATION ABOUT ENCEPHALITIS AND YOUR CHILD'S SPECIFIC DIFFICULTIES

## a) Provide information about encephalitis to the school.

Make sure key members of staff know about the Encephalitis Society's website and support line. Take a copy of the 'Returning to school. Guidance for educational professionals' (full guidance and/or summary guidance) to the school.

## b) Provide information about your child's needs.

It can be difficult to know how much information to give a school when a child is going back after an illness such as encephalitis. When your child first goes back, it is important to focus on the following three key matters:

- ▶ The information that staff need to know about your child's needs in school to ensure health, safety and confidence about being back in class.
- ▶ The staff member who family should be in regular contact with to ensure day-to-day information is being shared.
- ▶ The timescale of reviewing your child's progress and attendance.

Once the return to school is underway and the child's needs are being discussed in detail, it can be helpful to share reports (e.g. assessment from paediatrician, psychologist, therapist) that set out difficulties and needs clearly.

# PROBLEMS IN SCHOOL AND WHAT CAN HELP

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## THE IMPACT OF ACQUIRED BRAIN INJURY (ABI) ON DAY-TO-DAY SCHOOL LIFE NOW AND IN THE FUTURE

The ABI may have a significant impact on your child's learning and school life, with your child no longer performing and behaving as before the illness. It can be difficult for school staff to understand the unusual, and often subtle, problems your child may be having:



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

If your 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. In some children, their difficulties that the parents have seen at home may not be easily noticed in class or in the playground.

Allowances are often made when a child first goes back into school, and minor problems are overlooked. Then teachers may start to think: *"You've been back six months. I can't keep taking excuses about not handing your work in"* or *"You must try harder"*.

Their next teachers have probably never seen all the information you provided. Then, as children's brains develop through their teens, new problems may occur because of where the damage first occurred. It can then be hard to persuade teachers that these new difficulties could be because of an illness from the past.

Consider also that the changes in the school life and classroom demands as young people go through their Key Stages, and the day-to-day challenges of being in a large secondary school, are considerable.

# WHAT CAN HELP?

## Support in school

Most special educational needs and disabilities should be provided for in school routinely. When a child needs extra help, this should be discussed between the parents and the teachers from the start, and then at regular intervals, and the way forward planned with everyone's consent and support.

You need to work with the school to ensure that your child's educational needs are:

- ▶ fully recognised, understood and planned for in detail, in liaison with you.
- ▶ met throughout the school day by all staff.
- ▶ with your agreement (and possible presence), advised on by professionals such as an occupational therapist or psychologist.
- ▶ regularly reviewed and progress evaluated, in liaison with you.

Each school must have a special educational needs coordinator (SENCO). A SENCO is a teacher responsible for making sure the school does everything possible for each pupil who needs extra help because of 'special educational needs' or 'disabilities'. If your child has special educational needs, the teacher and SENCO should, with your permission, assess the situation fully and get advice from professionals when needed. You have the right to be there when your child is examined and tested by a specialist. However, it will be important to decide whether being there or not might affect assessment as it can be very difficult for older children to have 'mum watching'. Nevertheless, make sure you are in touch with



these professionals so you can give them additional information. When all the reports have been received, a plan of action and review will be decided. Make sure you are involved and informed of all interventions and their results.

It is the SENCO's responsibility to ensure that all relevant information is passed on to other staff and that staff are advised, trained and supported as appropriate to meet the educational needs of a pupil that they have taken on.

## Friendships

Friends can be a great support when a child is recovering from illness, and it is important to enable contact with schoolmates. How a child behaves towards friends does sometimes change as a result of encephalitis, and can cause problems. Schools can help in a variety of ways (e.g. having a buddy system; awareness lessons). If there are problems, such as lack of friends or bullying, talk with the school.

## When more is needed that the school can provide

According to the funding arrangements in schools and colleges, schools are expected to make some of the additional support for the child from their own budget. This means that there is no need to request LA funding if the child's needs can be met up by the school.

However, don't hesitate to seek support and ask for an education, health and care (EHC) needs assessment if your child's needs are not being met. Learning, emotional and behaviour difficulties resulting from ABI are complex. They may need detailed assessment, while the schools need very specific advice and guidance via an EHC plan. Above all, it is important to remember that an EHC plan is not just about extra funding, but is a legal document that states clearly what must be provided for your child's education.

## OTHER SOURCES OF SUPPORT AND INFORMATION

- ➔ **Child Brain Injury Trust (CBIT)** have regional child and family support coordinators who provide support to children, young people and families to help them live their lives to the full, within their local community.

**[www.childbraininjurytrust.org.uk](http://www.childbraininjurytrust.org.uk)**

- ➔ **Independent Parental Special Education Advice (IPSEA)** provides a great deal of information, including details about what schools should do without an EHC assessment and plan being in place.

**[www.ipsea.org.uk](http://www.ipsea.org.uk)**

- ➔ **Local information**, advice and support services, which are funded by local authorities in England, provide free and impartial support to parents and carers of children with special educational needs, and to young people who may have special needs.

Your local authority will give you contact details, or you can find them on the search page of the Council for Disabled Children website.

**[www.councilfordisabledchildren.org.uk](http://www.councilfordisabledchildren.org.uk)**



Find us online at **[www.encephalitis.info](http://www.encephalitis.info)**

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# EDUCATION, HEALTH AND CARE NEEDS ASSESSMENT

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## THE LAW AND GUIDANCE

When the extra help needed is more than the school can provide, an EHC needs assessment is required. Parents, schools, health professionals and others may request an EHC needs assessment for their child/pupil from the local education authority (LEA). When an EHC needs assessment is asked for, the LEA will give parents information about the process, what they need to do, who to be in contact with and where they can get independent help locally.

A brief overview of the process follows below.

- ▶ The LEA decides whether or not it is necessary to start the process.
- ▶ When the process is underway, the LEA asks for the information needed (e.g. information from you and/or your young person, school, medical and educational psychology reports).
- ▶ The results of the assessment are fully documented.
- ▶ You are consulted about the content and decisions reached by the LEA.
- ▶ As a result of the assessment, an EHC plan may be issued.

- ▶ An EHC plan is a detailed legal document that describes a child or young person's needs in detail and sets out what must be provided across education, health and social care to meet those needs throughout education, and to prepare them for adulthood.
- ▶ If specialist provision is needed, you are asked to give your views on where your child should go to school.
- ▶ The EHC plan can be in place up to the age of 25, if provision of education is needed until then.
- ▶ Once an EHC plan is in place, for children of school age onwards, it must be reviewed at least once a year.
- ▶ If an EHC plan is not being provided, you are told what your options are.

Going through the EHC assessment may take weeks. Sometimes a special school place is offered before this process has been completed. When this is not possible, or there is no place available, the local authority should ensure your child does receive appropriate education.

➔ **The Encephalitis Society** has developed a booklet, **'Education, Health and Care Plan'**, which you can download from our website – **[www.encephalitis.info](http://www.encephalitis.info)** – or request from our Support Service on **+44 (0)1653 699599** or **[support@encephalitis.info](mailto:support@encephalitis.info)**



Find us online at **[www.encephalitis.info](http://www.encephalitis.info)**



## YOUR INPUT IS VITAL

If you are requesting an EHC needs assessment or when you are asked for information by the LEA, it is essential to give clear, detailed and full information about your child and their needs. When you fill in forms, make sure you complete all sections, making reference to documents or additional explanations you attach. Do this even if you are repeating yourself. A checklist such as the one below could be helpful.

- ▶ Child's date of birth, schools attended and immediate family.
- ▶ Summary of development and school reports before having encephalitis.
- ▶ Child's age at time of onset of illness, if known.
- ▶ The effects of encephalitis (information available from the Encephalitis Society).
- ▶ Medical reports (e.g. what problems have been found and what advice has been given).
- ▶ Difficulties in specific areas that can affect learning and school life.
  - Memory
  - Planning and organisation
  - Attention and concentration
  - Language, speech and communication
  - Hearing, understanding and sensitivity to sound
  - Eyesight and sensitivity to light
  - Physical coordination
  - Epilepsy
  - Fatigue
  - Behaviour control
  - Social skills
- ▶ What parents find works best for their child.

## HELP WITH THE PROCESS

You will be given contact details for a support service in your area called a SEND Family Partnership or similar. This is funded by the LEA but it is independent. Additionally, voluntary organisations such as the Encephalitis Society or Child Brain Injury Trust (CBIT) may be able to help.

## OUTCOMES

You will be told whether or not an EHC plan is to be provided. If it is provided, you will be given the draft EHC plan to check and asked where you want your child to be educated. The choice of school will mainly depend on your child's needs. Most children have additional help in their local school.

When a place in a special unit or special school is needed (or preferred by you and agreed with the LEA), your authority will try to place your child in a school or college near to home, family and friends. If your child's needs are complex, high levels of skilled care are needed and/or there is no school in your area, a residential school or college may be needed.

Occasionally, a special school choice is agreed as there are no alternative options, but there is no place available at the time. It is very important to work with the LEA to agree how your child will be educated in the meantime.



## CHOOSING A SCHOOL

Before deciding on a school or college for your child, it is important to visit the place and speak with the Head or senior member of staff.

- ▶ Use the list of your child's needs and score the school or college against these.
- ▶ Look at the prospectus of each place you are considering, then visit and look round; talk with staff, students and other parents, if possible.
- ▶ If discussion with you is planned, make sure the person concerned has enough information about your child to discuss important points with you.
- ▶ Read the school's OFSTED report about the place's strengths and weaknesses.
- ▶ Make sure you are aware of matters such as additional costs (such as for transport), especially when a more local school or college has been offered by the LEA.
- ▶ Keep all information, notes and correspondence in a file, along with the date and who was involved. If anything is agreed over the phone or at a meeting, ask for this to be put in writing. You may need to refer to this later on.



### a) Specialist provision in mainstream schools

In many areas, schools have, or are developing, specialist provision within the main school. This can have many advantages:

- ▶ Children can go to school alongside local friends and family members.
- ▶ As much specialist teaching as needed can be provided.
- ▶ Integration with the main school can be arranged as and when appropriate.
- ▶ A 'special school' environment is provided within the 'Unit', such as small pupil numbers, additional specialist staff, individual study areas and close supervision.

Specialist provision in mainstream schools varies. It will need evaluating in respect of your child's specific needs. Some may be designed for specific groups of children (e.g. children with autistic spectrum disorder or speech and language difficulties) and also be ideal for your child. Others may have provision for students reluctant to attend school, or with poor behaviour control.

### b) Specialist residential provision

If your child's educational needs cannot be met within travelling distance from home, in some cases families may need to consider residential schooling. Paragraph 10.29 of the Code of Practice (England) says: *"If it is a residential placement, so far as reasonably practicable, those placing the child or young person should try to secure a placement that is near to the child's home. However, in making this decision they must have regard for the views, wishes and feelings of the child or young person and their families about the placement. Where the local authority names a residential provision at some distance from the family's home the*



*local authority must provide reasonable transport or travel assistance. The latter might be reimbursement of public transport costs, petrol costs or provision of a travel pass.”*

## **DISAGREEMENT WITH THE LOCAL AUTHORITY (LA) ABOUT YOUR CHILD'S SPECIAL EDUCATIONAL NEEDS**

If you disagree with the LA decision regarding the issue of an EHC plan, or, if one is issued, regarding the contents of the EHC plan, you can challenge their decision. Local authorities must always provide information about how to make complaints and deal with disagreements.

### **Mediation**

Mediation must be offered to help resolve disagreements locally. Parents and young people must consider mediation before they appeal to the Tribunal. If they go to mediation, their LA must go too. Whether parents go to mediation or not does not stop them appealing to the Tribunal.

### **Appeal to the SEN and Disability Tribunal**

Parents can appeal to the First-tier Tribunal (Special Educational Needs and Disability) against decisions made by their LA (England) about their child's special educational needs.

- ➔ For detailed information and forms to complete, see **[www.justice.gov.uk/tribunals/send](http://www.justice.gov.uk/tribunals/send)**
- ➔ **The Encephalitis Society** developed a booklet on 'Appealing to the First Tier Tribunal - special educational needs and disability (SEND)'. Request a copy from our Support Service: **[support@encephalitis.info](mailto:support@encephalitis.info)** or **+44 (0)1653 699599** or download one from **[www.encephalitis.info](http://www.encephalitis.info)**



# HOME TUITION

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Parents have the right to educate their children at home. They may do this by choice or because they feel the school their child is offered is not right for their needs. Sometimes home tuition is provided because a child has been excluded from school due to behavioural challenges developed after having encephalitis.

A disadvantage of home education can be lack of social interaction for a child, and some thought should be given to the importance of this to their general development. However, school is not the only provider of social contact with other children.

The advantages of home education for your child are that it is flexible and personal. There is no problem with falling behind if your child is tired, or unwell, or suffering seizures. Rest and changes of activity can be tailored around your child's immediate needs. This may also be worth considering until you feel your child is ready to return to full-time education.

Joint home and school education (a type of flexi-schooling) might be possible when appropriate for the child. This is an arrangement between the parents and the school where the child is registered at school in the normal way and attends the school only part-time; the rest of the time the child is home-educated.

If education at home is because there is no adequate local provision (e.g. the school cannot take the child, or it has said it is no longer suitable, following the effects of encephalitis) the LA should be made aware.



## FURTHER INFORMATION AND SUPPORT

- ➔ **Home Education UK's** website describes some of the advantages and disadvantages of 'flexi-schooling'.  
**[www.home-education.org.uk](http://www.home-education.org.uk)**
- ➔ **Education Otherwise** is a UK charity offering information and support to home educating families.  
**[www.educationotherwise.net](http://www.educationotherwise.net)**
- ➔ **School House** offers information and support to parents and carers throughout Scotland who seek to take personal responsibility for the education of their children.  
**[www.schoolhouse.org.uk](http://www.schoolhouse.org.uk)**

## PRE-SCHOOL CHILDREN

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After a young child has had encephalitis, it may be difficult to predict what their educational needs will be when they go to school.

- ▶ The assessments and tests may not be accurate (e.g. young children are easily distracted and may not cooperate with tests).
- ▶ Parents often have little time to stand back and reflect on their child's development and possible needs.
- ▶ Their brain is not fully developed at the time of the illness.

If you have concerns about your child's recovery and development, or want to know more about pre-school provision in your area, contact your local Family Information Service (FIS), details of which you can search for online or by contacting your LA.

The law (England) on ‘Setting the standards for learning, development and care for children from birth to five years (under 5s) foundation stage framework (early years foundation stage-EYFS)’ was updated in 2017. It says that:

- ▶ When your child is aged two to three, those caring for and working with your child must give you a written summary of their progress.

*“If there are significant emerging concerns, or an identified special educational need or disability, practitioners should develop a targeted plan to support the child’s future learning and development involving parents and/or carers and other professionals.”*

- ▶ At the end of the school year your child has their fifth birthday, so just before they go into Year 1, their ‘EYFS Profile’ must be written.

*This “provides parents and carers, practitioners and teachers, with a well-rounded picture of a child’s knowledge, understanding and abilities, their progress against expected levels, and their readiness for Year 1. The Profile must reflect: ongoing observation; all relevant records held by the setting; discussions with parents and carers, and any other adults whom the teacher, parent or carer judges can offer a useful contribution.”*

- ▶ You should be put in contact with the key person who will help ensure your child settles in well and has their needs met. This person should keep in touch with you regularly.

*“Providers must have arrangements in place to support children with SEN or disabilities. Maintained schools, maintained nursery schools and all providers who are funded by the local authority to deliver early education places must have regard to the Special Educational Needs Code of Practice.”*





## FURTHER INFORMATION AND SUPPORT

- **Portage** is a home-visiting educational service which offers support, help and advice to families with pre-school children who have special needs in England and Wales.

**[www.portage.org.uk](http://www.portage.org.uk) | 0121 244 1807**

## PLANNING FOR LATE TEENS AND EARLY ADULthood. TRANSITION PLANS

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Colleges and academies must provide for young people with difficulties. They are expected to work with them, meet their needs and get specialist advice on how best to do this when necessary. Young people with an EHC plan can stay in education up to the age of 25, when it is agreed that this is what the young person needs. If they decide to leave school early, they can still have an EHC plan as long as they are still receiving some education or training.

When a pupil or student has an EHC plan, this sets out their long-term aims, as well as the current objectives and detail about step-by-step work. Ideally, this means that planning for the future is already underway. From the age of 14/Year 9, each annual review should consider your young person's next steps in detail, ensure this is happening, and be updated with the latest information. A 'transition plan' must be put in place.

LA staff should work with your young person, along with you and support services, to develop, monitor and adapt the transition plan as necessary. This plan should describe what is aimed for and what they need to achieve this aim. All significant changes in the young person's life should be recorded. The plan must be updated every year.

National Institute of Clinical Excellence Guidelines (NICE) paper 1 sets out what should be provided through this process – quality statements – under the following headings:

1. Young people who will move from children's to adults' services start planning their transition with health and social care practitioners by school Year 9 (aged 13 to 14 years), or immediately if they enter children's services after school Year 9.
2. Young people who will move from children's to adults' services have an annual meeting to review transition planning.
3. Young people who are moving from children's to adults' services have a named worker to coordinate care and support before, during and after transfer.
4. Young people who will move from children's to adults' services meet a practitioner from each adults' service they will move to before they transfer.
5. Young people who have moved from children's to adults' services but do not attend their first meeting or appointment are contacted by adults' services and given further opportunities to engage.



## FURTHER INFORMATION AND SUPPORT

- ➔ **Contact** has comprehensive information about transition in England, Scotland and Northern Ireland.  
**[www.contact.org.uk](http://www.contact.org.uk)**
- ➔ **SNAP Cymru** provides information and advice about transition planning in Wales.  
**[www.snapcymru.org](http://www.snapcymru.org)**
- ➔ **Council for Disabled Children** provides information and shares good practice about transition.  
**[www.councilfordisabledchildren.org.uk/transition-information-network](http://www.councilfordisabledchildren.org.uk/transition-information-network)**

## GOING TO MEETINGS REGARDING YOUR CHILD'S EDUCATIONAL NEEDS

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Meetings with professionals to deal with your child's educational needs and to plan for the future can be daunting and stressful. The following checklist might help you get the most out of these meetings.

- ▶ Make sure you are clear about the purpose of the meeting, its legal status, who will be there and the time allocated; if the time seems insufficient, inform the person who is organising the meeting that more time is needed.
- ▶ Check if your main concerns are on the agenda, or key people are being invited to attend; if they are not invited, inform the person who is organising the meeting.

- ▶ Make sure you are clear beforehand about what outcomes you want from the meeting.
- ▶ Write down your questions, concerns and requests before the meeting.
- ▶ Check you have copies of key documents to take with you (e.g. educational, psychology or other medical reports).
- ▶ When each topic is discussed, make sure you are clear about the outcome (e.g. “What exactly will be done?” “Who do I speak to about this?” “When will we follow this up?”).
- ▶ Make sure you get to discuss every point before the meeting closes; if all the matters that concern you are not covered, ask for a further meeting (or alternative arrangements).
- ▶ Find out who is taking notes of the meeting’s main points and outcomes. Be clear that you should have a copy; follow this up if necessary.
- ▶ Consider taking an independent person to the meeting to support you (e.g. a family member, a friend or a person with experience in dealing with these sorts of meetings).

Your LEA will have a local independent service to support you, often called a **Special Educational Needs & Disability Information Advice & Support Service (SENDIASS)**.

- ▶ If you need to familiarise yourself with your and your child’s rights under the recent legislation on Special Educational Needs & Disabilities (SEND), get help before the meeting.
- ▶ Above all...when asked, be careful not to say “things are fine” when they’re not...



# BULLYING

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Schools need to know about bullying and deal with this immediately!

Bullying is when one person or several people deliberately hurt someone else physically, emotionally, verbally or psychologically. Bullying is serious. It can happen anywhere. If bullying goes on but is not dealt with, it has serious effects.

You may be able to check out the anti-bullying policy and actions of schools when you are choosing where to send your child.

- ▶ Are there clear, detailed anti-bullying policy, posters and information sheets?
- ▶ Are pupils and students actively encouraged to be friendly and supportive?
- ▶ Is supervision during movement about the school and during breaks well-managed?
- ▶ Are pupils encouraged to speak to a specific member of staff if they feel they are being bullied, then listened to and action taken?

You are in the best position to see any change in your child, regarding going to and from school and being with other children, other than the ones resulting from having to cope with the after-effects of encephalitis. If there may be a problem, keep a record of anything that does not seem quite right. Examples might be: facial expression, things being lost, books scribbled on, torn clothes and bumps and bruises.

As children grow up, they become less likely to 'tell it all' to parents. When being bullied, there is often pressure not to tell tales, and indeed threats. Being able to talk together at home is important.

If you think your child is being bullied at any time, in any way, make immediate contact with the person in school you are most often in touch with. If the situation is not being acted on straight away, speak to the Head of the school.

Work with the school to ensure that:

- ▶ your child is and will be safe.
- ▶ the bullying is being dealt with.
- ▶ your child's safety from bullying will be followed up now, next week and in the future.

Options when difficulties are not resolved include:

- ▶ getting advice from your local family support service.
- ▶ following the school's formal complaints procedure.
- ▶ raising the matter with the school governors or equivalent.
- ▶ contacting the LA (or other organisation responsible for the school) for advice and action.
- ▶ considering whether your child needs personal help which may be arranged through their GP.
- ▶ looking into the possibility of changing schools.
- ▶ seeking help from a voluntary organisation that specialises in bullying (strongly recommended).



- ➔ **Kidscape** provides bullying advice, helpline, information, anti-bullying resources and training.  
**[www.kidscape.org.uk](http://www.kidscape.org.uk) | 0845 120 5204**
- ➔ **Contact a Family** has produced a guide 'Dealing with bullying', for parents of disabled children and children themselves.  
**[www.cafamily.org.uk](http://www.cafamily.org.uk) | 0808 808 3555**

Parents may need to be aware that in rare instances the actions of a child with an acquired brain injury might well be interpreted as bullying also. Ongoing communications with the school regarding all the difficulties of your child, and having plans in place to meet their needs, may prevent this from happening.



## FURTHER SUPPORT AND INFORMATION

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- ➔ **Advisory Centre for Education (ACE)** provides free advice services for parents and carers on a range of education and schooling issues.  
**[www.ace-ed.org.uk](http://www.ace-ed.org.uk) | Helpline: 0300 0115 142**
- ➔ **Snap Cymru** all-Wales children's charity working with families, young people and professionals on issues regarding additional learning needs and disabilities.  
**[www.snapcymru.org](http://www.snapcymru.org) | 0845 120 3730**
- ➔ **Enquire** provides an advice and information service for special educational needs in Scotland.  
**[www.enquire.org.uk](http://www.enquire.org.uk) | 0345 123 2303**
- ➔ **Independent Parental Special Education Advice (IPSEA)** gives free legally based advice for parents who have children with special educational needs.  
**[www.ipsea.org.uk](http://www.ipsea.org.uk) | 0800 018 4016**
- ➔ **Nisai Virtual Academy (NVA)** is a virtual school that provides education to children unable to attend mainstream schools.  
**[www.nisai.com](http://www.nisai.com) | 020 8424 8475**
- ➔ **Network 81** gives information, guidance, help and advice on matters such as exclusion, admissions, SEN, bullying and attendance.  
**[www.network81.org.uk](http://www.network81.org.uk) | 0845 077 4055**
- ➔ **'Educating Children with Acquired Brain Injury'** by Sue Walker and Beth Wicks. This book will help teachers find out what an acquired brain injury is and how to maximise the learning opportunities for these children. The book is available on Amazon: **[www.amazon.co.uk](http://www.amazon.co.uk)**

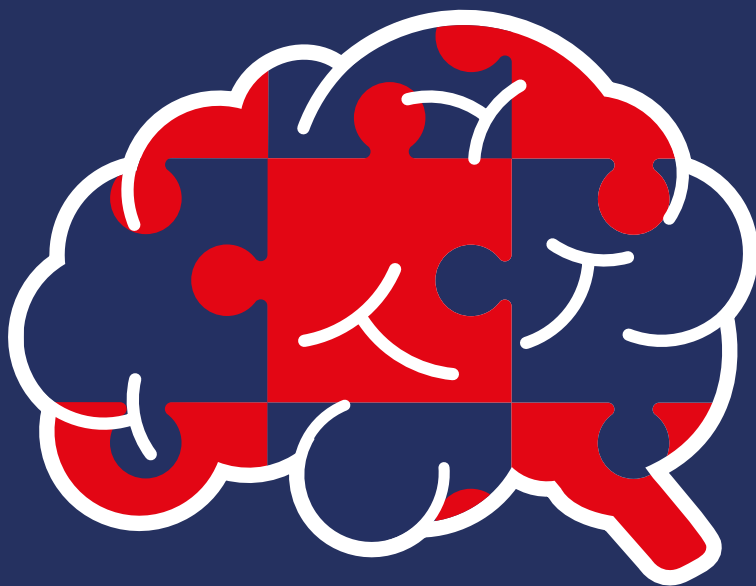


Find us online at **[www.encephalitis.info](http://www.encephalitis.info)**

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# THE ENCEPHALITIS SOCIETY



# WHO WE ARE

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We are an international charity and the only resource of our kind in the world, dedicated to supporting adults and children affected by encephalitis and their families.

## OUR VISION

is a world aware of encephalitis, its consequences and the support available.

## OUR MISSION

is to increase global awareness of encephalitis, saving lives and building better futures

## OUR AIM

To improve the quality of life of all people affected directly and indirectly by encephalitis, by:

- ▶ Providing support and information
- ▶ Raising awareness
- ▶ Promoting and collaborating on research

## OUR KEY MESSAGES TO YOU

You are not alone, we are encephalitis experts and can provide the support, advice, information and training you need. Encephalitis is serious and indiscriminate - we must all act now to raise awareness of this devastating condition.



Find us online at [www.encephalitis.info](http://www.encephalitis.info)

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## HOW WE CAN HELP YOU

- ➔ **Support Service** – [support@encephalitis.info](mailto:support@encephalitis.info) | +44 (0)1653 699599
  - ➔ **Website** – Containing factsheets, books, booklets and leaflets which cover various issues regarding encephalitis.  
[www.encephalitis.info](http://www.encephalitis.info)
  - ➔ **Connect Newsletter** features the Society's activities, news, events etc. You can download a copy from our website.
  - ➔ **Team Encephalitis Support Volunteers** who are trained to provide support to people with encephalitis and their families.
  - ➔ **Residential weekends, meetings and events** for all the family, details of which can be found on our website.
  - ➔ **Connections Scheme**, which has been set up to enable our members to make contact with others in similar situations to themselves. Further details from our website.
  - ➔ **Provision of training and education** about encephalitis and its effects to interested parties (e.g. health, social care and education professionals; schools; GPs; workplaces etc).
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## HOW YOU CAN HELP US

- ➔ Become a member of the Society. Membership is free and helps us to raise our influence among the general public and medical profession. Call us on +44 (0)1653 699599 or become a member online at [www.encephalitis.info](http://www.encephalitis.info)
- ➔ Be part of our Team Encephalitis Volunteers and provide support to other people. Email us on [mail@encephalitis.info](mailto:mail@encephalitis.info) or call us on +44 (0)1653 692583 to find out more info.
- ➔ Take part in World Encephalitis Day – **22nd February** each year.
- ➔ Connect with us on social media – Facebook, Twitter & YouTube.
- ➔ Make a donation – Call us on +44 (0)1653 692583, email our fundraising team on [fundraising@encephalitis.info](mailto:fundraising@encephalitis.info)

Support line +44 (0)1653 699599





**ENCEPHALITIS**  
**SOCIETY**

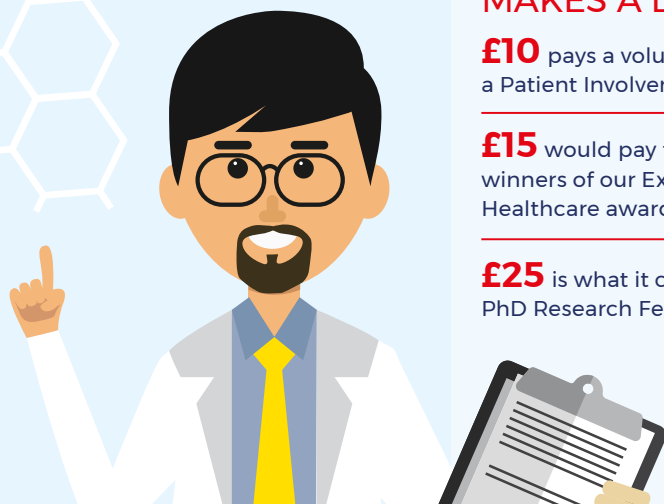
*Saving lives through research*

# ENCEPHALITIS RESEARCH



Research into encephalitis is important and we are committed to increasing the amount of research we fund and take part in so that people affected by encephalitis can benefit from scientific advancements sooner. We are focussing on research that looks at early diagnosis, the best ways of treating people and recovery and rehabilitation as we know that these areas will give us the best chance of saving lives and reducing the likelihood of brain injury.

A small monthly gift towards our research activities and other vital work can make a huge difference to the lives of people affected by encephalitis and their families.



## HOW YOUR MONEY MAKES A DIFFERENCE

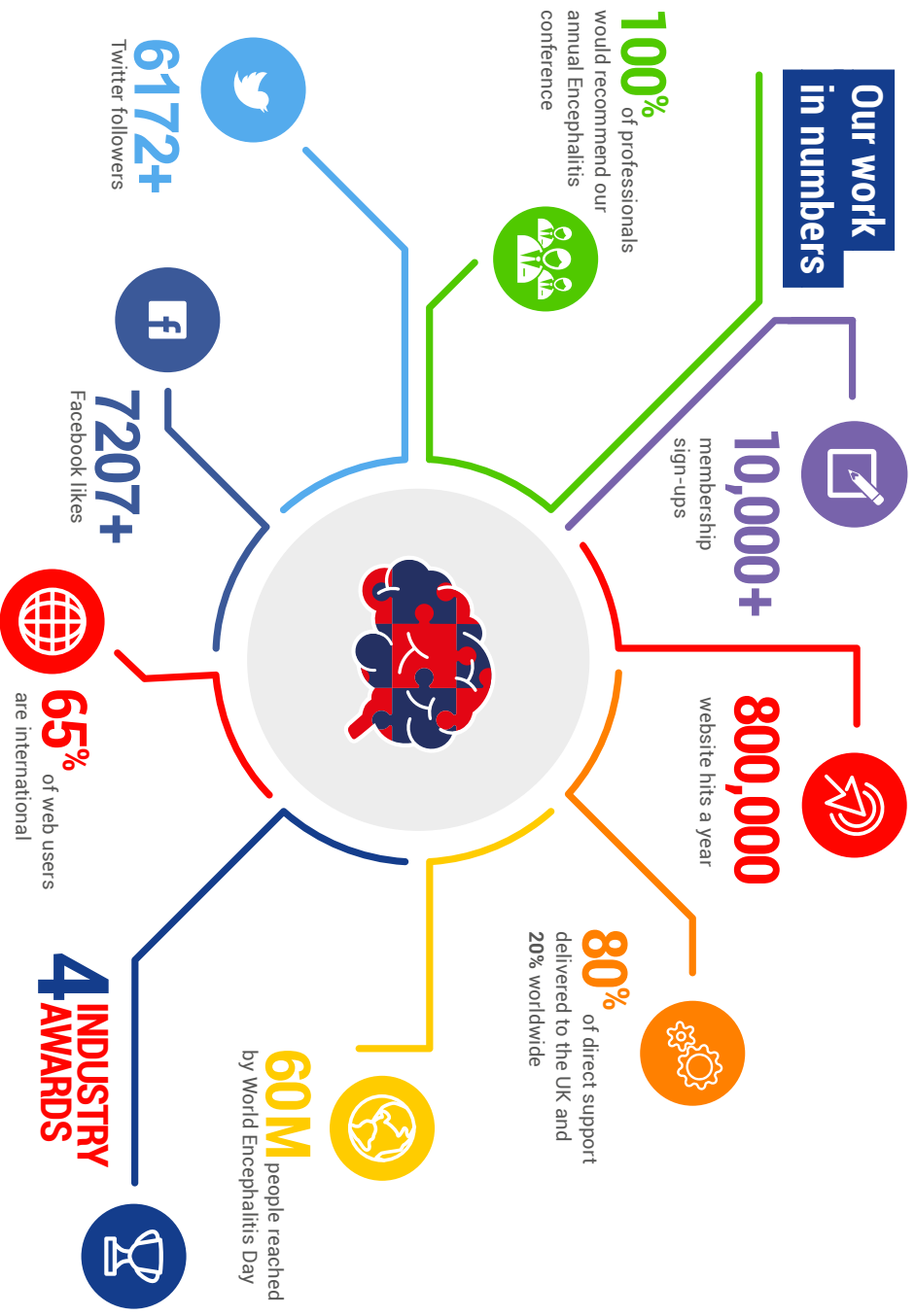
**£10** pays a volunteers' expenses to attend a Patient Involvement Panel.

**£15** would pay for the glass trophies that winners of our Excellence in Encephalitis Healthcare awards are presented with.

**£25** is what it costs for an hour of our PhD Research Fellow's time.

[www.encephalitis.info/donate](http://www.encephalitis.info/donate)

e: [fundraising@encephalitis.info](mailto:fundraising@encephalitis.info) t: +44(0)1653 692583





# ENCEPHALITIS SOCIETY

*The brain inflammation charity*

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## SUPPORT TEAM

+44 (0)1653 699599  
support@encephalitis.info

## ADMIN

+44 (0)1653 692583  
admin@encephalitis.info

## FUNDRAISING TEAM

+44 (0)1653 602062  
fundraising@encephalitis.info

## PRESIDENT

Professor Barbara A Wilson OBE

## VICE PRESIDENTS

Richard Lockwood  
Kika Markham  
Baroness Anne McIntosh  
Tom Naylor-Leyland  
Tiggy Sutton  
Robert Sutton

## AMBASSADORS

Rebecca Adlington OBE  
Mathew Bose  
Tonia Buxton  
Susannah Cahalan  
Aliko Chrysochou  
Simon Hattenstone  
Charlotte Leeming

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## The Encephalitis Society

32 Castlegate, Malton,  
North Yorkshire  
YO17 7DT, United Kingdom  
[www.encephalitis.info](http://www.encephalitis.info)

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The Encephalitis Society is the operating name of the Encephalitis Support Group  
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