Encephalitis International
The brain inflammation non-profit

Encephalitis in children

A Guide

Encephalitis in children – a guide

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Contents

> *"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."*
> (Parents' feedback)

> *"The book is great and it would have been great for the hospital to give us it when we were in hospital with T as we didn't know anything about encephalitis. It is great to have all the information in one pack."*
> (Parents' feedback)

About this guide

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 also 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.

No two children have the same course of the illness or the same after-effects. The outcomes of encephalitis are different for every child; some children may make a good recovery, while others might acquire mild or more severe difficulties. We have tried to encompass most situations and experiences of encephalitis in children. Therefore, readers should be aware that not all the scenarios in this guide will necessarily apply to your child.

Some of the content may be upsetting to read and we urge readers to consider the impact this may have before reading. Please consider skipping sections if you think they may be distressing and make sure you have support available if needed.

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

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Your input has been invaluable and has enabled us to produce a very useful resource for families of children with encephalitis.

DISCLAIMER

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 professional. You must obtain specialist advice before taking, or refraining from, any action based on 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 healthcare professional and/or our office on +44 (0)1653 699599 or support@encephalitis.info

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 or call +44 (0)1653 699599.

SECTION 1:
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 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 regardless of age, sex, nationality or culture.
- Encephalitis can be caused by an infection (e.g., virus, bacteria, fungus) or by the immune system attacking the brain in error. In many cases, a specific cause is not found despite extensive testing.
- The variety of causes and the presentation, which may include a rapid onset of symptoms that are often dramatic, may make the management of this condition a challenge for doctors.
- Early and correct diagnosis and treatment is likely to improve outcomes.
- The length of the 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.
- Children may appear not to have many effects after the immediate injury/early recovery, but later challenges can present as the brain develops. This is known as the 'sleeper effect'.

TYPES OF ENCEPHALITIS

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, flu virus, enteroviruses, parechovirus, measles virus, West Nile, Japanese encephalitis, La Crosse, St. Louis, Western equine, Eastern equine, tick-borne viruses, chikungunya). Any virus has the potential to produce encephalitis, but not everybody who is infected with these viruses will develop encephalitis. Some of the infections that can lead to encephalitis are contagious (e.g., measles), but encephalitis is not contagious.
- Bacteria (e.g. *Streptococcus Pneumoniae* or *Mycoplasma Pneumoniae*) can also cause encephalitis.
- Occasionally infections such as fungus, parasites, and amoebas can cause encephalitis.

Autoimmune encephalitis

- Some types of autoimmune encephalitis, such as acute disseminated encephalomyelitis (ADEM), occur following an infection or after 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 and/or cerebrospinal fluid. Antibodies, also called immunoglobulins, are produced by the immune system to identify and help remove foreign antigens such as viruses and

bacteria. In autoimmune encephalitis these antibodies attack the body's own healthy cells in the brain, which is mistakenly perceived as foreign or abnormal.

- In children the most common antibodies found are for the NMDA receptor and MOG protein. LGI1, CASPR2, GAD, AMPAR, and GABAR antibodies have also been reported but in much lower numbers. It is not always clear why people with autoimmune encephalitis produce these antibodies.
- Sometimes the antibodies can be generated by a tumour (benign or cancerous) or following a viral brain infection (e.g., herpes simplex virus encephalitis).

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

Infectious encephalitis frequently begins with a flu-like illness (e.g., headache, high temperature, lethargy). 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 or neck stiffness.

Autoimmune encephalitis often has a longer onset. Symptoms will vary depending on the type of encephalitis-related antibody but may include confusion, altered personality or behaviour, psychosis, movement disorders (movements the child cannot control), seizures, hallucinations, memory loss, or sleep disturbances.

In babies, the symptoms may be non-specific at the beginning and include poor feeding and lethargy.

DIAGNOSIS OF ENCEPHALITIS

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, bacteria 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 lifesaving.
- **Brain scans** such as computerised tomography (CT) which uses X-rays or magnetic resonance imaging (MRI) based on magnetic fields to scan the brain in cross section to show the extent of any inflammation. This helps exclude other neurological disorders like brain tumours and strokes (a 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). Some test results may take some time to come back.
- An **electroencephalogram (EEG)** may help confirm a diagnosis of encephalitis by recording the slowing of usual electrical activity in the brain. EEGs are frequently used in diagnosing 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., the patient is agitated). Nevertheless, it is important that investigations are carried out as soon as possible and repeated if needed as prompt diagnosis can reduce mortality and improve outcomes.

TREATMENT OF ENCEPHALITIS

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 (against fungus) drugs. 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. Aciclovir is the most frequently used antiviral drug. It is effective against herpes simplex virus (HSV). Aciclovir is usually given three times a day by direct infusion into the veins. The treatment with Aciclovir is usually continued for 14-21 days for confirmed HSV infection 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.
- Other immunomodulatory drugs as part of a second- or third-line therapy if needed (e.g., rituximab, bortezomib, tocilizumab).

Prompt recognition and initiation of these immunotherapies offer a good chance of substantial recovery in most children.

Some of the drugs have potential side effects but also important benefits as they reduce the inflammation of the brain. The main side effect in children taking corticosteroids or other immune treatments will be immunosuppression and resulting increased risk of other infections. Your doctor will explain what to do if your child is taking any of these medications or becomes ill at home. Children taking corticosteroids cannot have some types of immunisations. Please make sure any other healthcare professional involved with your child knows they are taking corticosteroids. In each patient the risk-benefit balance will vary and is carefully considered on an individual basis by their medical team.

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 and sedatives to reduce agitation is required. In addition, antidepressants may be prescribed for any psychiatric conditions which can arise, like anxiety or depression. 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 by mouth must be stopped for a while and substituted with a nasogastric (nose to stomach- NG) or orogastric (mouth to stomach) tube.

Prognosis of encephalitis

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 changes (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.

RELAPSES OF ENCEPHALITIS

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 are worsening symptoms despite on-going treatment (Aciclovir), it may be due to insufficient doses (often based on the patient's body weight) or other complications of encephalitis which may have developed, such as seizures.

In some patients (though this is rare) in whom there is a recurrence of infectious encephalitis early after stopping treatment (Aciclovir), 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, there are rare cases with some patients where there may be an early recurrence of encephalitis after stopping treatment that is due to inflammation even after the virus has cleared. Recognition of potential relapses requires ongoing vigilance from the patient's family and should be quickly reported to the patient's neurologist.

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 significant, treatment is often offered over a longer period. Despite treatment a small number of patients will still relapse.

DEATH FROM ENCEPHALITIS

Unfortunately, despite improvements in diagnostics 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, disease course, and timeliness of diagnosis.

When death occurs, it is usually because of severe brain inflammation. The brain is wrapped in a bony shell (the skull) and when the brain 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 is likely to be needed.

- Encephalitis International has produced the factsheet ‘Bereavement’ which features various resources which we hope might be helpful.

  This factsheet can be downloaded from our website www.encephalitis.info or requested from our Support Service on +44(0)1653 699599 or support@encephalitis.info

ENCEPHALITIS INTERNATIONAL ANIMATION SERIES

Our Understanding Encephalitis animation series support and inform the encephalitis community, and raise awareness of encephalitis amongst the general public. The animations look at the diagnosis, symptoms, treatment, effects, recovery and rehabilitation, and the wider impact of encephalitis.

- What is encephalitis?
- What are the symptoms of encephalitis?
- How is encephalitis diagnosed?
- How is encephalitis treated?
- What are the effects of encephalitis?
- What happens during encephalitis recovery?
- What to do at home for encephalitis recovery?
- How does encephalitis affect families and carers?
- Encephalitis and mental health
- Encephalitis in children: the impact on siblings

All our animations are available on our YouTube playlist, or you can find and watch each film separately on our website www.encephalitis.info/animations

The animations are also translated in various languages.

SECTION 2:
BEING IN HOSPITAL

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 might become suddenly and seriously ill and surrounded by machines and doctors.
- Seeing your child like that can be a very traumatic experience for the whole family.
- An acquired brain injury (ABI) can be a consequence of encephalitis; it is often 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/other children's needs when looking after your sick child; you can't help them if you don't take care of yourself/your family.
- It is good practice to have everything in place at home before discharge from hospital (e.g., care, adaptive equipment if required).
- Any concerns you have about the hospital stay need to be raised with the hospital staff in the first instance.

MEDICAL MANAGEMENT

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, blood pressure, level of awareness, respiration rates, oxygen levels, blood tests, and input and output of any fluids.

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

Your child may need:

- A catheter inserted in the urinary bladder to help pass urine in place of using the toilet.
- A tube into the nose (nasogastric tube) 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 when necessary.
- A ventilator to help with their breathing.
- Bedrails to prevent injury.

Doctors and nurses need to obtain your consent before any procedure, investigation or treatment is undertaken if your child is below the age of consent. Prior to requesting consent, they need to explain to you in detail what, why, and how they are going to manage your child.

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 affecting 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 be able to control it. They can also be oblivious to the impact their behaviour is having on those around them.

Observing your child in 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/family member. Most will probably 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.

Actions 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 and familiar objects from home.
- Try and talk to your child and explain what has happened if 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 might deal with this situation differently from 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 this.
- Chaplaincy services also exist in hospitals for religious support.
- 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 or 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 ICU or receiving long term support. So, it is advisable to ask the hospital.
- Contact Encephalitis International's Support Service +44(0)1653 699599 or support@encephalitis.info

DISCHARGE FROM HOSPITAL

Each hospital will have its own policy and arrangements for discharging patients. It is possible, however, 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 discharge should be in place to meet the child's needs. Parents may find it useful to invite a staff member from their child's school 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.

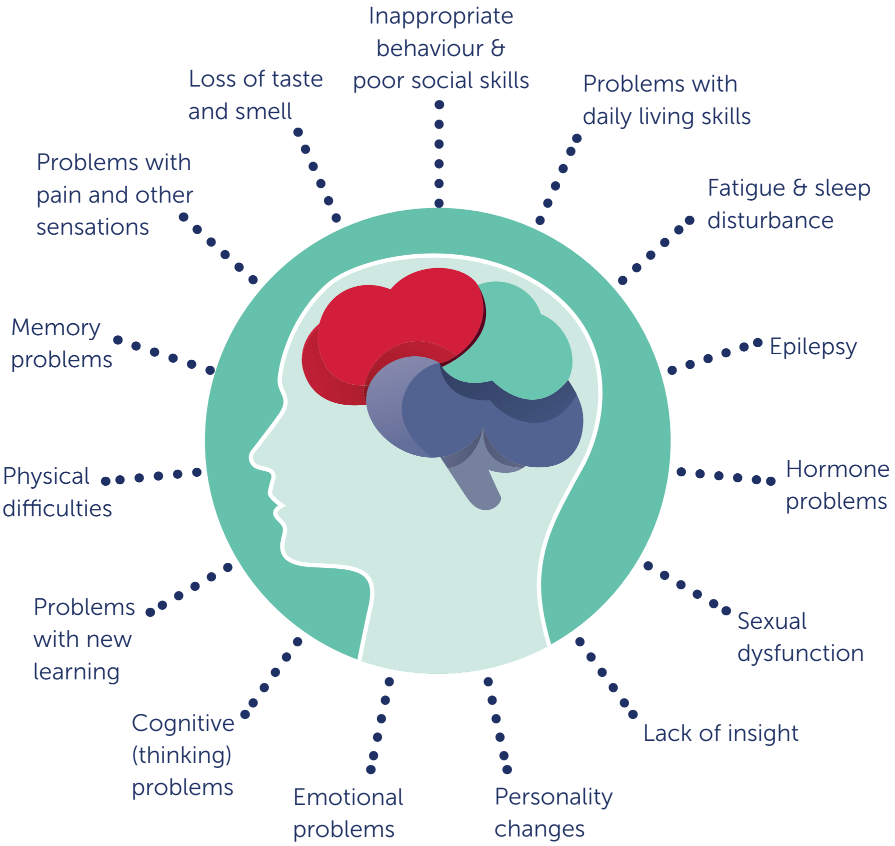
Sometimes, the difficulties children are left with may not appear to be significant and it may simply be assumed that the return to former life will not be problematic. However, problems can become more apparent when they are returning home and to school. It is therefore important to secure some method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

Where the needs of your child are more complex, detailed planning might be required, for example, for equipment or to ensure that rehabilitation programmes can be continued at home, or for additional social care needs for which a social worker may become involved.

If your child will soon become an adult, special attention and a plan to manage transition to adult services are required.

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/family doctor should receive a discharge letter from the hospital. However, it may be useful to inform the GP/family doctor about the discharge in case the letter has not yet arrived and discuss any immediate needs if required.

OUTCOMES AFTER ENCEPHALITIS



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SECTION 3:

THE EFFECTS OF ENCEPHALITIS

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

Key facts

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

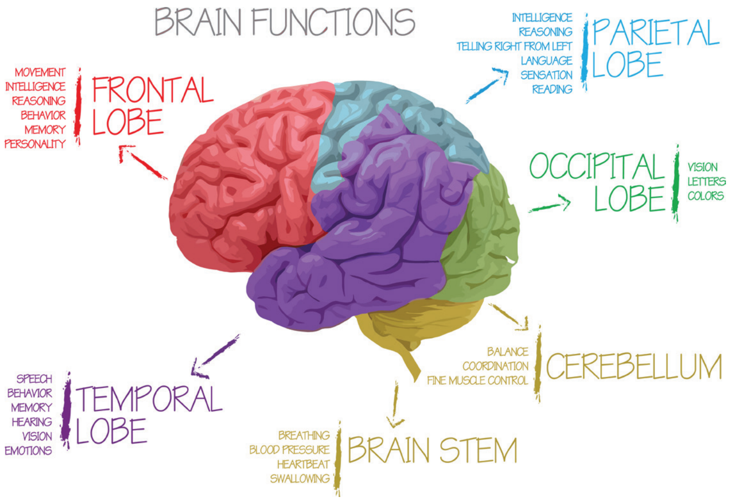
- **Unique**
  No two cases of encephalitis will have an identical outcome.
- **Hidden (Invisible)**
  The child may look exactly like they did before the illness, with effects being cognitive, behavioural, emotional and/or social rather than physical.
- **Lifelong**
  The effects of the illness can last forever. The child must be supported to learn to live and cope with them.
- **Sleeper effect**
  While some issues might present straight away, other difficulties might not come to light until much later in a child's development, sometimes years later.
- **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 be doing well in school in terms of achievements and milestones and/or comparing to others, but perhaps not to the same level as before the illness.

HOW THE BRAIN WORKS

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 can be divided into 4 different areas called lobes, each of which controls different functions. Damage to a certain region in a lobe can therefore result in particular symptoms. The frontal lobe is involved in decision making, personality, and movement. The parietal lobe is responsible for sensation and the occipital lobe for vision. The temporal lobe is responsible for memory and aspects of language. On a smaller scale, the brain and each of its lobes is made up of billions of nerve cells, otherwise known as 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.



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 viral encephalitis, a virus enters the brain and hijacks healthy brain cells to use their apparatus to replicate itself, damaging these cells in the process. In both post-infectious and autoimmune encephalitis, the immune system itself causes damage to brain cells, as it recognises components of the brain as a threat and mounts an attack against them in error. In all forms of encephalitis, the immune system, although well intended, can contribute to overall inflammation.

AGE AT DIAGNOSIS

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 to or 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) might begin to emerge.

  These difficulties might 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 going to work until you turn on the switch.

COGNITIVE DIFFICULTIES

Memory problems

Your child's ability to remember might 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 aspects might be affected or impacted 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 might 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 doing it. Or they may find difficult remembering names, faces, places or directions. It is important, therefore, to understand your child's specific difficulties to help them.

Attention and concentration

Your child's ability to concentrate may be reduced or they might be very distractible, compared with other children of the same age. They may not be able to divide their attention 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 might 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 when teachers move 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 a task 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 know when to stop doing it; to monitor our behaviour and know what behaviour is appropriate in different situations.

Difficulties in this area may present as subtle or extreme so that your child may appear more impulsive, totally disorganised or unable to tackle even the simplest of tasks. 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

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. They may instead recover the ability to speak well but develop more subtle language difficulties. 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 and 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, it 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

Encephalitis may impact your child's emotions with the child having difficulties 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 a 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, as well as 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 that this may 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

Some physical disabilities such as hemiplegia or hemiparesis (weakness on one side of the body) or ataxia (unsteadiness or tremor) are more visibly apparent. This can help to highlight adjustments that need to be made on the demands and expectations of your child. Other physical changes, however, may be less apparent. Your child may have a general problem with co-ordination and balance or know what they want to do but have difficulty putting a sequence of movements together. As a result, your child may 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 bowels functioning. The child may need support in trying to regain those functions.

FATIGUE

Both physical but especially neurological 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 and impact significantly on your child's performance.

Whereas children may normally tire gradually, your child may suddenly reach a threshold where they are over-tired 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

Sleep problems can be partly due to the disruption of your child's normal routine while in hospital and partly because of the inflammation on the brain. As babies grow older, they develop a type of chemical clock in their brain which encephalitis can disrupt. This could lead to sleeplessness, sleeping at odd times or sometimes sleeping too much. Of these, sleeplessness often causes the most problems for parents, especially if your child is also overactive in the daytime. Drugs are sometimes utilised to help with sleep. However, some of these drugs may have the opposite effect in susceptible children. This is not to say that they must never be used, but 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

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 (hyperacusis), sometimes extreme, to types of sound. This can also impact on the child's ability to focus, and it can exacerbate neurological fatigue.

It may also be that your child has difficulty interpreting or processing information that they see or hear if there are items within their field of vision which are distracting them or additional noises in the background.

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

Seizures can be both a symptom of encephalitis and a consequence 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 will happen, 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 eliminate all seizures).

DIFFICULTIES WITH SEXUAL FUNCTIONING & HORMONES

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

- A physical disability can have a direct impact on the young person’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 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 such that a young person doesn't reach physical maturity at the usual age range; growth, most commonly short stature; periods, which may stop in young girls; and a young person's sex drive (libido), which 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

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 recovery 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 might tend to be impulsive, irritable, and even aggressive, which can affect friendships.

If they have problems with memory or 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

A child's recovery depends on the degree and type of the brain injury left by encephalitis, the support from services, professionals, and school, and the involvement of family in their recovery.

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, assessments need to be undertaken several times across a child's developmental lifespan.

GUIDELINES FOR RECOVERY

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 adjustment required.

The brain takes much longer to recover from an injury than other parts of the body. Unlike other parts of the body, you cannot see your child’s brain repairing and might assume all is back to normal when in fact some areas are still in recovery. There is no set timetable for recovery, nor a sure answer from specialists of the level of recovery: every experience is different. 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.

Pacing

An initial period of rest and quiet will aid your child’s recovery. Try to avoid information overload and too much interaction with noise and visual stimuli, which could set back the process of recovery. Neurological fatigue after an acquired brain injury (ABI) may be misunderstood by those around your child. It is therefore important that clear information is provided to those who need to know.

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.

Gradual return to school or nursery

Plan a gradual return to school/nursery. Try not to worry about your child getting behind at school. They will catch up 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 can impact on the recovery 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 issues may only present 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, experts from health, social care, education, and the voluntary agencies can 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 it is possible for their age and level of understanding what happened to them, what to expect in the future, and what they can do to help themselves.

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

  You can order these books from our website www.encephaltis.info

WHAT IS REHABILITATION?

The main aim of rehabilitation is to try and help your child develop new skills, habits, and strategies for the future. The aim is to increase their independence as much as possible. It may be hard for parents to understand this, but rehabilitation does not cure your child and/or necessarily 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. School tends to be the rehabilitation setting for many children and young people. There are some instances where post-acute encephalitis requires hospital rehabilitation, or a specialist rehabilitation centre or a community service. Some may require more complex long term specialist support. At times, the child might 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. Goal-based activities/therapies aim to help families to set realistic achievable goals - this is the key in rehabilitation, and this often helps parents, children, and professionals to be on the same page.

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 to alleviate anxiety. Nevertheless, 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.

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.

The role of psychology

There are two main psychology services available. One is educational psychology and the other is clinical psychology. Both services can play an important role in helping your child progress. Psychological care providers can also aim to empower parents to understand and recognise why their child is behaving as they do.

Educational psychologists specialise in working with children and young people aged 0 to 25, helping to find ways of improving behavioural, 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.

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 for overcoming difficulties. Children might also receive individual psychotherapy and counselling to help them understand what has happened to them and the way it makes them feel.

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. They can advise on ways to manage those difficulties.

Various professionals often work together in multidisciplinary teams to provide support following acute brain injury both in the community and in outpatient settings. However, in some regions the health professionals work independently of each other.

It is advisable to speak with your child's GP/family doctor or neurologist 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.

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.
- Ask for copies of written reports and assessments.
- 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 for you and your child. Sometimes the goals you have may not be the same as the goals medical professionals have. This may lead to difference of opinion, but in the end you all work towards the same goals, so it may need so compromise might be needed.
- 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 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 to the meeting. It may be worth asking them to make notes during the meeting as you may well forget some of the things that are discussed. Sometimes the teams will provide summarised letters.

- Meeting medical 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.

PRACTICAL STRATEGIES FOR MANAGING THE AFTER-EFFECTS OF ENCEPHALITIS

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 a brain injury does not 'get better if you try harder', and this is true particularly in the early phase of recovery. Instead, it is recommended to help your child to use their remaining memory abilities more effectively.

Try to avoid asking children to guess an answer as, if they give the wrong answer, they may always remember the wrong answer. For example, if a child who has had encephalitis cannot read a word and is asked to 'have a guess' and then gives the wrong answer, they may 'over-learn' that response at that point and always make the same mistake again.

Instead of guessing, use 'errorless learning' which means exposing children to the answer several times before they are asked to remember it.

Children with attention problems because of encephalitis cannot simply improve their attention at will. Children after encephalitis can experience more difficulties with processing information. They need extra help in school to ensure that their learning is not impaired due to these difficulties.

Other practical strategies:

- Use reminders, checklists, labels, and colour codes.
- Use repetition and reinforcement of information and cues to aid their recall.
- Use simple instructions.
- 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 sufficient time for the child to understand what they have been told and how to respond appropriately.
- Allow them more time to get ready if there are changes to plans.
- Establish a routine.
- Keep the environment well organised, quiet, and calm.
- Help them prioritise activities.
- Break up activities/tasks into small steps.

Managing fatigue

It might require careful fine-tuning to establish how best your child copes with their fatigue. While the aim for activities is to learn, periods of timeout may be required in some instances to de-stimulate.

- Try to get your child to rest before they get tired, rather than having a rest after they are overtired as this will increase recovery time.

- Be aware of the imminent onset of fatigue and try to learn the signs of it.
- Keep a fatigue diary.
- Your child might not always know when they need a rest and may need reminders.
- Facilitate the family members and friendship group's understanding of 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 in 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 sleep

Managing a child's sleep after encephalitis is crucial for their recovery and overall well-being. Here are some important strategies for managing a child's sleep under such circumstances:

- Establish a consistent sleep schedule. This can regulate your child's circadian rhythm and establish a routine.
- Create a calm and comfortable sleep environment. Keep the bedroom quiet, dark, and cool for optimal sleep conditions.

- Limit stimulants. Minimise your child's consumption of caffeine and sugar, especially in the hours leading up to bedtime.
- Limit screens. Avoid screen time (TV, computer gaming, smartphone) before bedtime, as the blue light can disrupt sleep.
- Address anxiety. Use relaxation techniques, such as deep breathing exercises or meditation, to help your child relax before bedtime.
- Monitor medications. Some medications prescribed for brain injuries may affect sleep patterns. Discuss any concerns about medications with your healthcare provider and adjust dosages or timings if necessary.
- Assess and communicate. Continuously evaluate your child's sleep patterns and discuss any improvements and concerns.

Managing sensory overload

Often children struggle to regulate their sensory stimulus/response. For example, noisy environments can trigger emotional outbursts or coping mechanisms. It is important to acknowledge this problem. Making family members aware of any management strategies will be of help.

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 have lost the cognitive skills needed to respond in this way. They may not be able to:

- Understand cause and effect.
- Consistently remember what they must do to avoid punishment or to earn reward.
- Understand that good behaviour may be rewarded later.
- 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 and 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 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’.

SECTION 5:

THE IMPACT OF ENCEPHALITIS ON THE FAMILY

This section focuses on the different ways encephalitis might affect families and highlights the main issues for the family with different options for support. The way a family deals with the difficulties brought 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 point you towards 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.
- Disability following encephalitis can be hidden and those around you might 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

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 delays and uncertainties 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 your child's survival, whilst brothers and sisters see a sudden and prolonged focusing of attention on the sick child.

Emotions might 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 might think that everything is back to normal and do not understand your concerns and difficulties.

Sometimes there may be feelings of shame brought 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 actions/inactions become 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 for short bursts is a natural way to respond to difficult situations but excessive or prolonged stress can cause illness. You might experience physical symptoms such as headaches, nausea, sweating, indigestion, and palpitations.

Prolonged stress might lead to feelings of anxiety, fear, anger, frustration, and depression. You may find your behaviour changes too in a way 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

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

Acknowledge 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 hard. However, this may help you adjusting to 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 your child does/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 other people's similar experiences. Learn to take one day at a time. If you are having a bad day, remember it is temporary and it can get better.

If you are the main person providing care, you may suddenly find that people are calling you the 'carer' where 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 may need support.

Emotional support and counselling

The aim of emotional support is not to solve problems but instead reduce stress and improve mood. 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 negative impact on their emotional well-being. Don't be afraid to say 'no' sometimes and avoid people who raise your level of stress.

Other people may need professional help such as 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.

Some family members develop a severe emotional response and depression might begin to dominate their lives. If you or a member of your family is struggling with these emotions, consult your GP/family doctor 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 stories of other people who have experienced encephalitis is also often useful. Other people's stories 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 stories. 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 result. 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 recovery than in the immediate aftermath of diagnosis with encephalitis.

- Our website - 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 healthy also helps.

Try and do at least one thing a week that is just for you – coffee with friends, gardening, a movie, listening to music, 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 and 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.

Some people can benefit from religious social support because of their religious beliefs and participation in religious activities in the form of both emotional and physical support.

If your child has a disability, they 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 and also an employee, you may be entitled to support such as financial help or flexible working arrangements.

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/family doctor, consultant or health visitor on your side – get them to write letters for you explaining what you need and why you need it.

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 co-ordinated 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, so you may have to jump hurdles and 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 seems hardly 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 International runs Connections Scheme, through which you can be put in touch with other people going through similar experience.
  www.encephalitis.info | +44 (0)1653 699599
- Encephalitis International hosts various events and peer support gatherings to connect with other people
  www.encephalitis.info/events
  www.encephalitis.info/online-support-meetings/

FAMILY DYNAMICS

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 might 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 the 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, who can talk to—and cry with—each other in safe, confidential surroundings, make it easier to cope.

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 challenging, making it difficult to arrange evenings out or take breaks from the caregiving responsibilities..

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

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 such as family, friends, teacher, school councillor. 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 ok 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.
- Spend some focused time with each sibling. It doesn't need to be long - even giving 10 minutes of your full attention every week can make a difference to your child.

Further support and information

- Encephalitis International produced two information resources '***Gilley the Giraffe who changed'*** and ***'Medikidz***' which may help siblings understand what their loved one goes through. The books are available to order from our website www.encephalitis.info or from our office, mail@encephalitis.info or +44(0) 1653 692853

Grandparents and the wider family

Whether help and support are 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.

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 offer of support and advice, not knowing when to take a step back.

SOCIAL OPPORTUNITIES FOR A FAMILY

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.

"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 your child is too hard to include. 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 with 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 local 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 or equivalent for details.

- Encephalitis International organises social events for families, where parents and children get together, share experiences, and have fun in a comfortable and understanding environment. Join Encephalitis International and we will keep you up to date with the calendar of events. www.encephalitis.info/keep-in-touch/

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.

Encephalitis International 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. 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 because 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.
- If bullying happens raise this immediately with the school.

GUIDELINES FOR RETURNING TO SCHOOL

Too ill to go to school

When children are in hospital, parents/medical professionals should tell their school.

The school 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 may be keen for your child to return to school and for family life to get back to normal. It is important to realise that 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, rest and not be overloaded with activities.

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 over 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. When contacts are arranged, make sure that:

- friends and colleagues have knowledge about their friend, the illness, and its effects
- request the contact to be short because of the possibility of 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. In other times, it may become very clear that they will need a specialist school or specialist unit.

Plan for a gradual return

After having had encephalitis, many children look physically as though they have fully recovered, but remain unable to manage a whole school day or complete homework for quite some time. You and the school 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 in the 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 is aware that requirements might change.

Repeating a school year

Some pupils may be required 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 etc.
- 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. 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 Encephalitis International'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 the paediatrician, psychologist and/or therapist) that set out difficulties and needs clearly.

PROBLEMS IN SCHOOL AND WHAT CAN HELP

The impact of an Acquired Brain Injury (ABI)

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 might be having.

Such problems include:

- tiredness (cognitive fatigue rather than physical fatigue)
- problems with concentration especially in a noisy classroom
- difficulty working at speed
- difficulty following instructions
- difficulty changing tasks
- difficulty refocusing on a new issue
- poor memory
- sensitivity to sound
- difficulty remembering places and directions

- inappropriate behaviour
- lack of insight into their difficulties
- not being able to get ready for specific activities
- making misjudgements
- difficulty changing routines
- not understanding jokes
- forgetting what they were doing
- physical restlessness
- disruptiveness
- appearing to be daydreaming
- poor social awareness

Difficulties after encephalitis can lead to isolation, as others may not understand the cause of your child's changed abilities and behaviours. The child's confidence may diminish, 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 because 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 as 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 accepting excuses for late work" 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 school years, and the day-to-day challenges of being in a large secondary school are considerable.

What can help?

Support in school

When a child needs additional support, 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.

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 because 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.

HOME TUITION

Depending on location, parents may 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, unwell, or suffering seizures. Rests and change 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.

BULLYING

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 policies, 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 best positioned to notice any changes in your child's behavior related to going to and from school, interacting with other children or coping 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 communicate with parents. When being bullied, there is often pressure not to tell tales. 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:

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

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.

SECTION 7:
TRANSITION

Transition from childhood to adulthood involves major changes for young people affected by encephalitis. Support for navigating healthcare, school, finance, and relationships is crucial during this life stage.

Key facts

- Transition can disrupt patient-physician relationships.
- Medication and rehabilitation adjustments are common during transition.
- Access to multidisciplinary healthcare teams is crucial for comprehensive support.
- Disparities in transition services exist regionally, requiring thorough investigation of resources.
- Assessing capacity for informed decisions is essential, especially if brain health is affected.
- Education paths after age 16 include mainstream school, special school, college, or work-based training (apprenticeships).
- Transition impacts personal relationships; open communication and understanding are paramount.

HEALTH AND SOCIAL CARE

During the transition from childhood to adulthood, young people with encephalitis may encounter various changes in their health and social care journey. In principle, the transfer from paediatric to adult care should occur at 16 years of age, while in other cases, the shift to adult services is typically expected by the time they turn 18.

One significant change young people may experience is a transition from long-term paediatric care to an adult healthcare provider. This transition can happen with or without prior notification or preparation, which can sometimes be challenging for the young person and their family. While the shift to an adult healthcare provider is necessary as the individual enters adulthood and requires specialised care tailored to their changing needs, it can disrupt an established patient-physician relationship and familiarity built over the years.

In addition to the change in healthcare providers, young people may also experience modifications in their medication regimens and other aspects of their health and social care. As they transition to adult services, there might be adjustments in medication dosages, formulations, or even changes in the types of medications prescribed. This is to ensure that the treatment aligns with the specific needs and considerations of adulthood. The same applies for physical rehabilitation programmes.

Furthermore, the transition process may involve addressing additional health and social care needs beyond medical treatment. This could include the involvement of multidisciplinary teams, such as neurologists, psychologists, therapists, and social workers, to provide comprehensive support and interventions tailored to the individual’s evolving requirements.

To ensure a successful transition, it is crucial for young people and their families to collaborate closely with their healthcare providers. Clear communication, comprehensive care planning, and ongoing support are essential to facilitate a smooth transition and to address the unique challenges faced by individuals with encephalitis as they navigate the changes associated with entering adulthood.

Unfortunately, disparities in services for the transition to adulthood exist across different geographic regions. The availability and quality of support services may vary depending on the specific locality or country. Therefore, it is highly recommended to thoroughly investigate and verify the services and resources available in one's local or national area. Taking the time to investigate local and national services ensures that individuals and their families are well-informed and can make appropriate decisions based on the available resources and support systems. It helps to maximise the opportunities and benefits that come with the transition to adulthood and minimises potential challenges and uncertainties that may arise from regional variations in service provision.

Capacity

As young individuals progress towards increased independence in their educational, occupational, and personal lives, a key aspect of this transition involves assuming responsibility for their own health. The concept of "capacity" refers to an individual's ability to understand the relevant information, appreciate the consequences and implications of their decision, and communicate their choice effectively. Capacity is particularly important when a person's brain health is affected, such as in cases of encephalitis.

In situations where a person's brain health is compromised, their capacity to give informed consent may be impaired to varying degrees. It is essential to assess an individual's capacity on a case-by-case basis, considering their specific circumstances and the nature of the decision at hand.

The assessment of capacity typically involves evaluating the person's understanding of the relevant information and their ability to communicate their decision coherently. This assessment may involve input from healthcare professionals, psychologists, or legal authorities, depending on the context.

If it is determined that an individual lacks the capacity to provide informed consent due to their brain health, alternative approaches may be necessary. This could involve seeking consent from a legally authorised substitute decision-maker, such as a guardian. In some cases, a court-appointed representative may be involved to make decisions on behalf of the individual.

It is important to ensure that decisions regarding consent for individuals with impaired brain health are made in their best interests and with respect for their rights and autonomy. Legal frameworks and ethical guidelines exist to protect the rights and well-being of individuals in these situations, emphasising the importance of respecting their dignity and promoting their welfare.

Driving

Getting behind the wheel of a car is often seen as a significant milestone for many young individuals as they transition into adulthood. Learning to drive holds great importance and excitement in the lives of teenagers. It provides them with increased independence and freedom, allowing them to travel and socialise with friends more conveniently.

However, for some young people who have had encephalitis, the ability or desire to drive may be diminished. Alternative options such as public transportation, carpooling with friends, or even walking can still offer means of transportation and physical activity.

It is worth noting that having a brain injury does not necessarily mean that one cannot drive in the future. Understanding the legal requirements, factors that can assist in the learning process, and when driving may not be feasible after a brain injury is essential.

Driving after a brain injury can pose risks if the condition affects specific abilities. Therefore, it is essential to make an informed decision regarding readiness to drive. Several factors related to the brain injury may impact driving abilities, including concentration problems, slower reaction times, memory issues, difficulties with movement, fatigue, and sensory impairments.

Despite the potential challenges, it is important to recognise that depending on the individual's condition, it may still be possible to learn to drive or resume driving. If the brain injury occurred before learning to drive, the support of parents and family is crucial. While they may have concerns, involving them in the process, explaining the procedures, and seeking their assistance can alleviate the worries of all those involved.

Similarly, the process of learning to drive after a brain injury involves various paperwork, which may require time and attention. If there are offers of assistance from family or friends to help with the necessary forms, it is advisable to accept their help to expedite the process.

SCHOOL AND EDUCATION

All young people face difficult decisions when considering their options for higher education. They need to think about whether to continue studying at school and which subjects or qualifications will suit them best.

There are several paths available for young people after the age of 16. They can choose to stay at a mainstream school or attend a special school if there is a relevant curriculum for them. A further option is to enrol in a college for further education or participate in work-based training.

Many schools have established “link” courses with local colleges, allowing students in their final years of school to attend college on a part-time basis. This helps them explore their interests, prepare for further education, and try out new subjects.

The local careers service can assess the needs of young people with special educational needs who want to pursue further education or training. They collaborate with colleges and training providers to ensure appropriate support for these individuals.

Universities and higher education colleges offer education beyond A levels, AS levels, or NVQs for individuals aged 18 and above. Admission requirements vary among different institutions.

Our website has stories of young people who share their school experiences www.encephalitis.info/your-stories/young-peoples-stories/

PERSONAL RELATIONSHIPS

The personal relationships of young people can undergo various changes as they transition. It is important to note that personal relationships are highly individual, and the impact of encephalitis on relationships will vary. Open communication, understanding, and patience from both individuals affected by encephalitis and their social connections are vital in navigating changes, fostering healthy relationships, and building a supportive network of connections during this significant life stage. Seeking support from healthcare professionals, counsellors or support groups can provide guidance in navigating the complexities of personal relationships during the transition from childhood and adulthood with encephalitis.

Family

As young people transition to adulthood, family dynamics may shift in terms of roles and responsibilities. Family members may take on different roles to support the young person in areas where they may need assistance because of encephalitis. This could involve changes in caregiving, household tasks, and decision-making. Equally, family members may encourage and support the growing autonomy of the young person, allowing them to make decisions, take on more responsibilities, and explore their own interests and goals.

Communication may be key in navigating changes in family relationships. It is important for a young person to openly communicate their needs, challenges, and aspirations to their family members. Similarly, family members should strive to understand the experiences of the young person, listen to their perspective, and provide emotional support. In such scenarios, it is important to consider that encephalitis can impact emotions and mood regulation, which may influence family relationships. Such changes in emotions and behaviours resulting from encephalitis can create challenges in family interactions, which can be alleviated by open and honest communication.

Every family dynamic is unique, so the impact on family relationships will vary. Empathetic understanding and ongoing support from both sides can help foster positive and supportive relationships as a young person transitions into adulthood. Seeking guidance from healthcare professionals, therapists, or support groups can provide additional resources and strategies for navigating this important life stage.

Friendships

Friendships of young people who have had encephalitis can undergo changes during the transition from childhood to adulthood. Young people may encounter new environments such as higher education, vocational settings, or community programs. These transitions can lead to changes in social circles, and the individual may need to establish new friendships or adapt to new social dynamics. True friendships are often built on understanding and acceptance. Friends who have known the individual before encephalitis may already have a level of understanding and acceptance, which can help facilitate the transition. However, new friends may require more time and open communication to understand the challenges and unique needs associated with the ABI.

Depending on the impact of encephalitis, there may be communication challenges such as difficulty with speech, language comprehension, or nonverbal communication. Friends can play a crucial role in adapting to these challenges, being patient, and finding alternative modes of communication to maintain the connection. Moreover, an individual who has had encephalitis may face new limitations or require accommodations to participate in social activities. In such scenarios, friends who are understanding can help create an inclusive environment that accommodates the person's needs and allows for active social engagement.

Friends can offer emotional support and empathy, which is crucial during transition. They can provide a safe space to share frustrations, experiences, and emotions related to the challenges of encephalitis. Genuine friendships can offer a sense of belonging and support through difficult times. To this end, educating friends about encephalitis, its effects, and any necessary accommodations can enhance understanding and strengthen friendships. Sharing information and experiences can help friends better support the individual and foster a more inclusive and supportive friendship.

Overall, it is vital to remember that friendships are unique and can vary widely. Some friendships may remain stable and supportive, while others may naturally evolve or change over time. Nurturing genuine friendships that are built on understanding, empathy, and shared experiences can be beneficial for young people transitioning from childhood to adulthood with encephalitis. Seeking help from support groups or organisations focused on ABI or encephalitis can provide additional resources and opportunities to connect with others who share similar experiences.

Sexual relationships

During their teenage years, a person's sexuality develops at a rapid pace. This can be overwhelming for many adolescents, especially when combined with the after-effects of encephalitis. Many young people with acquired brain injuries feel the same pressure as their peers to form romantic relationships. While they desire to fit in, parents understandably may feel protective and concerned for their children. The vulnerability of some young people with acquired brain injuries can distress their parents.

Some children and young people with acquired brain injuries struggle to understand cause-and-effect relationships, making it challenging for them to make informed decisions. Their judgment and decision-making abilities may also be affected, leading to impulsive behaviour and a lack of foresight.

If a young person experiences these effects, they may not be able to make sound judgments regarding sex and relationships. However, it is essential to recognise that not all young people with acquired brain injuries face these challenges. Many can have the same relationships as their peers and are entitled to do so.

While discussing sex can be uncomfortable, open communication is paramount. Some parents may feel that their child's changed circumstances make conversations about sex irrelevant or worry about “giving them ideas” by discussing certain issues. However, as for all young people, education about sex is extremely important. They will need information about the physical aspects of sex and contraception.

FINANCE AND EMPLOYMENT

Finance

Taking care of finances is a vital part of the transition process. Your child may require assistance with tasks such as opening a bank account or understanding which benefits they are eligible for and how to apply for them. However, if they are unable to handle their own affairs, they will need someone else to manage their finances on their behalf.

Employment

After recovering from a brain injury to some extent, a young person might feel ready to start or go back to work. However, a brain injury can cause changes to one’s performance at work. A young person who has had encephalitis may discover that they can no longer carry out their previous job in the same manner or ensure their or others’ safety while doing so. This doesn’t imply that they are incapable of working, but rather that they may require adjustments in the workplace to accommodate their needs. Alternatively, it is possible to find a completely different role that suits one better, and so it is important to keep an open mind about work after encephalitis.

It is important to state that, legally, one is not obliged to disclose their brain injury to one’s employer, and the employer is not allowed to enquire about one’s health unless it directly affects their job requirements. Nevertheless, it is essential to disclose any health-related information that could potentially jeopardise the safety of anyone within the workplace.

Certain working environments may be unsuitable because of encephalitis. For instance, busy and noisy office environments can be challenging if you struggle with concentration and filtering out distractions. Jobs with high stress levels and strict deadlines may also not be suitable. It is crucial to ensure that the workplace itself is appropriate. Before attempting to return, it is advisable to consult with one's general practitioner and ensure that one will be covered by their employer's insurance. The employer may also need to conduct an occupational health assessment.

DEVELOPING A TRANSITION STRATEGY

i) Plan in advance: It is possible that social care and health services may delay. Starting late can make it challenging to secure the necessary support by the time your child turns 18, such as if they want to attend a post-16 independent specialist college. Initiate planning well in advance to ensure appropriate support is in place.

ii) Explore different options: At the initial stage, don't worry about the feasibility of your preferred plan. Focus on what you believe is best for your child's adult life. Consider independent living, supported living with social care services, or residential care placements. Identify areas such as education, employment, leisure, social life, and specific needs to plan for.

iii) Set a deadline: Communicate with various experts involved, keep records, and ensure tasks are completed on time.

SECTION 8:
ENCEPHALITIS INTERNATIONAL

Encephalitis International is the only resource of its kind providing direct support and information to people affected by all types of encephalitis, raising awareness about the condition, and furthering our understanding of encephalitis through promoting and collaborating with research.

HOW WE CAN HELP YOU

- **Support Service** to help you with information about the condition, signpost to appropriate services and listen to your experience.
- **Website** containing books, booklets, leaflets and factsheets which cover various issues from what encephalitis.
- **In-person and virtual meetings and events** for all the family, details of which can be found on our website.
- **Connections Scheme**, 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).
- **Social media channels** where you can connect with other people, hear about other experiences of encephalitis, learn about the condition and keep up to date with our news, events and activities.

OUR VISION

A world without death and disability from encephalitis.

OUR MISSION

Rebuilding futures around the world by saving lives, accelerating awareness and driving research.

OUR OBJECTIVES

EDUCATE: Educate health professionals in the prevention and management of encephalitis in order to improve outcomes

EMPOWER: Empower people affected by encephalitis to rebuild their lives

EXPAND: Expand global scientific and medical understanding in the prevention, treatment and impact of encephalitis

SCALE: Extend our reach to help more people internationally

FUND: Fund the delivery of the Encephalitis International Mission

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.

Can you help us to fund research into encephalitis?

Encephalitis International
The brain inflammation non-profit

With no statutory funding, Encephalitis International relies on the generous support of a number of philanthropic organisations and the encephalitis community - everyday people like you committed to helping our drive forward research into encephalitis to improve recognition, diagnosis and treatment globally.

Could you help by:

- Making a donation
- Taking part in a challenge event
- Seeing if your company offers support for charities
- Seeking support or an introduction to a charitable trust or foundation you know

How your donation could make a difference...

£25 helps fund Advances in Encephalitis Research Summary – our go-to guide for professionals working in encephalitis.

£50 contributes towards funding a research day for our seed funding projects.

£150 funds a place for early career researcher or physician at our international Encephalitis Conference.

Get in touch today

e: fundraising@encephalitis.info

Encephalitis International is a registered Charity and Charitable Company.
Our England and Wales Charity No. is 1087843 and our Charitable Company No. is 04189027.
Our Charity No. in Scotland is SC048210.
Encephalitis International is a Named Fund member of the Chapel & York US Foundation, Inc.
The Chapel & York US Foundation, Inc. is a 501(c)(3) tax-exempt organisation

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