




the eden dora trust  
FOR CHILDREN WITH ENCEPHALITIS



**Getting to know  
Childhood Encephalitis**



**The Eden Dora Trust was set up by Petrina after her six year old daughter became seriously ill with Encephalitis. The charity provides support for children and their families/carers affected by Childhood Encephalitis and the subsequent lifelong Acquired Brain Injury.**

**As well as support to help children and their families feel less isolated, different, misunderstood and alone, we also raise awareness and fund research in to the causes, diagnoses and treatments of Encephalitis.**

We also fund educational literature along with training workshops for families, teachers and health care professionals involved with the ongoing care and rehabilitation of children affected by this life changing illness. Please see our website for more details.

**[www.edendoratrust.org](http://www.edendoratrust.org)**

The Eden Dora Trust helps make life better and easier for children and families affected by Encephalitis through support, information and research; helping children and their families feel less isolated, different, misunderstood and alone.

The hope is that one day, The Eden Dora Trust will have helped to save lives and reduce the severity of the Acquired Brain Injury and the life-long impact of Childhood Encephalitis.

Anyone can develop Encephalitis at any time. The Eden Dora Trust is the only charity in the UK dedicated solely to helping children who suffer from this illness.

Images are courtesy of The Eden Dora Trust.

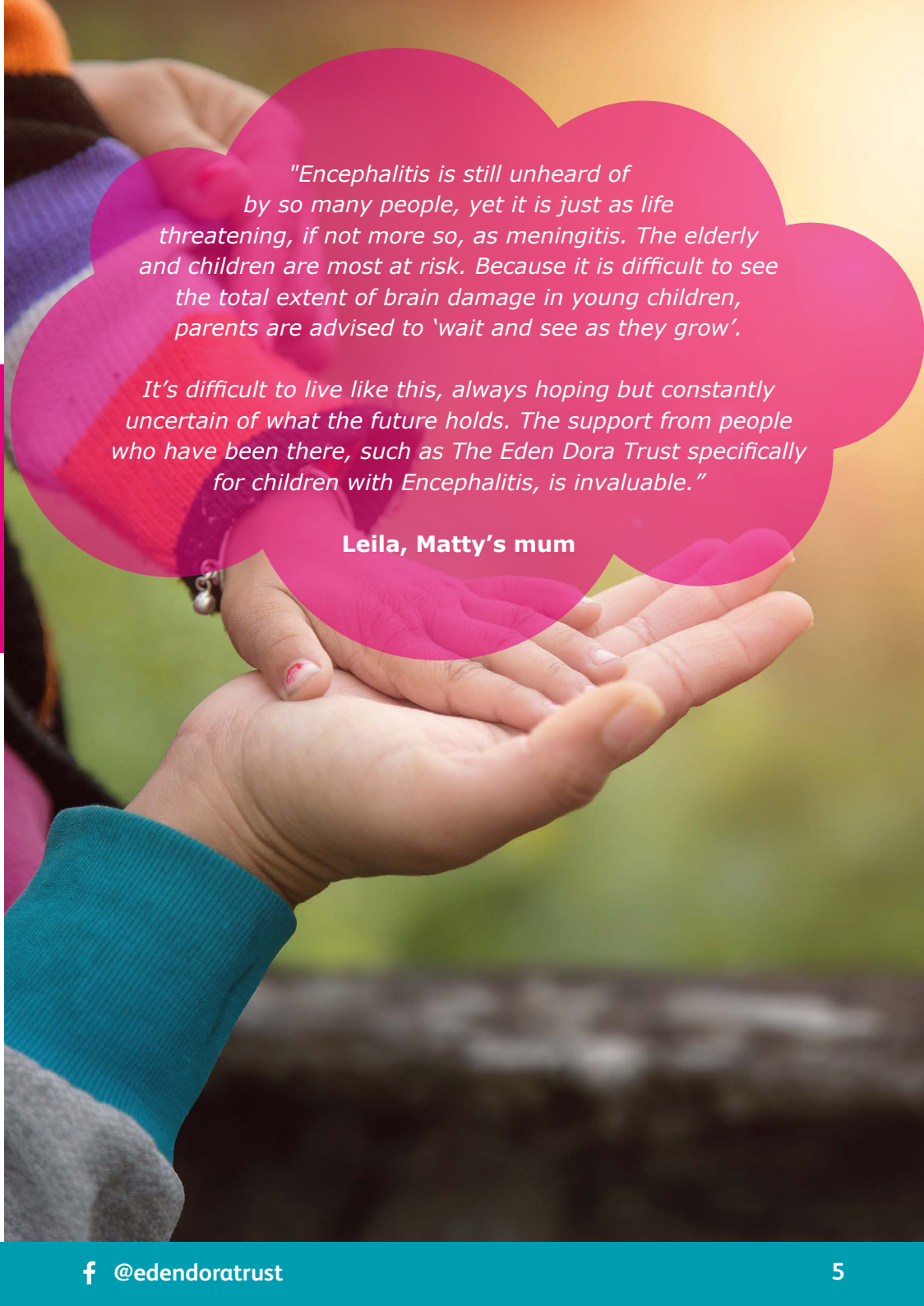


## About This Guide

The impact of Encephalitis on your child and the whole family can be life-changing. Whatever the outcome of the illness, there may be broader practical issues that can cause concerns. Some may be apparent immediately whilst others may not become apparent until later on.

This guide has been prepared to offer advice and support about some of the common issues which can arise following Encephalitis. These have been organised into the following sections:

- **FAQs**
- **Healthcare Professionals you Might Need**
- **Education**
- **Care and Support**
- **Access to Treatment and Continuing Healthcare**
- **Financial Support and State Benefits**
- **Medical Law and Negligence**
- **Employment Rights**



*"Encephalitis is still unheard of by so many people, yet it is just as life threatening, if not more so, as meningitis. The elderly and children are most at risk. Because it is difficult to see the total extent of brain damage in young children, parents are advised to 'wait and see as they grow'.*

*It's difficult to live like this, always hoping but constantly uncertain of what the future holds. The support from people who have been there, such as The Eden Dora Trust specifically for children with Encephalitis, is invaluable."*

**Leila, Matty's mum**

## FAQs

Encephalitis means inflammation of the brain. The inflammation is caused either by an infection invading the brain (viral/infectious Encephalitis); or through the immune system attacking the brain in error (Autoimmune Encephalitis).

### What exactly is Encephalitis?

Anyone can get Encephalitis at any age. There are up to 6000 new cases of Encephalitis each year in England alone.

### Who can get Encephalitis?

Viruses are the most common agents that cause Infectious Encephalitis. Within the British Isles herpes simplex virus (the cold sore virus) is the virus most frequently identified. More rarely bacteria, fungus and parasites can cause Encephalitis.

Autoimmune Encephalitis is caused by the immune system attacking the brain and impairing its function (ADEM).

### What causes Encephalitis?

## What are the main symptoms?

Childhood Encephalitis often begins with a 'flu-like' illness with symptoms such as fever, headache, poor appetite and loss of energy.

Typically, more serious symptoms follow hours to days later and can include the following: severe headache, nausea and vomiting, stiff neck, disorientation, personality changes, convulsions (seizures), problems with speech or hearing, hallucinations, memory loss, drowsiness and coma.

It's harder to detect some of these symptoms in babies and small children, but important signs to look for include: crying that doesn't stop or that seems worse when an infant is picked up or handled, vomiting, a full or bulging soft spot (fontanelle) and body stiffness.

Autoimmune Encephalitis symptoms can often mimic psychiatric disorders. There is often a longer onset than that seen in Encephalitis of infectious causes. Symptoms may vary depending on the cause but may include confusion, altered personality or behaviour and psychosis.

## How is Encephalitis diagnosed?

## How is Encephalitis treated?

### BLOOD TESTS

to confirm or exclude the presence or absence of certain viruses and bacteria in the blood. It is not unusual for the results of tests to be "normal" in cases of Childhood Encephalitis but it is important to initially exclude some more common and treatable diseases.

### BRAIN SCANS (CT or MRI)

to check for any change in the appearance of the brain, to exclude brain tumours, aneurysms and strokes and to show the extent of any inflammation and swelling.

### LUMBAR PUNCTURE

to detect inflammation, as well as the possible presence of bacteria or viruses in the spinal fluid.

### EEG

An Electroencephalogram is a recording of the electrical signals in the brain to check for any abnormalities.

When Encephalitis is thought to be caused either by a virus or bacteria, children are treated with anti-viral and antibiotic drugs. It is important that these drugs are started promptly, often before a definite diagnosis is made, so children are frequently given several different drugs at once.

Children are also treated for the symptoms caused by Childhood Encephalitis. Often children are treated with anti-convulsants to control seizures, or sedatives to reduce agitation. Often children require intensive care treatment including ventilation (mechanical help with breathing).

As Autoimmune Encephalitis is due to the immune system acting inappropriately, treatments aim to modify the function of the immune system. Treatment includes drugs such as steroids, intravenous immunoglobulin (an antibody collected from blood donors) or plasma exchange.



**Do people  
get better?**

Brain cells may be damaged or destroyed by the viral infection, the immune reaction and by pressure resulting from the inflammation. This damage is termed "Acquired Brain Injury" (ABI) and some loss of brain function is a probable outcome of Childhood Encephalitis.

In some cases this loss occurs on a relatively small scale, resulting in a minor impairment such as slowed speed of thinking. In other cases damage can be extensive, leading to significant impairments and physical disabilities.

Recovery may be a long and slow process. An initial period of convalescence with plenty of rest is necessary. This should be followed by a programme of graded activity with targeted rehabilitation depending on the child's specific needs. In more severe cases, a period in a brain injury rehabilitation unit may be necessary.



**What are the  
after effects?**

There will be wide variation in how Childhood Encephalitis affects the person in the long term. In children the after effects of Encephalitis can continue to manifest for many years after they have suffered the illness, also known as the silent disability.

Tiredness, headaches, difficulties with memory, concentration and thinking speed, speech and language difficulties, mood swings, aggression, and problems with social perception and understanding are often reported.

Physical difficulties may include weakness and paralysis, balance issues, clumsiness, slowed reactions, loss of sensation, and loss of control of bodily functions. Epilepsy, as well as being a feature of the acute illness, may develop weeks or months after the illness has subsided.

Even where there is complete physical recovery, significant changes may occur in day to day functioning and personality. Coming to terms with these problems can be very distressing and challenging for everyone concerned.

In children the after effects of Encephalitis can continue to manifest for many years after they have suffered the illness, ABI, also known as the silent disability.



## Healthcare Professionals you Might Need

When it comes to Childhood Encephalitis, there is a large team of experts who can help you with your child's rehabilitation.

### Neurologist

A Neurologist is a doctor who treats conditions that affect the brain and nerves.

### Neuropsychologist

Encephalitis and ABI can affect how a child thinks, behaves and feels. Neuropsychologists work with children to assess and help treat these difficulties.

### Educational Psychologist

Educational Psychologists help children or young people whose learning and participation in school and social interaction is affected. An Educational Psychologist will work in partnership with parents, teachers, social workers, doctors and other people involved in a child or young person's education.

### Occupational Therapist

An Occupational Therapist (OT) can identify strengths and difficulties your child may have in everyday life will help you work out practical solutions for them.

An OT can work with you to identify goals that can help you maintain, regain, or improve your child's independence by using different techniques, changing their environment and using new equipment.



### Physiotherapist

Physiotherapy can help to restore movement and function if your child is affected by physical disability from Childhood Encephalitis.

### Speech and Language Therapist

Speech and Language Therapy (SALT) provides treatment, support and care for children who have difficulties with communication or with eating, drinking and swallowing.

### Audiologist

Audiologists treat children who suffer from hearing loss and problems with balance.

### Ophthalmologist

An Ophthalmologist will help if your child's eyesight has been affected by Childhood Encephalitis.

### Social Workers

Social Workers work with children and families to support them through difficult times and to make sure that they are safeguarded from harm. Their role is to provide support and help in order to improve the outcome in a child's life.



*"We were a normal, run of the mill family until our 4 year old daughter contracted ADEM - a rare form of Encephalitis. It affects the brain and spine.*

*She spent two months in hospital and is still rehabilitating even now. Please support the Eden Dora Trust to help spread awareness of childhood Encephalitis and ABI."*

**Charmaine,  
Annabelle's mum**



## Educational rights

### What are Education Health and Care Plans?

An Education Health and Care Plan (EHCP) can be issued to a child or young person to ensure their needs are met, to provide support and to help a child to reach their potential.

EHCPs are replacing Statements of Special Educational Needs (SEN) for children in schools and young people in further education and training.

An EHCP can cover your child/young adult with additional needs from birth until the age of 25. It is a legal document and its purpose is to describe the child or young person's special educational, health and social care needs in one detailed document. It explains the extra support that is necessary and will be given to ensure those needs are met.



To obtain an EHCP you, your child's school/college, or your child if they are over 16, can ask your Local Authority to carry out an assessment.

The Local Authority will then draw up your child's EHCP following this assessment. The EHCP will include annual reviews and reassessments to ensure that provision is relevant and up to date.

Every child has the right to a good quality education and should be provided with the support they need to successfully complete their education.

If you would like more information then please contact the Eden Dora Trust.

## Care & Support

The effect of caring for a child with additional needs cannot be underestimated and everyday tasks can suddenly become daunting and unmanageable.

You may need guidance on how to approach Social Services to obtain the care and support your child needs, whether that is in the short term, such as respite care, or over the longer term.

On some occasions you may need someone to act as an advocate on your behalf in order for your child to receive the care that will fully meet their needs.

If your child is in need of longer term care your local Social Services department or Clinical Commissioning Group (CCG) can be approached to carry out an assessment and prepare a care plan setting out the services they feel would benefit your child. These support services can be provided directly by Social Services, the CCG or you can access your own care and support independently using your child's individual budget.



As a parent of a child with extra needs you may need additional support yourself. In these circumstances you are entitled to request a Carer's Assessment from your Local Authority.

Unfortunately, due to the pressures and constraints on Local Authorities and the CCGs more limited care may be provided to those who have greater needs or the care assessment may not recognise the extent of your child's individual needs. However, you can seek to challenge the assessment and funding your child receives to ensure that they are provided with the services to which they are entitled.

If you would like more information then please contact the Eden Dora Trust.

## Access to Treatment and Continuing Healthcare

Care, treatment and support for those diagnosed with Childhood Encephalitis can be provided by various sources, such as GPs and community care along with specialist neurology, rehabilitation and mental health services.

The aim of these services is to link together to provide a 'patient-centred' treatment plan that works for your child and the whole family - the standard of treatment can vary, depending on whereabouts you live and your child's needs.

It is important that parents are listened to and their wishes understood. Parents of a child who is receiving treatment have a right to understand the implications and side effects of any proposed treatment and to request a second opinion, if they wish.

When it comes to decisions about our child's health and general wellbeing, we place a great deal of trust in medical professionals to take care of our best interests. However, sometimes decisions about care and medical treatment can cause disagreements, for example:



- **General medical treatment** – where there's a disagreement over the nature of care or treatment appropriate for your child
- **Refusal of drugs or medical treatments** – where the NHS has refused to fund a particular drug or treatment.

Given the recent budget cuts to public services, many services can be denied, cutting you off from the care you need and leaving you unsure of where to turn for help.

If you would like more information then please contact the Eden Dora Trust.

## Financial Support and State Benefits

Children and young people diagnosed with Encephalitis and their families may be entitled to claim a number of benefits as a result of their illness, to lessen the financial burden of any increased expenditure.



The benefits system can be complicated but specialist advice and assistance is available when needed. A person's entitlement to state benefits will depend upon their age, care needs and employment status. Below is a list of some of the most common benefits your child/family may be entitled to claim:

- Personal Independence Payment (PIP), formerly Disability Living Allowance (DLA)



- Carer's Allowance
- Income Support
- Working Tax Credit
- Child Tax Credit
- Housing benefit and Council Tax Benefit

Depending on your income, there may also be financial help available, for example, to fund the cost of any on-going prescriptions and travel to and from hospital. If you need to make adaptations to your home because of your child's disability then you may be entitled to a grant to cover the cost of this work. It is also possible to apply for a Blue Badge which lets disabled drivers or passengers park closer to their destination.

If you would like more information then please contact the Eden Dora Trust.



# Medical Law and Negligence

## Making a complaint

Fortunately, medical treatment in the UK is of a high standard and mistakes are rare. However, Childhood Encephalitis is a life-changing illness, so early diagnosis and treatment is crucial to ensure the best possible recovery.

If you are concerned that there has been a delay in diagnosing your child with Encephalitis, then you may want an explanation and reassurance that lessons have been learnt in order to avoid the same thing happening to other children and families in the future.

If you wish to raise a formal complaint regarding any of your child's treatment then this can be done whether the treatment was provided by a GP, an NHS hospital or privately. For more information relating to the NHS complaints procedure, please see the following: <https://www.nhs.uk/NHSEngland/complaints-and-feedback/Pages/nhs-complaints.aspx>



## Medical negligence

In some circumstances a claim for compensation can be brought in order to ensure access to financial support, rehabilitation and care. For instance, it may be that your healthcare professional failed to recognise the early symptoms of your child's Encephalitis and delayed making a referral to hospital for treatment. Alternatively, it could be that the hospital failed to make the correct diagnosis or was slow to administer antiviral treatment which caused symptoms to worsen or resulted in permanent injury.

To bring a claim for negligence, it is recommended that you speak to a specialist solicitor and they will be able to guide you through the process.

If your child is still receiving ongoing treatment at the hospital or with the clinicians where the negligence occurred, this should not stop you from investigating a potential claim as the hospital clinicians continue to have a duty of care to provide the best treatment and care to their patients.



## Employment Rights

When you are caring for someone who has been diagnosed with a serious illness like Childhood Encephalitis, it may be difficult to cope with your workload or you may find that your job becomes too stressful for you to deal with.

Many employers will be very supportive when an employee suffers ill-health, or is caring for a family member. You may still be entitled to claim additional benefits should you be in employment when a diagnosis is received. In addition, you may also be entitled to further financial help from the state if you have become the main carer for a child who is diagnosed with Encephalitis.

Throughout this difficult time, your employer also has a duty to ensure that a more flexible approach to working is taken, such as having the time to attend hospital appointments and treatment/therapy sessions when necessary. Employers have a duty to make reasonable adjustments to working practices to accommodate their employees.

It may be that you need legal advice in relation to your work or your employer to make sure that you are receiving the support you need and are being treated fairly. If this is the case then you can approach your HR Department, Citizens Advice or a solicitor.

*"In 2011 I contracted Encephalitis out of the blue. Since then my recovery has been somewhat of a learning curve. I have had my ups and my downs, and made some huge life changes.*

*People I knew struggled to relate to the new me; the old Liz had gone, and in her place was someone very different. It's so difficult for someone that is still developing relationships. Children usually understand more than you may think, but when it comes to brain injuries, they struggle to comprehend the trauma. It is a huge comfort to me knowing that the Eden Dora Trust exists to support children and their families to carry on with their lives as well as they possibly can."*

**Liz Oldershaw**



Irwin Mitchell is proud to have worked with The Eden Dora Trust since they launched, supporting the charity's fundraising activities and helping to raise the profile of the fantastic work they do on a daily basis.



For legal assistance with any matter raised in this booklet please contact Irwin Mitchell:

📞 08000 23 22 33 🌐 [irwinmitchell.com](http://irwinmitchell.com)





## How we help...

*"It was February 2013. Our four-year-old son, Lewis, came home with what we thought was an ear infection. He had all the symptoms – pain in his ear, sickness, a temperature, the doctors were adamant it was a viral infection. Deep down I knew there was more to it, and we got him to A&E just in time.*

*Five days and a MRI scan later, my boy was diagnosed with A.D.E.M - Acute Disseminated Encephalomyelitis. Lewis is recovering with treatment, but he will never be the same boy he was before. That's why we support the Eden Dora Trust in campaigning for, and funding, research into quicker diagnosis: so that other children can get quicker, relevant medical attention."*

**Kaye, Lewis's mum**

**S**upport - for those affected by Childhood Encephalitis to find out what help is available and how they can access it.

**P**rovision - of funding to support further research into the causes, symptoms and potential cures for Childhood Encephalitis.

**E**ducation - funding essential training for those who support children with Encephalitis and ABI.

**A**wareness - increasing understanding of Childhood Encephalitis and Acquired Brain Injury (ABI) in children.

**K**nowledge - providing and sharing with other children, families and carers.

**Contact  
The Eden Dora  
Trust for children  
with encephalitis**

**EMAIL:**  
**[contact@edendoratrust.org](mailto:contact@edendoratrust.org)**

**WEBSITE:**  
**[www.edendoratrust.org](http://www.edendoratrust.org)**

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