Encephalitis International
The brain inflammation non-profit

Know Your Rights
Neuro-Legal Handbook

Preferred Legal Providers

CLARKE WILLMOTT

Offices: Birmingham, Bristol, Cardiff, London, Manchester, Southampton, Taunton

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www.clarkewillmott.com

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www.leighday.co.uk

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www.moorebarlow.com

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About this handbook

At some point in our lives, we all need to use a solicitor. We can't emphasise enough how important it is that people affected by encephalitis, and their families, seek advice from law firms that truly understand the impact of the condition and how life may change for the whole family.

For the majority of people the journey through encephalitis, from diagnosis to accessing services for their recovery, is smooth, complicated only by the unique difficulties inherent to this illness. However, for a few people there is a struggle to get an accurate diagnosis, appropriate treatment, support for recovery, educational support, and protection for vulnerable relatives.

This handbook aims to provide clear guidance on some legal matters, which may be appropriate for your situation. It does not intend to blame medical professionals or support people entering the justice system unnecessarily. Medical errors are often the result of a failure in systems rather than in individuals.

While bringing a clinical negligence claim may seem to some people to be an emotional and expensive process, our legal partners will ensure that the whole process runs as smoothly as possible causing you the least amount of stress. There is of course not only the benefit of financial gain that may mean you or a loved one can be properly looked after into the future, but there is also the additional benefit that some mistakes will not be made again.

This handbook focuses on various legal topics, not all of them involving court procedures: rights you may be entitled to (e.g. NHS continuing healthcare, special educational needs), how to get the support you need before something goes wrong (protecting vulnerable adults, workplace discrimination, power of attorney and wills) and also where to go if something goes wrong (clinical negligence).

We have partnered with a limited number of law firms who we believe can provide you with the right legal support. We have considered their experience, professionalism, ethics and values: putting their clients' needs first; sensitively approaching personal matters; their personal approach to each case; the positive impact of their work; innovation; and their commitment to corporate social responsibility.

Legal services may involve substantial costs, making people understandably nervous and possibly unwilling to consider fighting for their rights. Please note that all our legal partners are offering a free, no obligation consultation and will discuss funding issues with you (including eligibility for legal aid) in detail.

Acknowledgements

We are extremely grateful to our legal partners who have contributed to the production and publication of this handbook, and for the services they provide to our supporters. The legal partners in this handbook provide financial and gift-in-kind support to Encephalitis International.

Disclaimer

Encephalitis International has established partnerships with firms that we believe are best placed to conduct work with our supporters and who have high levels of professionalism and ethical conduct. However, we cannot offer any guarantee as to the information or service that the firms involved may or may not provide. No liability can be attached to Encephalitis International or any of its servants or agents as a result of any person relying upon this handbook and the contacts provided therein.
This booklet is aimed at people affected by encephalitis who live in the UK. If you live in Northern Ireland, we suggest that you contact the Association of Personal Injury Lawyers, www.apil.org.uk, to find a specialist local to you.

Complaints process

All solicitors must comply with the professional ethics and standards, which are set by the Solicitors Regulation Authority (SRA) (www.sra.org.uk).

If for any reason you are not happy with the service that your solicitor is providing, please contact the firm directly through their own complaints management system.

This information can be found on their website.

If you've complained to your solicitor and you aren't satisfied with their response, we suggest that you contact the Legal Services Ombudsman.
www.legalombudsman.org.uk Tel: 0300 555 0333.

Encephalitis: key facts about the illness

- Encephalitis is an inflammation of the brain caused either by an infection invading the brain (infectious encephalitis caused by viruses, bacteria or other micro-organisms) or through the immune system attacking the brain (post-infectious or autoimmune encephalitis). In 40-60% of encephalitis cases no cause is identified (Granerod et al., 2010).
- Striking adults and children alike, encephalitis is indiscriminate, showing no respect for age, gender, ethnicity or culture. The initial stage of the illness commonly manifests as serious and acute, often followed by varied degrees of injury to the brain.
- It is important to differentiate encephalitis from other disorders that may cause similar neurological symptoms but have very different treatments. Disorders that mimic those of encephalitis include bacterial meningitis, stroke, brain tumours, drug reactions and metabolic disturbances.
- Aciclovir is the most frequently used anti-viral drug. It is effective against the herpes simplex virus and varicella zoster virus. Unfortunately, for many viral infections, there are no specific treatments at present.
- Because autoimmune encephalitis is due to errors with the immune system, treatments include drugs such as steroids, intravenous immunoglobulin (IVIG) and plasma exchange.
- The degree and type of damage will vary according to the cause, the severity of the inflammation, the parts of the brain affected and any delay in treatment.
- The acute stage of encephalitis may be followed by a phase of rapid improvement and a slower recovery can continue over the years to come.
- Around 6,000 people in the UK and 1.5 million worldwide are diagnosed each year, with mortality (death) rates up to 40% depending on the cause. (Granerod et al., 2013; Günther et al., 2019; Wang et al., 2022).
- Acquired brain injury (ABI) is a consequence of encephalitis for many survivors. Some of the difficulties people may struggle with can be seen in the figure on the next page.
- Prompt diagnosis and treatment, including access to appropriate rehabilitation, can reduce death rates and improve outcomes.

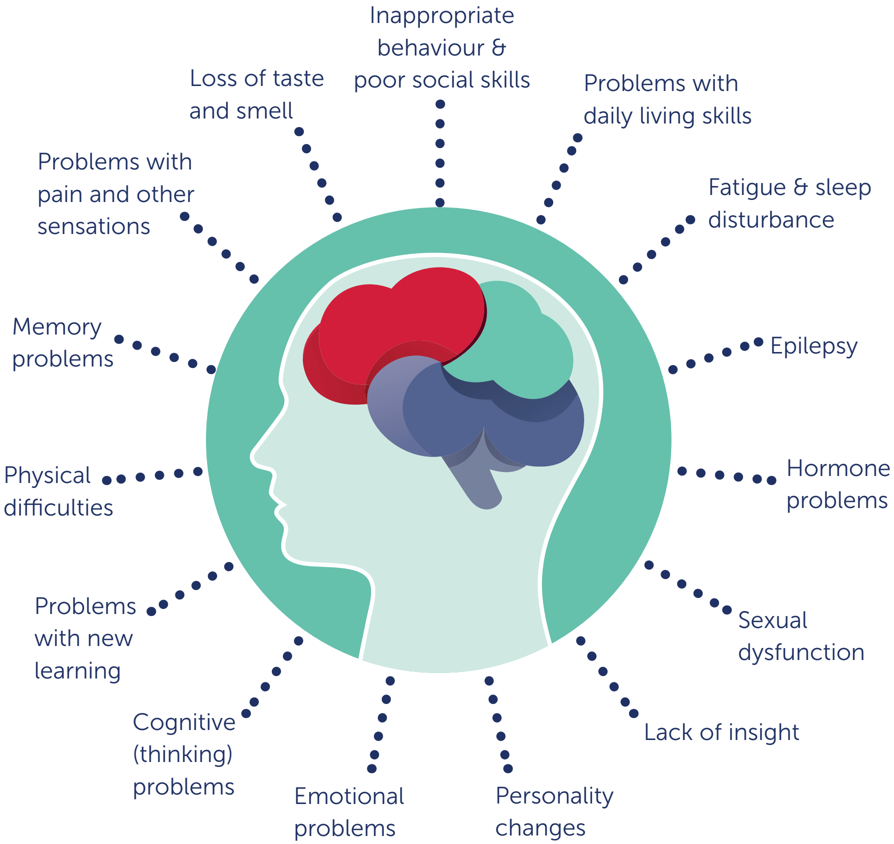
Granerod J., Ambrose H.E., Davies N.W., et al. (2010) Causes of encephalitis and differences in their clinical presentations in England: a multicentre, population-based prospective study. Lancet Infect Dis; 10 (12):835-44.

Granerod J., Cousens S., Davies N.W., et al. (2013) New estimates of incidence of encephalitis in England. EID Journal. 19(9).

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

Wang,H., et al. (2022) Global magnitude of encephalitis burden and its evolving pattern over the past 30 years. Journal of Infection; 84.

Outcomes after encephalitis



Getting the best from your solicitor

Solicitors are professionals who advise and represent you in your legal matters, but they are not your counsellor or doctor. A successful relationship between you and your solicitor needs to be built on honesty, professionalism and effective communication. You need to care about your cause as it is difficult to fight for somebody who does not believe in themselves. Prepare well for the meetings, as this will save not only your and your solicitor's time, but also your money.

Honesty and professionalism

- You need to be realistic about what you would like to achieve and understand how solicitors can help you.
- You need to be aware of the costs involved and the implications of these costs for you.
- You need to work together and not against each other.
- Be punctual and keep to deadlines.

Effective communication

- Make sure you tell the solicitor everything.
- Make sure you send them everything you agree to send.
- Make sure you know how to get in touch with them, but also let them know how they can reach you.

Prepare well for meetings

- Make sure you bring what they ask for.
- Prepare a list of questions in advance.
- Try to summarise your points of view.
- Ask if you don't understand something.
- Take somebody with you.

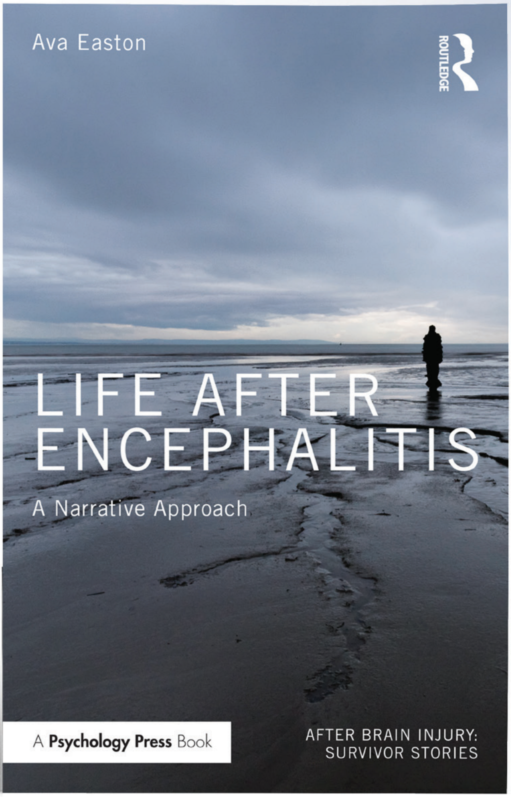
Have a backup

- Keep copies of all documents you hand.
- Keep records of everything: meetings, emails, forms, conversations, timings and payments.

Remember: If you think you may need a solicitor, it is better to get the help sooner rather than later. It will not only alleviate your anxiety about not knowing what to do, but it also may bring better outcomes. Build a relationship of trust with your solicitor. You are both embarking on a journey, which may be emotional and exhausting, but also rewarding.

Life after encephalitis.

A narrative approach including survivor and family member stories by Dr Ava Easton



"Dr Ava Easton has done something remarkable with this book: she has given life and support to patients and families living through this silent disease. From the first-person cases to the in-depth research and passionate dedication to her work as the head of the Encephalitis Society, Ava Easton has given us a gift with this tremendously important book".

Susannah Cahalan, author of Brain On Fire: My Month of Madness

"Encephalitis is undoubtedly a thief, and Easton does an excellent job at explaining why."

Jules Morgan, The Lancet Neurology

Order online now from www.encephalitis.info/LifeAfterEncephalitis

Clinical negligence

Misdiagnosis or mistreatment of encephalitis can have fatal consequences. You may not know this, but it is estimated that there are 6,000 new cases of encephalitis each year in the UK alone.

Encephalitis is a condition which is considered a medical emergency, and needs to be diagnosed and treated urgently by healthcare professionals.

If the condition is left untreated or misdiagnosed, it can lead to a patient receiving inappropriate medical care, the long-term complications of which can be severe. For example, an acquired brain injury, the degree and severity of which will vary according to the treatment received.

Learning of an encephalitis diagnosis can be incredibly daunting, with many families facing new challenges at what is a very emotional time. The acquired brain injury is also often a hidden disability which requires specialist clinical, therapeutic, rehabilitative interventions and support to assist your loved one and you to adjust to a life following illness.

Our legal partners often see cases where failure to diagnose, or where the condition hasn't been cared for appropriately, has led to complications and sometimes deaths that could have been avoided.

If you think you experienced clinical negligence, you can discuss initially with Encephalitis International Support Team on 01653 699599 or support@encephalitis.info

Special educational needs

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

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

Every local authority is required to identify, assess and make provision for children with special educational needs in its area. If a child has considerable difficulty in learning compared to others in the class or if the child is not able to make use of facilities in school, the child may have special educational needs for which a formal education, health and care (EHC) needs assessment is necessary. Schools should consider making a request for an EHC needs assessment if it needs to make educational provision for a child that is different from the provision it makes other children of the same age who do not have learning difficulties. Getting an EHC plan in place is a lengthy process, so if an assessment is needed, it is important to request this as soon as possible.

Furthermore, in some instances parents struggle to have the EHC plan put in practice because the school does not fully understand the child's needs and the importance of the support or they lack the resources to implement the plan.

Returning to school after encephalitis is a very important step in the child's recovery, in terms of both their social and educational reintegration. However, sometimes returning to school is a continuous battle to get the right services for the child at the right time.

Support and guidance from experts can help the parents navigate through the maze of legislation and regulations and make a huge difference not only to the child's life, but also to the family's life.

Workplace discrimination

The Equality Act 2010 protects against discrimination at work because of a disability in a way that if you are disabled you have the same rights as other workers. If you think you have been treated unfairly at work because of your disability, it may be unlawful discrimination. Every employer should have a policy in place so all employees know what is acceptable and expected of them as individuals and as part of the organisation.

Who can discriminate? Employers, other colleagues, employment agencies or third parties. Discrimination can refer to recruitment, terms and conditions, pay, benefits, promotions, training, dismissal, retirement, redundancy and pensions. There are different types of discrimination:

- Direct when someone is treated differently and not as well as other people because of disability.
- Indirect when a practice or procedure at a workplace is applied to all employees, but disadvantages those who are disabled.
- Arising from your disability when the unfair treatment is because of something connected to your disability, rather than the disability itself.
- Failure to make reasonable adjustments when an employer fails to ensure its workplace or practices do not disadvantage.
- Harassment when a behaviour towards a person's disability causes a distressing, humiliating or offensive environment for that person.
- Victimisation when somebody is treated differently because they have made a discrimination complaint.

Disability is defined as being a physical or mental impairment, which has a substantially adverse and long-term effect on somebody's ability to carry out normal day-to-day activities. Long term means the effect of the impairment has lasted, or is likely to last, for at least 12 months. Substantial means not minor or trivial impairment.

What can you do if you think you are discriminated against at work?

- Talk to your employer first to try to sort it out informally. If you can't resolve it, you could follow the grievance procedure at your workplace.
- Use mediation. The Advisory, Conciliation and Arbitration Service (Acas) offers a free Early Conciliation Service. If you want to take a disability discrimination challenge against your employer at the Employment Tribunal, you have to contact Acas first and you need proof that you have done so before you can start a claim.
- Make a claim in the Employment Tribunal. If you are successful, the Tribunal has power to award you compensation (financial), order a reasonable adjustment, and/or order your employer to pay your legal fees.

Lasting power of attorney

Anybody who has mental capacity (capacity to make decisions for themselves) can make a lasting power of attorney. This means deciding how they want their financial and welfare affairs to be managed if they lose their mental capacity in the future by appointing an attorney to make decisions for them. You can choose as attorney anybody you trust who is over 18 years of age and has mental capacity.

There are two types of lasting powers of attorneys: one concerning property and affairs and one concerning health and welfare. You can have the same or different attorneys and you can have one or both lasting power of attorneys.

The procedure: You need to choose your attorney, fill in the forms to appoint them as attorney and register your lasting power of attorney with the Office of the Public Guardian.

What is the benefit of a lasting power of attorney?

If you don't have lasting power of attorney and you lose your mental capacity, then your family or friends need to go through the Court of Protection procedure to be able to make decisions for you. This is a costly and long process and adds to the burden for your family and friends, who already need to overcome the fact you have suffered an illness.

Wills

Making a will lets you decide what happens to your money, property and possessions when you die. These things are sometimes called your 'estate'. You can also use a will to decide who should look after any children under 18. If you're affected by encephalitis, you might want to make a will so that you can make these decisions yourself and to help your loved ones feel less worried about the future. If you haven't made a will or your will is invalid, your money, property and possessions will be shared out according to the law.

Encephalitis International offers a free will writing service, with our trusted partner, Farewill. For more information contact: fundraising@encephalitis.info or 01653 692583.

Inquests

What is an inquest?

An inquest is a public investigation into the circumstances of a sudden or unexpected death. The inquest aims to answer the following four questions: Who died? When did they die? Where did they die? How did they die?

An inquest does not determine either civil or criminal liability. It is about what happened, not who was responsible for what happened. Family and friends of the deceased may be disappointed that the inquest will not establish the guilt. However, they need to bear in mind that an inquest provides the best opportunity to shed some light on circumstances leading to death that may be of help in any subsequent civil proceedings, for example arising out of medical negligence.

What is the procedure?

A doctor, the police or registrar of death can refer the death to the coroner (independent judicial office holder). If family members consider that an inquest should be held, they need to make their concerns known to the coroner as soon as possible. It may be that after an initial examination of the evidence, the coroner decides the death was natural, so an inquest is not necessary. If the inquest is necessary, it will be held in the county where the deceased died and must be completed within six months of the date on which the coroner is made aware of the death or as soon as reasonably practicable after the date.

An inquest is a public hearing; anyone, including press, can attend. The family of the deceased can be represented by a solicitor, barrister, legal executive or a properly interested person (normally a parent, spouse, child, partner or the personal representative of the deceased).

Findings and recommendations

The result of an inquest is called the verdict (term used in the past), conclusion or findings. It may state that a death was due to unlawful killing (to which may be added 'by a person or persons unknown'), natural causes, accident or misadventure, alcohol/drug related, industrial disease, lawful killing, open finding, suicide, road traffic accident, stillbirth, neglect or self-neglect.

The coroner has an important role in trying to prevent further deaths. The coroner may make recommendations to bodies such as the NHS to improve on protocols/guidelines and other procedures relevant to patient care. In such a case, the coroner will report the matter in writing to the person or authority who may have the power to take such actions.

The Court of Protection

The Court of Protection is a specialist court created under the Mental Capacity Act 2005, which makes decisions about financial and welfare matters for people who lack mental capacity (e.g. emergency medical treatment for someone, where a person should live) and appoints deputies to act on behalf of these people.

What is mental capacity?

People who have mental capacity can make decisions for themselves. People may lack capacity to make particular decisions at certain times. It does not necessarily mean that they lack capacity to make any decisions at all. One should always assume an individual has the capacity to make a decision themselves, unless it is proved otherwise through a capacity assessment.

Who can apply to the court?

Anybody can apply to the Court of Protection including the person concerned, family, friends, solicitors, public guardian, professionals, carers, advocates, NHS Trust and local authority. The Court of Protection process can be long, complicated and daunting. In the cases where an immediate decision is needed, there is an urgent procedure to follow.

What is a deputy?

If the person who lacks mental capacity has not nominated an ‘attorney’ through a lasting power of attorney, then somebody else (e.g. family or friends) can apply to the Court of Protection to become a deputy for this person. If there are no other suitable family or friends or if the decisions that need to be taken are complicated, a solicitor can be appointed as a deputy.

The deputy can only make decisions the court allows them to do, if the person lacks mental capacity regarding those decisions at that time and in the person’s best interests. The deputy needs to apply to the court if circumstances change and there is a need for other decisions to be made.

The deputy may need to provide regular reports to the court. A deputy can’t make decisions such as making a will, making large gifts of money or transferring money and properties in their name.

What is the procedure to become a deputy?

It is very important for the applicant to know exactly what powers they need to apply for and request these powers by filling in some forms. A doctor’s certificate confirming that the person concerned lacks mental capacity is also required. The Deputyship Order may have a limited duration and the deputy may need to apply to the court again when this expires.

NHS continuing healthcare

NHS continuing healthcare is a package of continuous care arranged and funded by the NHS for individuals found to have significant, ongoing healthcare needs because of an accident, disability or illness.

You can receive this package whilst you are at home (paying for services such as a community nurse or specialist therapist and personal care), or in a care home (as well as healthcare and personal care, the NHS will pay for your care home fees).

Applying for NHS continuing care

In theory, anyone who appears potentially eligible for NHS continuing healthcare should have a continuing healthcare needs assessment. In practice, the assessment does not always take place; there are many people who are eligible but they do not receive it because either they do not know about it, they think they are not eligible, or they gave up the complicated process of receiving it.

To apply for NHS continuing healthcare, you can make a request for an assessment to any health or social care professional involved in your care, or directly to the clinical commissioning group (CCG). Any individual 18 years and over who has substantial and ongoing care needs related to their health has the right to ask to be assessed.

First, there is an initial screening by the local CCG and then, if you pass this screening, there is the full assessment. The assessment will rate the individual’s level of need in a whole range of areas (12) from mobility to continence. These are sub-divided into different bands for scoring purposes (priority, severe, high, moderate, low and no needs). The levels will reflect the nature, intensity, complexity and unpredictability of your condition.

The NHS has nationally agreed criteria (the National Framework) for making decisions about eligibility, which should mean that they have been made consistently and fairly. Where urgent consideration of eligibility is required, for example where an applicant has a rapidly deteriorating condition, CCGs should accept and immediately action a properly completed Fast Track Pathway Tool recommending NHS continuing healthcare eligibility.

Challenging decisions

If you are turned down by the CCG, you could ask them to reconsider. If, after the assessment, you are rejected, you could challenge the decision via a two-stage process: a local review managed by the CCG, and an independent review panel. If all that fails, you can take your case to the Health Service Ombudsman.

Welfare benefits

After having had encephalitis, money can be a concern. Encephalitis and associated consequences may affect employment and a family's finances.

If the person who has had encephalitis was employed before they were ill, their employer should pay them in line with any company sickness package or at least ensure they receive Statutory Sick Pay. This can be paid for the first 28 weeks of an illness.

Claiming benefits can also help to ease the pressure. However, the process involved is often not easy. The system is complex and can be confusing. Applying for benefits can be a frustrating experience, especially for someone who has problems with memory or communication (e.g. understanding, talking).

Some after effects are not picked up in the assessment process nor do the assessors have special training on encephalitis and acquired brain injury.

Sometimes you have already been assessed as being entitled to benefits. Your medical situation hasn't changed, but you find that your benefits have suddenly been stopped. When mistakes are made regarding your entitlement to benefits, it can make things extremely difficult financially for you and your family. Furthermore you may find yourself in the position that you need to challenge and appeal against these decisions.

Specialist support provided quickly and efficiently can help you resolve financial issues and get you back on track.

Safeguarding

Safeguarding means protecting a person's right to live in safety, free from abuse and neglect. Abuse can be financial or material, physical, psychological, sexual, neglect, psychological, domestic, organisational, discriminatory. Abuse may consist of single or repeated acts. Abuse can occur anywhere. Any form of abuse or neglect is unacceptable .

A range of organisations (e.g. social and health care facilities, the police, educational institutions, housing institutions, local authorities) must be aware and follow safeguarding principles if they come into contact with children and adults at risk. An adult at risk is any person who is aged 18 years or over and at risk of abuse or neglect because of their needs for care and or support. However, in order to protect children and adults at risk, it is important that everyone (e.g. family, friends) should be aware of the possible signs of abuse or neglect.

Children and adults who have experienced encephalitis and subsequently a brain injury can be at risk of abuse. If you think that you or someone you know is being abused you should report it to the local authorities or tell someone you trust who can help you report it. This could be anyone such as a family member, a friend, a social, educational or healthcare professional, a police officer or someone else that you trust. You should seek consent to share information from the person being abused if safe, possible, and appropriate.

Supporting people when concerns are raised about abuse can be very distressing for everyone involved. Deciding what is the right thing to do can be difficult, especially if the person you are concerned about is reluctant to accept support. The responsibility for the investigation of concerns of abuse generally resides with the local authorities. Once notified, they have a duty to respond appropriately.

Encephalitis International can become aware of the welfare of children and adults within the context of providing support and when undertaking organised activities. We have a duty to safeguard and promote the welfare of children and adults at risk; this includes reporting abuse to the relevant authorities. Encephalitis International's safeguarding policies are available on our website (www.encephalitis.info/safeguarding).

Other sources of support regarding safeguarding issues:

- **NSPCC Helpline** 0808 800 5000 or email help@nspcc.org.uk.
- **Age UK Advice Line** 0800 678 1602 or email contact@ageuk.org.uk.

If you think that somebody is in immediate danger please contact the Police on 999.

About Encephalitis International

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

Key services provided by Encephalitis International

- Website which contains all our information about encephalitis, including useful factsheets. www.encephalitis.info
- Telephone / email support line / online chat for advice, support and information about encephalitis. Call us on +44(0)1653 699599 or email support@encephalitis.info
- Team Encephalitis Volunteer Scheme which is an expanding network of global volunteers.
- Meetings and events (face-to-face and virtual) for all the family.
- Connection Scheme which connects people affected by encephalitis.
- Seminars, training and education about encephalitis which are provided to health, social care, legal and education professionals.
- World Encephalitis Day (22 February each year) which raises awareness about encephalitis worldwide.
- Research into encephalitis by funding, collaborating and participating in research with medical and academic partners.

Further information about our services and events can be found at www.encephalitis.info or by contacting us on +44(0)1653 692583 or admin@encephalitis.info.

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TeamEncephalitis
Volunteer Scheme

Support Encephalitis International!

Join our community

Help us have a bigger presence worldwide and show the real impact of this condition. Call us on +44(0)1653 692583 or online at www.encephalitis.info

Be part of Team Encephalitis

Encephalitis happens everywhere in the world. Join our Team Encephalitis Volunteers, a network of worldwide Information, Support and Awareness Volunteers and help us reach out even further.

Call us on +44(0)1653 692583 or email admin@encephalitis.info

Help us raise awareness

Most people who haven't been touched by encephalitis, still haven't heard of it or the impact it has on families. Help us spread the word by taking part in World Encephalitis Day – 22nd February.

Call us on +44(0)1653 692583 or email comms@encephalitis.info

Connect with us on social media: Facebook, Instagram, Youtube and Linkedin (details on the back cover).

Take a challenge

Visit www.encephalitis.info/events to join one of our fundraising challenge events.

Give a regular gift and support life-changing encephalitis research.

If you have found this information helpful, please consider making a donation to help us continue our life-saving work in the future.

By donating £10 per month, you can enable new pioneering research into encephalitis, helping to build a brighter future for the 1.5 million people affected each year by this devastating condition. Through new research, we can accelerate our understanding of encephalitis and aid the development of new treatments and therapies that will be truly life-changing for those with brain inflammation. Your regular gift will also ensure our support services can continue to offer vital help and information to people affected by encephalitis, both now and in the future. Without our amazing supporters, these initiatives would simply not exist.

For more information, visit www.encephalitis.info/donate or call +44(0)1653 692583.

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