The Encephalitis Society

Support, Awareness & Research for Inflammation of the Brain

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The Encephalitis Society is the operating name of the Encephalitis Support Group. Registered Charity Number: 1087843
Charitable Company registered in England and Wales Number: 4189027

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• To talk to someone about the illness
• To ask about recovery and rehabilitation
• To discuss getting back to work
• To discuss your child returning to school
• To find the services in your area that can help
• To be in touch with others

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Financing the work
Like most charities, The Encephalitis Society relies on its supporters to help achieve its aims. Donations from friends and families, grants from Charitable Trusts, gifts and services from corporate supporters and money from individual fundraising efforts all provide invaluable support.

Donations can be made:
• By Phone +44 (0)1653 692583
• By Text ENCE11 followed by an amount (e.g. £5) to 70070
• Online via our Just Giving page at www.justgiving.com/encephalitisociety for all our activities
• Online via our Just Giving page at www.justgiving.com/memorium in memory of a loved one
• By Cheque payable to The Encephalitis Society
• By Phone +44 (0)1653 692583 or email fundraising@encephalitis.info

You can make a real difference to the lives of people affected by Encephalitis by supporting us.

World Encephalitis Day
22nd February

World Encephalitis Day is the global day of awareness that takes place on February 22nd each year. Find out more at www.worldencephalitisday.org

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Awareness
We raise awareness through conferences, workshops and seminars for medical professionals, ensuring that they can recognise the early indicators of Encephalitis in their patients. We provide tailor-made training packages for health, education and social care professionals as well as collaborating with other health organisations.

We are also the driving force behind ‘World Encephalitis Day’. A global day of awareness that takes place on February 22nd each year. Find out more at www.worldencephalitisday.org

Research
Historically, research into Encephalitis has lagged behind that of other conditions. Encephalitis was seen as being relatively rare, about which little could be done. The Encephalitis Society has striven to change this and is proactive in the field of research, particularly in respect of its social consequences which have remained of secondary importance.

We promote, conduct and contribute to Encephalitis research by appointing leading medical and health care professionals to our Professional Advisory Panel. We conduct research and work in partnership with leading researchers and research institutions around the world. We are members of the Association of Medical Research.

We award grants for research into Encephalitis and hold annual competitions for medical and neuropsychology students.

Information
We have developed a comprehensive resource of evidence-based information comprising of factsheets, books, leaflets, DVDs and newsletters. This information is available in hard copy and also electronically from our website at www.encephalitis.info. In addition, our information is disseminated in various other ways such as speaking and exhibiting at a range of conferences and events around the world. Our health information is accredited by the NHS England Information Standard.
What is Encephalitis?

Encephalitis is inflammation of the brain. This is often caused by infection, usually viral, or by the body’s own immune system attacking the brain. In some cases the cause is never found. Survivors may be left with an Acquired Brain Injury (ABI), of varying degree and severity. It can occur at any age and can affect anyone.

The inflammation is caused either by an infection invading the brain, or by the body’s own immune system attacking the brain in error (Autoimmune Encephalitis).

Viruses are the most common cause of Infectious Encephalitis. Within the British Isles, the Herpes Simplex Virus (the cold sore virus) is the most frequently identified. Worldwide other viruses are responsible, many of which are transmitted by mosquito or ticks. In some patients the identity of the infecting virus is not conclusively determined despite extensive laboratory testing.

Autoimmune Encephalitis in some people is triggered by infection, in which case the term “Post-infectious Encephalitis” is used. Acute Disseminated Encephalomyelitis (ADEM) is a post-infectious Encephalitis in which the spinal cord may also be involved. Typically there is a delay of between a couple of days, to two to three weeks from the initial illness to development of Encephalitis.

There are also other types of Autoimmune Encephalitis. Some of these may vary by detecting a specific antibody that targets the brain. These conditions include Potassium Channel Complex Antibody-associated Encephalitis and N-Methyl-D-Aspartate-Receptor associated Encephalitis.

Symptoms

Infectious Encephalitis frequently begins with a flu-like illness or headache. 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 or drowsiness, to loss of consciousness and coma. Other symptoms include a high temperature, seizures (fits), aversion to bright lights, inability to speak or control movement, sensory changes, neck stiffness, or unconventional behaviour.

Autoimmune Encephalitis often has a long onset. Symptoms will vary depending on the cause but may include confusion, altered personality or mood, psychosis, convulsions or fits, memory disorders, hallucinations, memory loss, or sleep disturbances.

Diagnosis and Treatment

Diagnosis: Encephalitis is made when evidence of inflammation or swelling of the brain is identified. The range of possible symptoms and their rate of development vary widely, and are not just found in Encephalitis. Therefore making the diagnosis of Encephalitis can be difficult.

Investigations undertaken in hospital are likely to include a brain scan (CT or MRI) to show the extent of the inflammation, a brainwave test (EEG) to determine unusual patterns of brain activity and a lumbar puncture (LP) to detect inflammatory cells and infections in the spinal fluid.

Treatment

The first step is to ensure that the patient receives specific treatment for the cause of their Encephalitis. Where the Encephalitis is caused by infection, patients are treated with anti-viral and/or antibiotic drugs. It is important that these drugs are started promptly and as such they will often be started before a definite cause is found. Aciclovir is the most frequently used anti-viral drug. It is effective against Herpes Simplex Virus and is given into a vein. Unfortunately for many viral infections there are no specific treatments at present.

Because Autoimmune Encephalitis is due to the immune system acting inappropriately, treatment aims to modify the function of the immune system. These include drugs such as steroids, immunosuppressants or immunoglobulin (IV Ig) which contains antibodies collected from blood donors or plasma exchange which is the filtering of antibodies from blood.

The second aim is to treat the complications arising from the Encephalitis and to support the patient whilst they are not able to perform their usual bodily functions. Treatments with anti-convulsants to control seizures, or sedatives to reduce agitation may be required. Sometimes patients require Intensive Care treatment including ventilation (mechanical help with breathing).

Outcomes

Outcomes and the management

Inappropriate Behaviour or Poor Social Skills

Problems with Daily Living Skills

Fatigue/Sleep Disturbance

Memory Problems

Physical Difficulties

Problems with New Learning

Cognitive (thinking) Problems

Emotional Problems

Personality Changes

Emotional or Behavioural Consequences

Family, friends or colleagues

Assessments

Each person who has had Encephalitis will have different types of problems. Therefore each person may require, at various steps throughout their recovery, individual assessments so that their particular rehabilitation or therapy needs are addressed.

Assessments could include the following:

Neuropsychological Assessment

To discover any problems with the cognitive (thought processes), emotional and behavioural functions of the brain. These may include attention, concentration, memory, reasoning and speech, emotional and behavioural problems.

The Encephalitis Society now offers an in-house Neuropsychology Service. For more information on the service and how to make referrals please visit www.encephalitis.info/neuropsychology

Speech and Language Assessment

For physical problems, e.g. mobility, posture, balance, coordination, muscle weakness.

Physiotherapy Assessment

For physical problems, e.g. incoordination, emotional or behavioural consequences.

Speech and Language Assessment

To assess receptive and expressive language, understanding language and also any problems with swallowing.

Occupational Therapy Assessments

For skills that are relevant to independent living and returning to work.

Social Services Assessments

To assess any aids and systems to help reduce the loss and encourage independence is a central component.

No two cases of Encephalitis will have an identical outcome. Outcomes vary between those who are able to return to their former work and lifestyle (with perhaps only a slight change in their cognitive ability) to those left profoundly disabled, physically, cognitively or both. A small percentage of those affected by Encephalitis will need to remain in residential care for the rest of their lives.

Nerve cells may be damaged or destroyed in a single part of the brain (focal), many parts of the brain (multi focal) or across the brain (diffuse). The resulting condition is termed an Acquired Brain Injury (ABI). The loss of brain function from ABI can range from very minor impairment, such as some loss in speed of thinking, to more significant impairments. The degree and type of damage will vary according to the underlying cause, the severity of the inflammation and the parts of the brain affected.

Significant changes may occur in personality and in the ability to function day-to-day even if there is a complete physical recovery. Coming to terms with living with the brain injury may be very distressing and challenging for everyone concerned. The child or adult you know, or who you are, may have changed and the child or adult they have become, or you have become, may present with a number of problems. It is important to consider that it may take time for the individual and the whole family to adjust, in both practical and emotional terms, to their new situation.

Rehabilitation

Good rehabilitation is a holistic approach. It recognises the complex cognitive, behavioural, social, emotional and medical problems faced by people affected by Encephalitis and their families. It is a practical approach using the main strengths of the person affected, to develop coping abilities. It is also an educational process which helps the individual develop adaptive strategies for coping. Training in the use of compensatory aids and systems to help reduce the loss and encourage independence is a central component.

Key Facts

• Encephalitis is inflammation of the brain.
• Inflammation is usually caused by infection or an inappropriate auto-immune response.
• There are up to 6,000 cases of Encephalitis in the UK and potentially hundreds of thousands worldwide each year.
• Anyone can become ill with Encephalitis, at any age.
• Encephalitis has a variable mortality rate depending on the type of cause.
• As early treatment improves the outcome, anti-virus treatment will often be started before a specific cause has been found.

• The Acquired Brain Injury (ABI) that may be caused by Encephalitis can result in a wide range of symptoms.

Death from Encephalitis

Encephalitis has a different risk of death and disability depending on the underlying cause. When death occurs it is usually a result of the brain swelling because of inflammation. The brain is encased in a hard shell (the skull) and when it swells it can push downwards onto the brainstem. The brainstem is a part of the brain that controls the vital functions of breathing and heart rate. When the brainstem is subjected to severe pressure it will function normally.

Recovery

With improvements in drug therapy and intensive care treatments, many more people survive Encephalitis than before. The acute phase of the illness (the time of active brain inflammation) can last anything from a few days to two or three months. This may be followed by a phase of fairly rapid improvement which slows down but can continue over a sustained period. Many people feel that they need rest and a slow, gradual return to normal activity, including school and work. Recovery can be a long, slow process and should not be rushed.

Advice for friends and family

Hospital visits may need to be kept short, and visitors should not overwhelm the affected person with too much information. People with long-term Encephalitis may suffer from memory problems or have difficulty controlling their emotions, for example they may become easily upset. Friends and family need to be aware of this and try to avoid causing undue stress.

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