Encephalitis International
The brain inflammation non-profit

What is encephalitis?

Information booklet

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About this booklet

This booklet is for people affected by encephalitis, their families, friends and carers. It provides key information about the symptoms, diagnosis, treatment and effects of encephalitis to help people come to terms with what happened to them and know what to expect in the future. It also gives information about prevention and travel advice.
More detailed information on encephalitis can be found on our website www.encephalitis.info

If you would like information on the source material and references used to write this booklet please contact support@encephalitis.info

DISCLAIMER
The information presented here is not reflective of every situation where encephalitis is involved and some of the information may not be relevant to every patient. Information provided in this booklet is designed to support, not replace, the relationship that exists between a patient and medical professionals.

Should any of the information raise issues or give you reasons for concerns we would ask you contact us on +44 (0) 1653 699599 or support@encephalitis.info

Thank you to
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What is encephalitis?

Encephalitis is an inflammation of the brain. Anyone at any age can get encephalitis. There are up to 6,000 cases in the UK each year and potentially hundreds of thousands worldwide. In the USA there were approximately 250,000 patients admitted to hospital with a diagnosis of encephalitis in the last decade.

Causes of encephalitis

The inflammation is caused either by an infection invading the brain (infectious encephalitis) or through the immune system attacking the brain in error (post-infectious or autoimmune encephalitis). Viruses are the most common cause of infectious encephalitis (e.g. herpes viruses, enteroviruses, West Nile, Japanese encephalitis, La Crosse, St. Louis, Western equine, Eastern equine viruses, measles and tick-borne viruses). Any virus has the potential to cause encephalitis, but not everybody who is infected with these viruses will develop encephalitis. Very rarely, bacteria, fungus or parasites can also cause encephalitis.

Some types of autoimmune encephalitis, such as acute disseminated encephalomyelitis (ADEM), are caused by infection in which case the term 'post-infectious encephalitis' is used. Other forms of autoimmune encephalitis are associated with finding specific antibodies in blood such as such as anti-LGI1, CASPR2, NMDA receptor, AMPAR, GABA and other antibodies. Antibodies, also called immunoglobulins, are large Y-shaped proteins which identify and help remove foreign antigens such as viruses and bacteria. The reason why these antibodies are produced by the immune system in people with autoimmune encephalitis is not known in most cases. Sometimes a tumour (benign or cancerous) or an infection may generate the antibody.

In approximately half of the patients, the cause of encephalitis cannot be found despite extensive laboratory testing.

Symptoms of encephalitis

Infectious encephalitis usually begins with a 'flu-like illness' or headache followed by more serious symptoms 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 uncharacteristic behaviour.**

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, seizures, hallucinations, memory loss, or sleep disturbances.**

Diagnosis of encephalitis

Symptoms alone often are not sufficient to distinguish between the many diseases that can look like encephalitis. Therefore, doctors perform a variety of hospital tests such as lumbar puncture (spinal tap), brain scans (computerised tomography–CT or magnetic resonance imaging– MRI), electroencephalogram (EEG) and various blood tests. Sometimes, some of the tests cannot be taken immediately because of the patient's medical state (e.g. patient is agitated). Nevertheless, it is important that investigations are carried out as soon as possible as **prompt diagnosis reduces mortality and improves the outcomes.**

When making a diagnosis, the doctor will consider the history of the illness, the results of the tests, the symptoms, and the patient's reaction to the treatment if any given.

Treatment of encephalitis

Treatment of patients with encephalitis has two aims. Firstly, the patient will receive specific treatment for the cause of their encephalitis: antivirals for viral types of encephalitis (e.g. aciclovir for herpes simplex encephalitis); antibiotics for bacterial types and immunotherapies for autoimmune encephalitis (e.g. steroids, intravenous immunoglobulin, plasma exchange, rituximab). For some types of encephalitis there is no specific treatment aimed at the cause (e.g. West Nile encephalitis). Secondly, treatment is aimed at the symptoms and complications arising from encephalitis (e.g. seizures, agitation) and to support the patient whilst they are not able to perform their usual bodily functions (e.g. ventilation, insertion of a urinary or a feeding tube).

Some of the drugs (e.g. steroids) have potential side effects but also important benefits. In each patient the risk-benefit balance may vary, so the choice of treatment depends on each individual case. It is important that **the treatment is started promptly, sometimes before a definite cause is found, as delay in treatment can be associated with unfavourable outcomes.**

Sometimes a patient may be placed in a medically induced coma which is a temporary coma brought on by a controlled dose of drugs to shut down the brain and allow time to recover from the swelling caused by encephalitis. The doctors decide the length of the coma depending on the extent of injury and the way the patient reacts.

During and after the acute phase of encephalitis the patient may be uncharacteristically uncooperative, aggressive and even violent (acute confusional state). During this time, the patient is not aware of their behaviour or the impact it has on those around them or able to control it. When in this state, patients benefit from a 'low stimulation' environment. This means a quiet environment in which noise (e.g. from the television or telephone) and visits from others are minimised.

The after-effects of encephalitis

Nerve cells (neurons) may be damaged or destroyed and this damage is termed acquired brain injury (ABI). The damage may vary according to the cause and the severity of the inflammation, the area of the brain affected and any delay in treatment. No two people will have the same after-effects. These effects can be long-term and hidden (more cognitive, emotional and behavioural than physical).

In children, injury to the parts of the brain that are not developed at the time of the illness can manifest later in life, well after the illness with encephalitis.

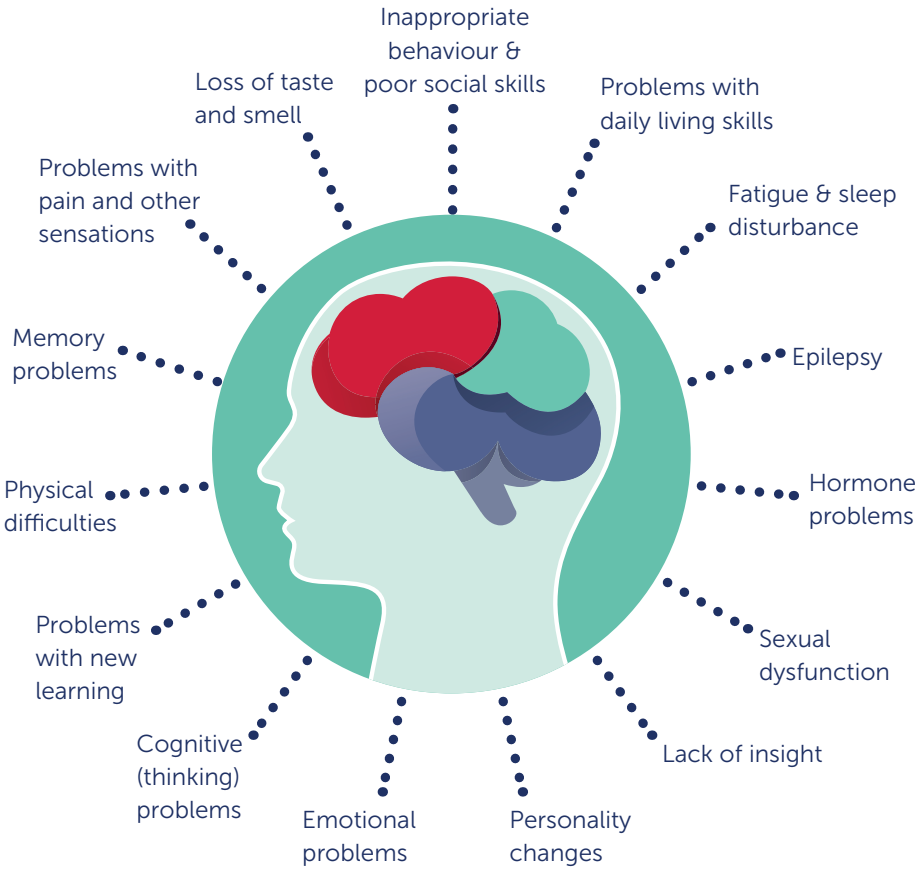
Tiredness, recurring headaches, difficulties with memory, concentration, balance, mood swings, aggression, clumsiness, epilepsy, physical problems (weakness down one side of the body, loss of sensations and of control of bodily functions and movement), speech and language problems, reduced speed of thought and reaction, changes in personality and in the ability to function day-to-day, problems with senses, hormonal problems and mental health difficulties may be reported. The potential impact on social and family relationships should not be underestimated. Returning to work and school can be difficult.

Recovery and rehabilitation after encephalitis

The brain takes much longer to recover from an injury than other parts of the body such as muscles, bones and skin. Recovery can be a long and slow process and should not be rushed. The main aim of rehabilitation is to help the person affected by encephalitis develop new skills, habits and strategies for coping with their remaining difficulties. Depending on the nature of the person's problems, rehabilitation may range from residential programs to home-based client services. The needs of each patient are unique and multiple. **Input from various professionals, tailored to the individual needs is necessary** (neuropsychologist, educational psychologist, occupational-therapist, speech and language therapist, physiotherapist, psychiatrist, dietician and/or nurses specialist).

Coming to terms with the problems left by encephalitis can be potentially distressing and challenging for everyone concerned. Unlike other parts of the brain, you cannot see the brain injury or the brain repairing. People assume all is back to normal when in fact some areas are still in recovery. **Encephalitis can be described as an invisible disability which affects not only one person, but the whole family.** Emotional support for the whole family may be needed.

OUTCOMES AFTER ENCEPHALITIS



Bereavement

Unfortunately, despite improvements in specific and more supportive treatments (i.e. intensive care management), encephalitis still has a high mortality rate (10–40%) depending on the type of encephalitis and the disease course. 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 counselor, a doctor or voluntary organisations may be needed.

Prevention and travel guidance

Some types of infectious encephalitis such as mosquito-borne encephalitis (Japanese, West Nile and Dengue virus encephalitis), tick-borne encephalitis and rabies encephalitis can be prevented by taking adequate measures when living/travelling to areas with high incidence of these illnesses:

- wearing mosquito repellent, long sleeves and trousers to avoid being bitten and ensuring homes and communities are free from stagnant water
- taking vaccination if available (e.g. Japanese encephalitis, tick-borne encephalitis and rabies)
- adequate and prompt removal of the tick in case of the tick bite
- seeking medical attention immediately after the bite in case of rabies

If travelling to an endemic area, it is recommended that you check with your doctor if you need any vaccinations before your trip.

Other forms of infectious encephalitis (e.g. measles) may see an increase because of people's reluctance to get vaccinated. Please get accurate and reliable information about the risk of having the illness/complications opposed to the risk of vaccination.

How can Encephalitis International support you?

Encephalitis International provides information and support to people affected by encephalitis, their families and friends worldwide; provides information and educational opportunities for health and social care professionals; raises awareness of this condition; and conducts and promotes research into the condition.

The support services include:

- Helpline via telephone, email, or Zoom chat.
- Information about encephalitis and its consequences in hard copy or digital format via email, website, Youtube and podcasts.
- Opportunities to connect with other people via the Connection Scheme, Health Unlocked forum and in-person and virtual gatherings.
- Educational and networking events.

To access these services or for more information, please get in touch at:

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

"I just read your leaflet and found it very helpful. Reading this is giving us hope."

GLOSSARY

ANTIVIRAL DRUGS
drugs used for treating viral infections by stopping the virus multiplying.

COMA
A state of unconsciousness where a person is unresponsive and cannot be woken.

COMPUTED TOMOGRAPHY OF THE BRAIN
A brain scan which uses special x-ray equipment to create detailed pictures of your brain.

ELECTROENCEPHALOGRAPHY
A procedure which involves attaching special sensors called electrodes to the head measuring and recording the electrical activity of the brain.

IMMUNOGLOBULIN
A blood product given into the vein in a drip which can help regulate an overactive immune system.

IMMUNOMODULATORY DRUGS
Drugs used to reduce the response of the immune system.

MAGNETIC RESONANCE IMAGING OF THE BRAIN
A brain scan that uses strong magnetic fields and radio waves to make pictures of your brain.

PLASMA EXCHANGE
Some of a person's blood is taken out from a vein, and the plasma part of the blood (which contains antibodies) is separated and replaced with new plasma. This is then put back into the vein in a drip.

PSYCHOSIS
When you perceive or interpret reality in a very different way from people around you.

LUMBAR PUNCTURE (SPINAL TAP)
Procedure which involves passing a needle, under local anaesthetic, between two of the backbones at the base of your spine to collect the cerebrospinal fluid (CSF).

STEROIDS
Drugs used to reduce inflammation.

How can you get involved?

Keep in touch with us
Help us have a bigger presence worldwide and keep up-to-date with all our news and activities
www.encephalitis.info/keep-in-touch

Submit your story
Your stories help to raise awareness of encephalitis and inspire others whose lives have been touched by encephalitis.
www.encephalitis.info/submit-your-story

Take part in research
Help scientists and researchers advance the understanding and management of encephalitis in order to save and improve the quality of lives.
www.encephalitis.info/research/research-currently-recruiting

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.
www.encephalitis.info/world-encephalitis-day

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

Take a challenge
Visit www.encephalitis.info/fundraise-for-us to join one of our fundraising challenge events.

Donate now
If you have found this information helpful, please consider making a donation to help us continue our life-saving work in the future.
www.encephalitis.info/donate

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