

## FACTSHEET

# Encephalitis

Encephalitis is a rare but serious condition which causes inflammation of the brain and can have serious debilitating and life-threatening consequences. The earlier treatment is started, the more successful the outcome will be.

### What is encephalitis

Encephalitis is a rare but serious condition which causes the brain to become inflamed either through infection or through the body's own immune system attacking the brain.

It can affect anyone at any age and its impact can vary greatly but the earlier treatment is started, the more successful the outcome is likely to be.

### Types of encephalitis

**There are two main types of encephalitis:**

- Infectious encephalitis – viruses are the most common cause and of these, the herpes simplex virus is most frequently identified. It may also be caused by bacteria or parasites, but these are more rare.
- Autoimmune encephalitis – this form occurs when the body's own immune system attacks the brain. This occurs occasionally following an infection such as acute disseminated encephalitis (ADEM) but the majority of this form are associated with a finding of specific antibodies in the blood (for example, VGKC complex or NMDA, GAD, AMPAR and GABA antibodies). Sometimes the cause may be due to a tumour (benign or cancerous) but generally it is unknown what causes these antibodies to be produced in most cases.

## What are the symptoms?

In infectious encephalitis symptoms may begin with a flu-like illness, such as a high fever and headache followed by more serious symptoms hours, days or few weeks later, including:

- disorientation, confusion or drowsiness, to possible loss of consciousness
- seizures
- aversion to bright lights
- high temperature
- behavioural changes
- difficulty in speaking
- weakness or loss of or inability to control movement

Autoimmune encephalitis has a longer onset, in some cases months or even years, and the symptoms will vary depending on the type of antibody but will likely include any of the following:

- confusion
- seizures
- altered personality or behaviour / psychosis
- hallucinations
- movement disorders / clumsiness / unsteadiness and falls
- sleep disturbances, including difficulty sleeping at night, excessive sleepiness during the day, sleep walking, talking in sleep, obstructive sleep apnoea
- memory loss

## Diagnosis and Treatment

The symptoms and history at presentation will provide some indication of the condition but medical tests will be required to confirm the diagnosis of encephalitis. These may include a lumbar puncture to take a sample of spinal fluid for testing, brain scans (CT and / or MRI) which may show an specific area or appearance typically associated with encephalitis, an electroencephalogram (EEG) which may also indicate patterns typical in encephalitis and also blood tests for signs of infection or antibodies.

In all cases, treatment is required urgently and so if there is any delay in carrying out investigations, this should not delay treatment which should be started immediately.

Specific treatment will be required for the underlying cause of encephalitis. This will be anti-viral medication for viral infections such as acyclovir for herpes simplex encephalitis; antibiotics for bacterial types and medications known as immunomodulatory drugs for the autoimmune types. These will be based on each individual's clinical features and test results but may include intravenous steroids, intravenous immunoglobulins, plasma exchange and immunosuppressant drugs.

Treatment is also required to treat and support the symptoms and complications that may arise. This may involve a period of ventilation to assist with breathing and a feeding tube to provide nutrition or it may be additional medication such as treatment for seizures.

## After-effects and Rehabilitation

Encephalitis affects people differently and recovery will likely be a long process. It is a distressing and challenging period for those affected and for the whole family. Some people may recover fully and be able to work and live independently while others will be left with significant long-term problems needing help with everyday living and be unable to work.

Long-term effects may include memory loss, personality or behavioural changes, seizures, difficulties with attention, planning, and problem solving. Sometimes the after-effects may be subtle but can still have a significant effect on a person's ability to function as they did before. Coming to terms with this is difficult and you will need help in rebuilding your life.

In these circumstances tailored input from a range of professionals will be required to aid rehabilitation for greater independence and provide emotional support and coping strategies not just to the affected person but for the whole family.

## Further information and Support

However you or a loved one may be affected, the Encephalitis Society, [encephalitis.info](https://www.encephalitis.info) will provide further information and support for people living with encephalitis. The Encephalitis Society is committed to raising awareness, raising standards and is at the forefront of research into causes, treatments and outcomes in this area.

## Clinical negligence

Our NHS provides an outstanding service for the most part but sadly mistakes do happen. If you feel mistakes may have been made leading to a delay in diagnosing and treating your encephalitis or that of a loved one, you, or they, may be entitled to compensation.

Moore Barlow has vast experience in dealing successfully with encephalitis claims. We understand that bringing a claim whilst living with encephalitis is not easy but we will support you through the process so if you have concerns about your own treatment or that of a loved one, please do call us for a free, no obligation discussion so we can advise you how we may help you.



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