

## Support Groups Aims

To offer information and support to survivors, caregivers, loved ones, and people who seek to understand

To raise awareness among relevant professionals, statutory agencies and the wider public about the condition and subsequent problems

To promote research into encephalitis

## Contact Information

*"A BIG Welcome to our group, there are lots of supportive loving and kind people here and we are here for you..."*

### World Wide

#### Encephalitis Global

International information and support

[www.encephalitis.ca](http://www.encephalitis.ca)  
[www.encephalitisglobal.com](http://www.encephalitisglobal.com)

#### Encephgroup

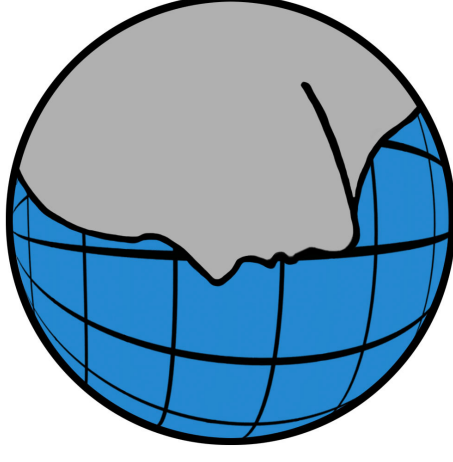
Encephalitis discussion forum

<http://groups.yahoo.com/group/encephgroup>

#### Encephalitis Stories

A collection of actual encephalitis cases

<http://members.aol.com/danielstown/encephalitis>



## Comments

*"... You look normal. You must be normal. I cannot believe in my wildest dreams that one does not see the results of encephalitis. It is a brain injury, and it's clear as a bell.*

*Personality is affected, just one clue. The being of who you were and what you could accomplish ... It doesn't go away. Sorry it doesn't go away. You can build and rehab to make it better. ...."*

*"People argue and say, "Memory loss? That's nothing! I forget stuff all of the time!" To which I reply, "Yes. You forget things two or three times a day. I forget things, two or three times an hour. Every hour."*

# Encephalitis

# We are here to help.

UK - Encephalitis Support Group  
Registered charity for encephalitis  
[www.encephalitis.info](http://www.encephalitis.info)

Yes! This document may be reprinted.

## What is Encephalitis?

Encephalitis is an inflammation of the brain. There are many types of encephalitis, most of which are caused by viral infection.

## Symptoms

Symptoms may include the following: confusion, drowsiness, headache, irritability, light sensitivity, loss of consciousness, memory loss, muscle weakness, poor judgement, seizures, stiff neck and back, sudden fever, sudden severe dementia, unstable walking and vomiting.

## The patient's view

Many of the symptoms you have been experiencing in the acute stage of your illness, especially the life threatening ones, are due to inflammation (swelling) in your brain.

Once this inflammation settles down, the problems caused by this begin to resolve and you start to regain normal consciousness and movement.

This moment can be a source of conflict between you and your friends and family. They have been through a very traumatic experience and may have been prepared to lose you, so their feelings are of relief and joy that you have survived.

You may remember nothing of the illness and in fact not even feel ill. You may be confused, even angry at finding yourself in a hospital. You may also find that your brain doesn't work as well as it used to.

-----  
*This information is intended as a general information discussion guideline only and should never be construed as medical advice.*

*For further information contact your local health care provider*

-----  
*If you have any question in your mind regarding any health concern, seek medical assistance from a qualified health professional*  
-----

## Advice to family and friends

Recovery is helped by a structured timetable of gradual mental activity followed by rest; rest periods should be long and activity periods short.

Hospital visits should be kept short, and visitors should not overwhelm the affected person with information, or questions.

People who have been ill with encephalitis often have memory problems. Research has shown that if they are asked to make a guess and give the wrong answer, they may remember the incorrect answer. They often become easily upset and have difficulty controlling their emotions.

## What is the prognosis?

The prognosis for encephalitis varies. Some cases are mild, short and relatively benign and patients experience a full recovery. Other cases are more severe, and permanent impairment or death is possible.

The acute phase of encephalitis may last for 1 to 2 weeks, with gradual or sudden resolution of fever and neurological symptoms.

Neurological symptoms may require many months before full recovery. The impact of encephalitis is often measured after a two-year recovery time frame, although improvements may continue after that time.

Some individuals will have permanent disability; be prepared for some loss of brain function. Compare this to the loss of a finger or hand from an accident. The only difference is that you and others may not see the difference. It can be a "hidden" disability.

Friends and family need to be aware of the possible effects and avoid causing undue stress.

Talking to others with the same problems can help. Encephalitis support groups can put you in touch with other people who are experiencing the same difficulties.