

## Objectives of Encephalitis Global, Inc.

- To support those affected by encephalitis by offering information, resources and hope;
- To create a network of survivors and caregivers sharing treatments, therapies and medications for optimal recovery;
- To raise awareness of encephalitis, striving for swift diagnoses, and optimal long-term treatments and therapies;
- To advocate for research in partnership with our survivor community, medical institutions and researchers;
- To encourage experts in encephalitis to partner for educational purposes; and
- To honor families whose loved ones have died of encephalitis.

## An Invisible Disability

Encephalitis can be an invisible disability, as a survivor appears healthy but is struggling with serious neurological issues. These invisible disabilities may include problems with learning, memory, attention, problem solving and behavior. Please be patient!



**Encephalitis Global, Inc.**  
Is a U.S.A. 501(c)(3) nonprofit  
organization which shares information  
and support internationally

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## An Attitude of Gratitude

“I have moved on from blissful ignorance of my disability, through overwhelming anxiety, resentment and anger to gratitude for what I have left, what I can do, and what may grow fuller in time. I can get better.”

James, encephalitis survivor

Yes! This document may be reprinted.

# ENCEPHALITIS GLOBAL, INC.

You are NOT alone...  
We are here to help!



**Encephalitis Global Inc.** is an alliance of persons impacted by encephalitis.

This group functions to connect encephalitis survivors and caregivers.

With this connection, we share information to alleviate unnecessary suffering and to raise awareness. By raising awareness, we also strive to prevent untimely death.

## General Information

### What is Encephalitis?

Encephalitis is an inflammation of the brain usually caused by a viral infection. Types of infectious (viral) encephalitis include herpes simplex encephalitis and mosquito-borne encephalitis. There are other types of encephalitis including autoimmune encephalitis, Hashimoto's Encephalitis, Rasmussen's Encephalitis, limbic encephalitis, ADEM (Acute Disseminated Encephalitis), HIV encephalopathy and postvaccinal encephalitis.

### Symptoms at Onset

In milder cases, symptoms may resemble the flu. In severe cases of encephalitis, symptoms may include some (or all) of the following:

Behavioral and personality changes, coma, confusion or disorientation, difficulty swallowing or breathing, extreme fatigue, fever, headache, inability to emote, lack of concentration, lethargy and reduced consciousness, loss of consciousness, memory loss, muscle weakness, partial paralysis, rash, sensitivity to light, seizures, speech, hearing and vision problems, stiff neck and back, tingling and numbness, and/or vomiting.

All of the information in this pamphlet 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 questions regarding health concerns, seek medical assistance from a qualified health professional.

## Early Phases

### Acute Phase

As herpes simplex encephalitis is progressive, antiviral medication such as acyclovir is often administered before a definitive diagnosis of HSE to improve chances for recovery and prevent complications.

In the case of autoimmune encephalitis the first treatment is usually high-dose steroids.

There is no cure for arboviral (mosquito or tick-borne) encephalitis and the goal of treatment is to relieve symptoms. Care may include:

- \* intravenous fluids to prevent dehydration
- \* antibiotics to prevent secondary infections
- \* diuretics to reduce intracranial pressure
- \* benzodiazepines to prevent seizures.

### Post Acute Phase

With an acquired brain injury, goal-directed therapeutic rehabilitation is often yielding good results. The rehabilitation program may include one or more of the following:

- \* Neuropsychological Testing
- \* Cognitive Therapy
- \* Speech Therapy
- \* Physical Therapy
- \* Occupational Therapy
- \* Balance Therapy
- \* Psychological Therapy
- \* Biofeedback or Neurofeedback

## Survivor Message & Prognosis

### Message to the Survivor

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 it has caused begin to resolve and you start to regain normal movement and consciousness.

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.

### 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.

Neurological symptoms may require many months before full assessment can be made.

Recent studies have focused on brain plasticity (neuroplasticity) - the ability of your brain to recover, repair, and regain functionality that had previously been lost.

Researchers have found that there is NO limit or deadline to brain recovery.