



**Encephalitis
International**
The brain inflammation non-profit



Encephalitis in adults

A Guide

Encephalitis in adults – a guide

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*"This book has been useful to refer to as and when things crop up, although we both read it all cover to cover."
(Family members)*

*"The guide you sent me is now my bible. You've given me a great insight and the guide has helped my family a lot too."
(Person affected)*

*"I wish I had this information sooner. I spent weeks not knowing what was going on with my husband after his encephalitis. Now I have read your guide I can see his recovery is everything should be expected."
(Person affected)*

About this guide

This guide provides information about encephalitis in adults from descriptions of the condition, its diagnosis and management through to important information and guidance on the stages that follow, such as recovery, rehabilitation and the impact on the family. The guide concludes with some information about our organisation and ways we can help each other.

The guide is very comprehensive; however, it is designed in a format in which people can dip into as and when they need it to avoid being overwhelmed by the information.

The aim of this guide is to enable people affected and their families/ carers understand what has happened to them, make informed decisions regarding their care, treatment and recovery and find ways of coping with the life changes brought by this illness.

We hope you find this guide useful. If you have any questions or feedback, please get in touch with us
support@encephalitis.info or +44(0)1653 699599.

Acknowledgements

This guide was developed after consultation with and feedback received from people affected by encephalitis and their families, volunteers and professionals.

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THANK YOU! Your contribution enabled us to produce this much-needed resource.



DISCLAIMER

No two people have the same course of the illness or the same effects. The information in this guide is not reflective of every situation where encephalitis is involved and/or may not be relevant to you/your family member. We have tried to ensure that the information presented here is accurate and reflects best practice at the time of publication. However, the information provided in this guide is designed to support, not replace, the relationship that exists between a patient and medical professionals. You must obtain specialist advice before taking, or refraining from, any action based on the content in this guide.

Should any of the information raise issues or give you reason for concern we would ask that you contact your health care professional and/or our Support Service: support@encephalitis.info or +44(0)1653 699599.

We used both professional experience and academic sources in writing this guide. If you would like information about the references used please contact our Support Service (contact details above).

SECTION 1:

ENCEPHALITIS THE ILLNESS

1

This section provides information about the acute illness: types of encephalitis, symptoms, diagnosis and treatment. While we have tried to provide information that fits an ideal scenario, we recognise that facilities for diagnosis, treatment and recovery vary greatly depending on geographical location.



Key facts

- Encephalitis is inflammation (swelling) of the brain.
- Anyone can get encephalitis irrespective of age, sex, nationality or culture.
- Each year, between 1 and 1.5 million people develop encephalitis worldwide.
- Encephalitis can be caused by an infection (e.g., virus, bacteria, fungus) or an inappropriate immune response. In some cases, a specific cause is not found despite extensive testing.
- The variety of causes and presentations, along with the rapid onset (often dramatic) may make the management of this condition a challenge for doctors.
- Early and adequate diagnosis and treatment improve the outcomes.
- The length of time spent in hospital (acute illness) can vary from days and weeks in some cases to months in others.
- Encephalitis has a variable mortality (death) rate depending on the underlying cause.



WHAT IS ENCEPHALITIS?

Encephalitis is inflammation (swelling) of the brain. Anyone at any age can get encephalitis but some people, like young children, can be more at risk than others. 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/autoimmune encephalitis). Encephalitis is different from meningitis. Meningitis means inflammation of the meninges (protective layers that cover the brain). Sometimes patients have both meningitis and encephalitis and this is called meningoencephalitis. In some patients, the cause cannot be found despite extensive laboratory testing.

TYPES OF ENCEPHALITIS

Infectious encephalitis

Viruses are the most common cause of infectious encephalitis. Many of these viruses cause infections elsewhere in the body such as stomach infections, skin rashes or cold sores, but not everybody who is infected with these viruses will develop encephalitis. For some types of viral encephalitis, there are vaccinations available.

Some of the viruses that can cause encephalitis are:

- Herpes viruses (e.g., herpes simplex virus, varicella-zoster virus, cytomegalovirus, Epstein-Barr virus).
- Enteroviruses and flu viruses.
- Insect-borne viruses (e.g., West Nile virus, Japanese encephalitis virus, La Crosse encephalitis virus, St. Louis encephalitis virus, Western equine, Eastern equine viruses, dengue virus, Zika virus).
- Tick-borne viruses.
- Measles, mumps and rubella.
- Rabies.

Bacteria, fungus and parasites can cause infectious encephalitis more rarely.

- Bacteria (e.g., mycoplasma, meningococcal, pneumococcal, listeria).
- Fungi (e.g., histoplasma, cryptococcus, candida).
- Parasites (e.g., malaria, toxoplasma).

POST-INFECTIOUS ENCEPHALITIS


Although viruses infecting the brain are a major cause of encephalitis, the body's reaction to a virus or other microbe can lead to encephalitis. This occurs when the immune system tries to fight off the virus and attacks the brain at the same time by mistake.

Acute disseminated encephalomyelitis (ADEM) is a post-infectious encephalitis. This illness usually follows in the wake of a mild viral infection or immunisations. Typically, there is a delay of days to two to three weeks between the triggering infection and the development of encephalitis.

AUTOIMMUNE ENCEPHALITIS

Other forms of encephalitis, in which the immune system attacks the brain in error, are called autoimmune encephalitis. They are associated with finding specific levels of antibodies in blood and/or cerebrospinal fluid (CSF). Antibodies, also called immunoglobulins are produced by the immune system to identify and help remove foreign agents such as viruses and bacteria. The trigger for the attack is not known in most of the cases. Sometimes a tumour may generate the antibody (e.g. ovarian teratoma, lung cancers).

Autoimmune encephalitis is often classified by the target of the antibody (this is not an exhaustive list):

- 
- LGI1 and Caspr2.
 - NMDA-receptor.
 - AMPA-receptor.
 - GABAA/B receptor.
 - GAD.

Factsheets for most types of encephalitis are available on our website – www.encephalitis.info/factsheets or from our Support Service: support@encephalitis.info or +44(0)1653 699599.

SYMPTOMS OF ENCEPHALITIS

Symptoms of encephalitis may reflect the specific areas of the brain affected by the inflammation and the type of encephalitis and so they can vary. However, different forms of encephalitis can have overlapping features.

Infectious encephalitis frequently begins with a flu-like illness (e.g., headache, high temperature). 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 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 vary depending on the type but may include confusion, altered personality or behaviour, severe psychiatric symptoms including psychosis, movements

that the person cannot control, clumsiness, difficulty walking, seizures, hallucinations, memory loss or sleep disturbances.

It is increasingly recognised that autoimmune encephalitis is more common than infectious encephalitis.

DIAGNOSIS OF ENCEPHALITIS

The range of possible symptoms and their rate of development vary widely and are not just found in encephalitis. There are diseases that can mimic encephalitis such as: bacterial meningitis, strokes, brain tumours, drug reactions, metabolic encephalopathy (neurological disorder caused by diabetes, renal or heart failure).


However, these illnesses are usually sufficiently different based on clinical assessments. Typically, the diagnosis of encephalitis is made by going through the symptoms and the history of the illness, looking at the results of the tests and, if available, understanding patient's response to treatment.

Tests, which can help confirm the diagnosis:

- **Lumbar puncture (LP) (spinal tap)**

This test allows a doctor to sample the cerebrospinal fluid (CSF). The CSF is produced within the brain and flows out at the base of the brain to surround and cushion the brain and spinal cord. All patients suspected of encephalitis should have a lumbar puncture as soon as possible unless there is a clear contraindication.

The procedure involves passing a needle, under local anaesthetic, between two of the backbones at the base of the spine. Approximately 10% of adult patients suffer a headache after this procedure. This headache is typically mild and worse upon being upright and better lying flat. It usually improves with simple painkillers and by drinking plenty of water. Some doctors advocate caffeine from tea or coffee to help with a headache.



Various laboratory tests are performed on CSF. Some tests give results within hours whereas others often take days. Immediate tests performed on CSF include analysis under the microscope to assess the number and type of white blood cells present. A raised number of white blood cells in CSF is indicative of inflammation within the brain, spinal cord or lining of the brain (meninges).

Other CSF tests are more complicated and include culture for microbes, antibody studies, or molecular tests to detect viruses or bacteria (polymerase chain reaction -PCR). The LP may often have to be repeated during an individual's illness.

- **Brain scans**

Computerized tomography (CT) or magnetic resonance imaging (MRI) scans may show the extent of the inflammation in the brain. In the early stages, brain scans may show nothing abnormal. Significant inflammatory changes may only occur later in the illness.

- **Electroencephalogram (EEG)**

EEG may help confirm a diagnosis of encephalitis by recording the slowing of usual electrical activity in the brain. It can also pick up seizure activity.

- **Antibody screening**

If autoimmune encephalitis is suspected, the blood and the CSF are screened for the antibodies associated with these diseases (e.g., NMDAR antibody, LGI1 antibody).

- **Other laboratory screening**

Blood, urine, as well as other body fluids can help detect and identify brain and/or spinal cord infection, or exclude other causes of encephalitis' mimics.

It should be noted that the results of the tests may depend on the time they were performed and are correlated with the evolution of the illness. It

is not unusual for the results of some tests to be 'normal' at the beginning of the illness, but then change during the illness.

TREATMENT OF ENCEPHALITIS

Treatment of patients with encephalitis has two objectives:


THE FIRST IS to ensure the patient receives specific treatment for the cause of their encephalitis, if there is treatment.

It is important that appropriate drugs are started promptly, particularly in the case of herpes simplex encephalitis (HSE), and even, before a definite cause is found. Therefore, patients may be given several different drugs at once.

In cases of viral encephalitis, patients are treated with antiviral drugs. Aciclovir is the most frequently used antiviral drug. It is effective against herpes simplex (HS) and varicella zoster viruses. Unfortunately, there are no specific treatments at present for many other viral causes of encephalitis. For bacterial causes of encephalitis, patients are given antibiotics.

As autoimmune and post-infectious encephalitis are due to the immune system attacking the brain, treatment involves suppressing the immune system, and may include:

- **Steroids** (drugs to relieve inflammation).
- **Intravenous immunoglobulin (IVIg)** (a blood product given into the vein in a drip).
- **Plasma exchange** (a person's blood is taken out from a vein, the plasma part of the blood, which contains antibodies, is separated and replaced with new plasma and this is put back into the vein in a drip).
- In addition, some patients are treated with other drugs, which further dampen down the immune system, such as cyclophosphamide and rituximab.



All treatments have potential side effects. In general, the risk of harm from any of these side effects is outweighed by the good that they do in patients with encephalitis. However, in each patient the risk-benefit balance may vary.

THE SECOND IS to manage the complications arising from encephalitis and to support the individual whilst they are not able to perform usual bodily functions.

Often this treatment, coupled with close observation, necessitates the patient being on an intensive care unit (ICU) or high dependency unit (HDU). Interventions may include controlling seizures (antiepileptic drugs), controlling brain swelling, sedation, supplying fluids, treating hospital-acquired infections and ventilation (mechanical help with breathing). Sometimes feeding has to be stopped for a while; it can be restarted using a nasogastric (nose to stomach) or orogastric (mouth to stomach) tube.

GUIDELINES FOR MANAGEMENT OF SUSPECTED ENCEPHALITIS

Treatment of encephalitis is effective if started promptly; in contrast, delays in treatment can be devastating. At the time of printing this Guide, Guidelines for Managing Encephalitis are waiting to be finalized. These guidelines intend to be a ready reference for clinicians encountering cases of encephalitis. They will be available from Encephalitis International's website (www.encephalitis.info/management-of-viral-encephalitis-guidelines) or Support Service: support@encephalitis.info or +44(0)1653 699599.

RELAPSES

Infectious types of encephalitis tend to occur only once. It is rare for infectious types of encephalitis to recur later in life. However, in the cases where there is worsening despite on-going treatment (Aciclovir), it may be due to insufficient doses (often based on the patient's body weight) or other complications of encephalitis may have developed, such as seizures. In the unusual cases in whom there is a recurrence of the infectious encephalitis early after stopping treatment (Aciclovir), it may be because the treatment was not given for a sufficient length of time. In these cases, it is often appropriate to restart treatment promptly. Nevertheless, in very few cases, there may be an early recurrence of the encephalitis after stopping treatment that is due to inflammation, even after the virus is cleared.

In some types of autoimmune encephalitis there is a recognised risk of recurrence, such as with NMDAR-antibody associated encephalitis. It is difficult to accurately predict who will relapse but if the risk of relapses is considered to be significant, treatment is often offered over a longer period of time. However, despite treatment a number of patients will still relapse. Recognition of potential relapses requires ongoing vigilance from the patient and their relatives and should be reported to the patient's neurologist quickly.

Recently, it has been discovered that viral encephalitis such as HSE may sometimes be followed by the development of anti-NMDAR-antibody encephalitis. Therefore, the patients will need to be treated again, but this time with immunotherapy.



DEATH AND BEREAVEMENT

Encephalitis is a serious condition. Unfortunately, despite the improvements in specific and more supportive treatments such as excellent intensive care management, it still has a high mortality (death) rate. When death happens it is usually because of brain swelling caused by severe inflammation. The brain is wrapped in a bony shell (the skull) and when it swells it pushes downwards onto the brainstem. The brainstem is the part of the brain that controls the vital functions of breathing and circulation. When the brainstem is under this type of a severe pressure it stops to function.

The rapid course of encephalitis can be traumatic and overwhelming. The fact 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. Death is always difficult for those who are left behind, but even more difficult when it is totally unexpected.

Encephalitis International's Support Service can talk through issues that family and friends may have, and, if appropriate, put bereaved families in touch with each other. Such sharing of difficult experiences is known to help the grieving process for some people.

FURTHER INFORMATION

Factsheets Death from encephalitis and Dealing with bereavement are available from our website www.encephalitis.info/factsheets or Support Service: support@encephalitis.info | +44(0)1653 699599

Our podcast on Death from encephalitis is available on YouTube: www.encephalitis.info/the-encephalitis-podcast

VACCINE-PREVENTABLE ENCEPHALITIS AND TRAVEL HEALTH

Encephalitis can be a complication of vaccine-preventable diseases such as Japanese encephalitis (JE), tick-borne encephalitis (TBE), influenza (flu) virus encephalitis, varicella-zoster (chicken pox) virus (VZV) encephalitis, rabies, Dengue fever, and encephalitis caused by measles, mumps, rubella (MMR).

These infections can be transmitted from human-to-human and are highly contagious (e.g., one infected person can transmit measles to nine other non-immune/not vaccinated people) or can be transmitted from a bite of a mosquito or a tick. Not everyone with these infections will develop encephalitis, but a proportion of people will develop it. Some individuals (e.g. babies, elderly, people with compromised immune system) may be at risk of acquiring these infections and thus have an increased risk of encephalitis.

It is vital that people seek advice from their doctors about vaccines and other routine immunisations, for themselves and those they care for.

Some of the vaccine-preventable encephalitis types mentioned above are endemic in different parts of the world. It is important to check with a doctor and/or travel clinic about vaccination requirements and the risk of the illness, but also about the consequences of acquiring the infection and possible encephalitis.

For more information on the specific vaccine-preventable encephalitis types, please visit our website

www.encephalitis.info/types-of-encephalitis/

SECTION 2: BEING IN HOSPITAL

Being in hospital can be a confusing and stressful time for the person affected and their family/friends. This section provides some ideas about how you and your family members can navigate through this time.

2



Key facts

- Being in hospital can be a challenging experience for the whole family.
- The person affected may be seriously ill and even in a coma.
- Brain injury can be a consequence of encephalitis and it is difficult to appreciate the extent of this in the early stages.
- When the inflammation begins to resolve the person affected may not remember anything from being ill.
- The patient's behaviour may be bizarre. This is common and called an acute confusional state.
- During an acute confusional state, the patient benefits from being in a quiet environment and visitation should be minimised.
- It is good practice to have everything in place at home before discharge from hospital (e.g. care, adaptive equipment).
- Any concerns you have about the hospital stay need to be raised with the hospital staff in the first instance.
- If you care for a person affected by encephalitis, remember your own needs as you can't help them if you don't take care of yourself.



MEDICAL MANAGEMENT

On admission to hospital and regularly throughout the patient's stay, nursing staff will conduct careful and repeated observations. These include recordings of temperature, pulse, level of awareness, respiration rates, blood tests, input and output of any fluids.

The patient may also need:

- A catheter inserting in place of using the toilet.
- A tube into the nose (nasogastric tube) in order to provide essential nutrients and fluids if they are at risk of choking on food or drink.
- A percutaneous endoscopic gastrostomy (PEG) tube into their stomach ensuring that sufficient levels of nutrition and fluid are received if long-term artificial feeding is required.
- An intravenous line inserted into a vein enabling essential drugs to be administered as and when necessary.
- Anti-embolism stockings or regular blood-thinning injections to reduce the risk of a deep vein thrombosis (DVT) (blood clots) which there is increased risk of developing if they are immobile in bed.

The Glasgow Coma Scale (GCS) is used to assess levels of consciousness, via eye opening, verbal and motor responses. The scale is also used to classify brain injury as 'mild', 'moderate' or 'severe'. The scores are monitored over time and a deterioration is reported immediately to doctors by nursing staff.

Sometimes a patient may be placed in an **induced coma**. An induced coma is a temporary coma brought upon by a controlled dose of drugs to shut down the brain and give time to recover from the swelling caused by encephalitis. The doctors decide the length of 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. This may be due to the impact of swelling and inflammation in the brain on emotion and behaviour both during the illness and soon after, resulting in a **post-acute confusional state**. This state can persist in the early stages of recovery. The family must realise that this behaviour is not within their relative's control. They are not aware of their behaviour or the impact it is having on those around them. The image of a patient who experiences injury to the brain and perhaps coma, who is subsequently calm, awake and serene to the delight of their family is a myth perpetuated by television and other media. The patient is more likely to be confused, disoriented, aggressive and rude. It is not unusual for patients to run away from their bed during these stages of agitation.

These experiences are distressing for all and can present a number of management problems for those trying to care for these patients. If you feel somebody is at risk, discuss your concerns with the nursing staff. They may be able to reassure and show you strategies or interventions they have in place to minimise risk. Sometimes nursing staff use bedrails to prevent injury, especially where there is concern about seizures. However, if patients are very agitated, it may be necessary to nurse them on a specially adapted bed that lowers to the floor. This prevents any secondary injuries caused by falling.

ADVICE FOR FAMILY AND FRIENDS

Many of the symptoms in the acute stage of the illness are due to inflammation. Once this inflammation settles these symptoms begin to resolve. However, cognition may be impaired and there may be behavioural changes or physical disability.

Friends and family will have feelings of relief and joy that their loved one has survived. However, the person who has been affected may remember

nothing of the illness. They may be confused and even angry at finding themselves in hospital. This can be a testing time for all.

People who have been ill with encephalitis often have memory problems. Research has shown that in the early stages it is important to provide the appropriate information rather than asking patients to 'guess'. That is, say *"This is Uncle Tom"* as opposed to *"Who is this?"*

Seeing your family member/friend in hospital can be a very distressing experience. Most of you will not have heard of encephalitis before. Trying to communicate with the hospital doctors and nurses can sometimes seem difficult.

Lack of information or too much specialised information can also be very daunting. You may not understand medical terminology. Practical issues such as lack of sleep, time to eat, no appetite and losing touch with family and friends can all add to the impact the illness has. At times, you may feel helpless, isolated and confused.



Below there is a list of things which may help

- Create a quiet and familiar environment around your family member/ friend. They will probably benefit from having lots of rest. It is best not to encourage many visitors and additional noise such as television, telephone conversations or other stimuli.
- Try and talk to your loved one and explain what has happened if possible. Reassure them that you are there for them.
- Get to know the key staff involved in their care.
- Communicate with health care staff. Write down what you want to ask and take any opportunity to ask questions.
- Some hospitals provide Family Therapy, which may help you deal with the stress and emotions at this difficult time. Ask a member of staff if this is available in your hospital.
- Acknowledge your emotions and be aware that other family members may react differently.
- Contact Encephalitis International's Support Service. They may be able to answer your questions and provide information to help you understand the illness and know what to expect in the future.
- Get your family and friends to do some research and bring to the hospital some information about the illness and its consequences.
- Involve your friends and family in doing some chores for you. Take them up on their offer of help. If they have not offered, ask them to prepare some food, do some washing, shopping or look after your children. Some of them probably want to help but do not know how.



DISCHARGE FROM HOSPITAL

Planning for discharge should start from the moment you are admitted to hospital, and ideally be managed by the professional who is in charge of your care. You cannot be discharged if your condition is unstable. When it is time for your discharge, you should be offered a discharge assessment to ensure that support and care will be provided to meet your needs. You and/or your carer should be involved in this assessment so that the discharge plan is as realistic and achievable as possible.

Each hospital has its own policies and arrangements regarding discharge. If you have any concerns regarding your discharge please raise them with the hospital staff

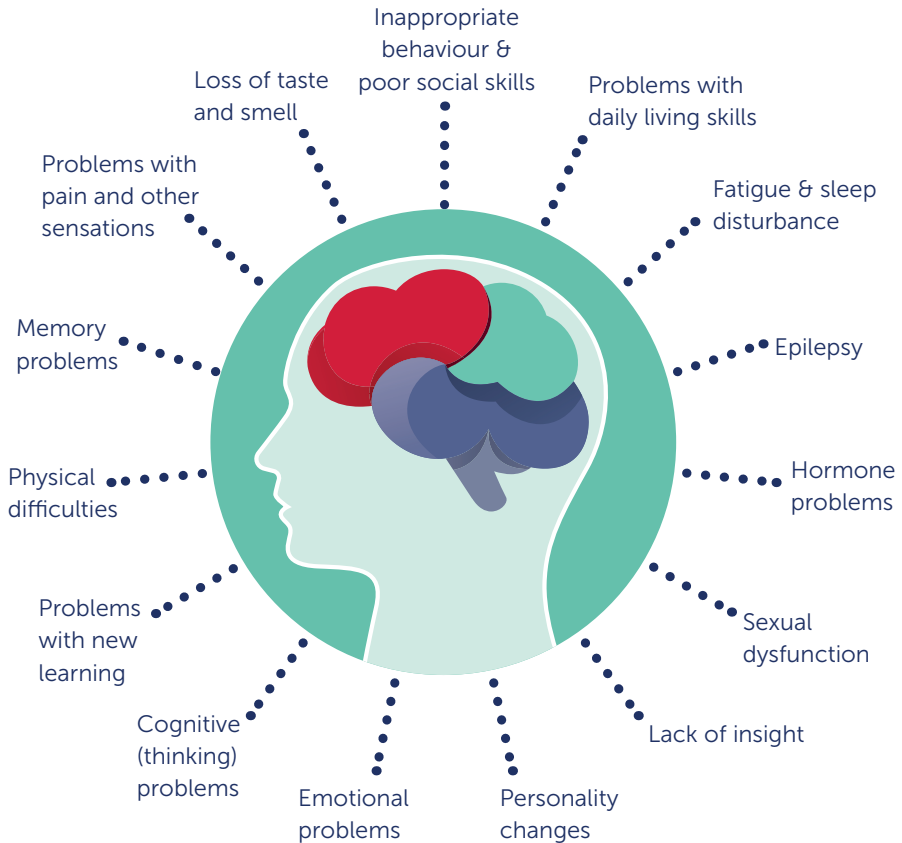
Considerations regarding encephalitis

You should be given an explanation of your diagnosis and information about possible effects. Most people affected by encephalitis are left with some form of acquired brain injury (ABI) and therefore discharge planning requires the involvement of other professionals for assessing the likely long-term issues.

Your problems may not be fully evident at the time of discharge from hospital. It is important to find out:

- The name and contact details of the doctor that treated you in hospital.
- Who you should contact in case there are problems following discharge.
- The services that you are being referred to so you can call them to discuss any problems (e.g., occupational therapy, physiotherapy, neuropsychology, speech and language therapy).

OUTCOMES AFTER ENCEPHALITIS



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SECTION 3:

THE EFFECTS OF ENCEPHALITIS

This section covers a broad range of effects of encephalitis on the brain and the kinds of problems that can be associated with encephalitis. Again, it is important to remember that every individual is unique and differentially affected. Some will experience none or only a few problems and others will experience severe, lifelong difficulties. Problems are described individually for clarity, but of course, their combined effect must also be considered.

3



Key facts

The effects of encephalitis vary greatly from one person to the next.

- In some people, encephalitis may cause an acquired brain injury (ABI).
- The degree and type of brain injury sustained will vary according to the cause, the severity of inflammation, the parts of the brain affected and any delay in treatment.
- The loss of brain function from ABI can range from minor impairments to ones that are more significant.
- There may be changes in thinking skills, emotion, behaviour, mental health and physical functioning.
- Although physical changes are easy to spot, changes in thinking skills can be subtle and difficult to recognise.
- Some of the effects of encephalitis become obvious when the person affected attempts to go back to work and school.



HOW THE BRAIN WORKS

In order to understand the effects of encephalitis on the brain, it can be helpful to know how the brain works. The brain is an amazing organ which controls everything you think, feel and do. All the various parts, that make up the brain, work together to help people communicate, move and behave.

The brain is made up of approximately 100 billion nerve cells (neurons). Each neuron makes between 1,000 and 10,000 connections to other neurones. This neural network is similar to the way roads connect to make road networks.

At birth, all the neurons you will ever have are present but there are very few connections. During early development, the neurons form trillions of connections. These connections are fine-tuned by the neurons' electrical activity: useful connections are maintained, some are added and others often disappear. A protective coating called the myelin sheath gradually covers axons that become regularly used. A good analogy is the covering a main road with tarmac allowing traffic to flow more freely.

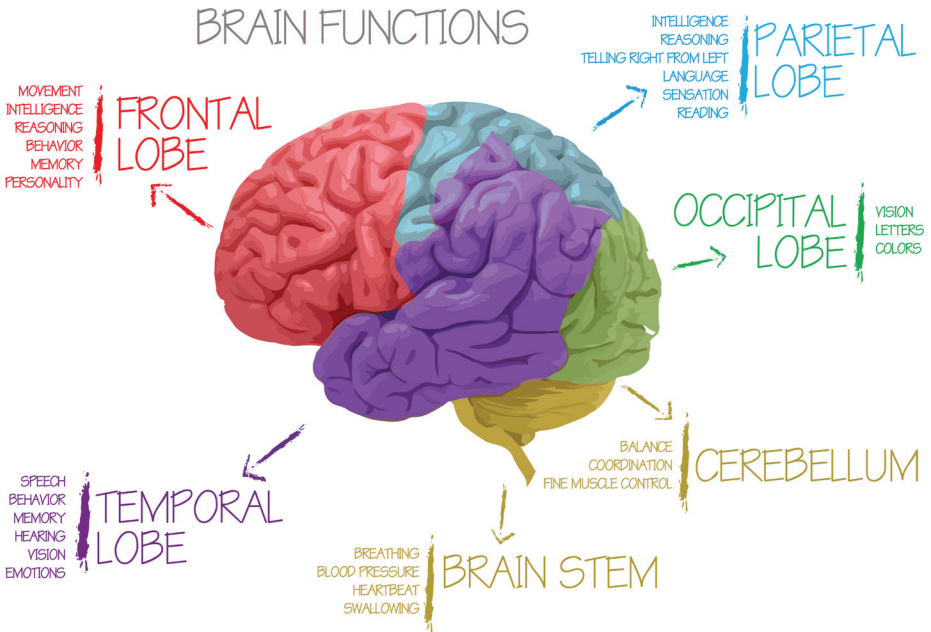
Neurons communicate with one another via specialised chemicals called neurotransmitters. Neurons transmit electrical and chemical signals, and this transmission of signals between neurons is how the brain functions.


The brain is protected by a blood-brain barrier, which prevents any large molecules passing from the blood into the brain. The blood-brain barrier acts very effectively to protect the brain from many common infections. Thus, infections of the brain are very rare. The outcome of any virus infection is dependent upon the ability of the virus to cause disease and the response of the immune system.

The immune response evolved to protect organisms against injury and infection by delivering white blood cells to sites of injury to kill potential pathogens and promote tissue repair. However, the powerful inflammatory

response also has the capacity to cause damage to normal tissue. Unfortunately, the immune response to an infection of the brain can contribute more to the disease process than the infection itself.

In infectious encephalitis, viruses entering neurons utilise components of the cell in order to replicate (make copies of themselves). This uses up energy stores and oxygen and damages the cell. In post-infectious/ autoimmune encephalitis, the immune system makes antibodies that cause damage to neurons or other brain cells. In both types of encephalitis, by-products of the immune system's actions (e.g., fluid, white blood cells, the contents of dead nerve cells and disabled viruses) can significantly alter the fluid surrounding neurons and affect their functioning. For instance, the characteristics of the cell membrane may be altered, disturbing the electrical properties of the neuron.





Swelling resulting from additional fluid entering the brain can interfere with blood supply causing anoxic (lack of oxygen) damage.

The extra-unwanted fluids build up rapidly. The glial cells try to absorb the unwanted chemicals and fluids in order to protect neurons from harm, and in the process, they swell up too.

Glial cells act as sponges and scavengers of toxic by-products, caused by the inflammation but when they become overloaded, they die and then re-release the toxic chemicals back into the fluid, where they kill additional neurons. The extremely high levels of these substances are sufficient to kill vulnerable and weakened neurons by damaging their membranes or by exciting them to a point where they 'burn out' and die.

At the site of inflammation and in nearby tissue, there is biological chaos, as the brain tries to adjust and fight the consequences of the damage. The dying cells give off chemicals that activate macrophages (white blood cells), which move from the bloodstream into the injury area, to absorb and eliminate debris. Glial cells and their helpers, which have gathered at the site to clean it up, now begin to form the scar tissue that will remain a part of the brain's new architecture. Sometimes, the glial barriers prevent healthy, remaining neurons from restoring axonal connections.

In other cases, nerve terminals cannot pass the scar, and abnormal activity is then generated that can lead to epileptic seizures.

COGNITIVE DIFFICULTIES

Cognition refers to the way we perceive, learn about and process the world around us. It can refer to mental processes such as those involved in information processing, memory, understanding, communication, problem solving, planning and organisation.

These processes underpin our everyday activities from running a household to maintaining friendships, working, driving and studying.

No single cognitive skill contributes alone to the success of completing each everyday activities. Rather, we rely on a number of cognitive abilities to perform tasks. For example, to make a telephone call we need to remember the number, the details of our relationship with the person and how to use a telephone; we must be able to produce speech, take in and understand what is said to us; and make a decision based on the information discussed.

Following encephalitis, an individual may experience changes in these cognitive abilities to varying degrees and, in turn, have trouble in their everyday activities.

Memory

Memory problems are common after encephalitis. They can have a devastating impact upon an individual's everyday functioning, including their sense of who they are. Memory function can be affected in different ways:

- Difficulties with learning new information such as remembering the names of people and places; following directions and finding locations; following the storyline of a book or movie; remembering recent conversations and remembering what they have to do at a future time, such as appointments or paying bills.
- Difficulties with recalling information from their past, before the brain injury.
- Difficulties trying to learn a new skill, a lesson at school or how to use technology (e.g., a new mobile phone).



Attention and concentration

Following encephalitis a person may be more distracted or find it hard to concentrate. Fatigue may also be an issue with poor mental stamina across the day. It may also be difficult to process and take in information quickly which may result in a slowness to answer questions or the need for increased time to complete tasks. Changes in attention and concentration abilities may lead to an overload of information and a sense of being overwhelmed by conversation or noise. It may be harder to keep up in conversation and difficult to think and respond quickly in an emergency.

Executive function

The term 'executive function' refers to complex cognitive skills required to identify and successfully complete goals. This includes abilities such as planning, problem solving, organisation, flexibility in changing a strategy and holding back (possibly inappropriate) responses. Difficulty in one or all of these areas occurs to varying degrees following encephalitis, having a significant impact on everyday life and relationships.

Poor planning and problem solving

Following encephalitis people may have difficulty solving problems, planning, organising things or self-monitoring. They or their family member may report that they are 'less organised' than they used to be. They may struggle to get to appointments on time, fail to complete tasks once started or have trouble juggling multiple tasks at work, making decisions or getting things done. They may be inflexible in their thinking, becoming fixed on one particular thought and unable to consider alternatives.

Lack of initiative


Following encephalitis, some people lose their 'get up and go', which makes it very difficult to start new activities or to finish what they have started. This reduced drive reflects the direct effect of encephalitis on the brain. It is distinct from 'not being bothered' or having low motivation due to loss of interest. Low mood can also add to a lack of drive and initiative.

Perceptual and visuospatial skills

Perception involves interpreting information that we receive from our senses. Following encephalitis, some people may lose the ability to recognise the taste of food or appreciate the difference between hot and cold. Some people lose the ability to judge distances and may appear clumsy. Other people may have 'neglect' for one side of pictures or their body; others may have difficulty recognising objects (agnosia) or people (prosopagnosia). The pattern of perceptual difficulties will depend on the areas of the brain affected by encephalitis and will differ from person to person.

Communication/language

Language problems are common after encephalitis. Many people experience word-finding difficulties and struggle to get their message across. As noted above, some people may also find it difficult to take in and process conversations so that an individual experiences an overload of information. Others may find it difficult to understand what is being said to them. When talking we need to choose which words to use and put them together. Communicating with others also requires that we take turns in conversations, interpret and respond to social cues, show interest in others, use humour appropriately and shift between topics of conversation. These aspects of communication may be affected following encephalitis to varying degrees. Changes may also occur to an individual's ability to



monitor the correct volume and speed of speech, with difficulty using the correct tone and inflections.

EMOTIONAL AND BEHAVIOURAL PROBLEMS

Social behaviour

Following encephalitis social behaviour may change due to cognitive difficulties (communication, impulsivity and memory) and emotional changes (anxiety, low mood and irritability). Individuals may have difficulty judging how to behave in social situations. Some individuals may appear to be self-involved with a lack of consideration for the feelings and needs of their family and friends. This lack of consideration and empathy can be very distressing for family and friends, leading to a strain on relationships.

Insight

Following encephalitis, an individual may have reduced awareness of their difficulties as a direct result of the brain systems affected.

It may be hard for them to recognise both changes in their thinking or behaviour and the effects they have on everyday life, including driving and working. They may appear to be 'self-centred' or 'lacking in empathy'. Conversely, an individual may also find it difficult to accept the impact of encephalitis (understandably) and deny that they have any problems.

Challenging behaviour

Changes to behaviour are common following encephalitis. For some individuals cognitive and emotional changes produce behaviours that are challenging to manage. For example, a person may be aggressive, sexually inappropriate or confused and vulnerable. Families and friends

may struggle to understand and cope with these new behaviours, which may reflect a very different personality to how the person was before encephalitis.

Frustration and anger

Expressions of anger and frustration may reflect the direct effect of encephalitis on the brain systems that control emotional responses. For example, following encephalitis a person may act inappropriately and say or do things without thinking due to changes in frontal system functioning. At the extreme, this may include acting with verbal or physical aggression. Frustration and anger may also arise from information processing problems, with a reduced ability to tolerate noise or multi-tasking. Frustration, irritability and anger may also be a response to everyday difficulties that arise from cognitive, motor or behavioural changes. For example, it can be frustrating to misplace belongings or not be able to get the words out when you want to. Other people may express frustration at not being able to return to work or join in their usual social activities.

Emotional lability

Following encephalitis, some people experience difficulty controlling their emotions and experience uncharacteristic extremes of emotion. They may become tearful more easily and without warning. Others laugh or smile inappropriately such as when being told a sad story or bad news. For some people the brain injury can cause what seems to be an absence of emotion. A person may intellectually 'know' that something is distressing, but they are detached from the experience and do not 'feel' the distress caused. Such emotional lability can be very confusing for the individual and their family.



Anxiety

Following encephalitis, some people may experience worry or anxiety. Anxiety is a common response to the new world that people find themselves in after encephalitis when trying to make sense of the cognitive, emotional and behavioural changes. Anxiety may also reflect the direct effects of encephalitis on the emotional regulatory centres of the brain. This means that the sense of threat is amplified or there is difficulty taking on feedback to dampen down a sense of anxiety.

Changes to self-esteem and confidence are common following encephalitis. Previous coping strategies may no longer be helpful. Some people experience worry and anxiety related to their memory and attention problems as they find it difficult to keep track of plans, what they have done or where they have put things.

Some individuals may experience extreme anxiety in the form of panic attacks, associated with a reduction in their usual activities. Other people may develop checking behaviours to help manage anxiety and develop a sense of control over their situation. This is different from increased checking due to memory problems.

Mental health

Encephalitis can cause mental health problems with symptoms ranging from mood changes to severe issues like suicidal thoughts. Treatment includes therapy and medication and recovery involves managing stress, fatigue, and finding coping strategies. It is important to maintain one's mental health after encephalitis, by undertaking regular exercise and perhaps connecting with others who have similar experiences.

Encephalitis International offers support through our support helpline, virtual gatherings, and our online information resources.

Impulsivity and disinhibition

Impulsive and disinhibited behaviour can manifest in a number of ways. The person may appear to lack 'tact' after encephalitis and be more direct or use offensive language. They may engage in risky sex practices that were not characteristic of them prior to this illness. Alternatively, there may be problematic use of alcohol or drugs. Impulsive, disinhibited and aggressive behaviour post encephalitis has a negative impact on families and relationships.

Personality change

People affected and families may report that they/their family member's personality has 'entirely changed'. For example, they may suggest that their partner is 'more laid-back' than they used to be or that they are now more 'extroverted' than was previously the case. Changes in personality typically reflect the direct contribution of the brain injury although emotional adjustment can also play a part.

Encephalitis can potentially also lead to or exacerbate obsessive-compulsive disorder (OCD) symptoms in some cases. The inflammation can disrupt normal brain function, potentially affecting areas involved in OCD-related behaviours and thought patterns. Some patients have reported sudden onset or worsening of OCD symptoms following encephalitis. However, it's important to note that not all encephalitis cases lead to OCD, and the relationship is complex and not fully understood.



PHYSICAL PROBLEMS

Fatigue and sleep difficulties

Fatigue is one of the most common and disabling problems people experience after ABI. Even activities which are considered to be relaxing such as reading a book or watching television can be tiring. The cause of fatigue is not clear but may be due to a range of things including changes in attentional systems, the extra effort required to compensate for cognitive changes, anxiety and depression.

Difficulties with sleep may also affect fatigue. Sleep problems may be a result of the brain injury itself or a result of fatigue, pain, stress, social consequences of the brain injury (e.g., difficulties returning to work, changes in family relationships). Sleep problems have a huge impact on an individual's cognitive, physical and emotional functioning and so influencing the recovery and rehabilitation.

Difficulties with movement, balance and coordination

The brain controls our ability to coordinate movement and balance. Following encephalitis people may experience paralysis, weakness, difficulty controlling their movement and/or dizziness. They may appear to be clumsy or unstable on their feet. Difficulties with movement can also be related to 'apraxia', which involves problems with translating 'intention' into effective 'action' with a negative impact on everyday activities including dressing and cooking.

Epilepsy and seizures

Seizures (fits) are the result of abnormal electrical activity in the brain. Seizures may occur during the acute illness and/or develop weeks, months, or even in some cases, years afterwards depending on the type of encephalitis. Seizures may be classified into different types depending on:

- Where in the brain the seizure starts: focal (one side of the brain), generalised (both sides), unknown.
- The level of awareness in case of focal seizures: focal aware or focal impaired awareness.
- Whether the seizure involves movement: motor seizures or non-motor seizures.
- When the seizure activity lasts for 30 minutes or more (most seizures are brief or last for a few minutes), this is termed 'status epilepticus'.

Sensory changes

Vision, hearing, smell, taste and tactile sensation can all be affected by encephalitis. Examples include changes in visual and auditory acuity, double vision or tinnitus. Partial or total loss of smell is called 'anosmia'. Where sensation is concerned, people may experience 'pins and needles', or difficulty gauging 'hot' and 'cold'.

Headache and pain

Headache can follow encephalitis. It, for example, may happen because of stress and tension, when the person tries to do too much, or may be a sign of anxiety. Pain can influence how a person functions cognitively and how they behave. Pain is also associated with depression. It is important to note pain characteristics such as onset, duration, location and triggers.



Sexual functioning

Changes in sexual functioning may be a direct result of damage to the brain areas affected by encephalitis or else an indirect consequence. Sexual problems associated with physical difficulties might include: parts of the body not being aroused in response to touch, certain positions causing pain, or clumsiness in lovemaking. Fatigue may interfere with sexual desire or the ability to sustain sexual activity. The impact of changes in thinking skills might include: forgetting about contraception, becoming distracted during sex or even forgetting having had sex previously. Where emotional factors are concerned, a person might fear having an accident or embarrassing themselves.

Alternatively, life circumstances such as relationship problems following brain injury can also lead to sexual dysfunction. Understandably, problems with sex affect not only the person with encephalitis but also the sexual partner.

Hormonal changes

Encephalitis may cause damage to structures in the brain that regulate hormones, such as the hypothalamus and/or pituitary gland. This can result in insufficient or increased release of one or more hormones, disrupting the body's ability to maintain a stable internal environment (homeostasis).

There are many symptoms that might be experienced by changes in hormone levels, and each one of them is caused by a change in the particular hormone produced by the pituitary gland. Some of the symptoms include: depression, sexual difficulties, headaches, fatigue, visual disturbance, weight gain, muscle weakness, reduced body hair, changes in skin texture, fatigue, mood swings and difficulty regulating body temperature.

SOCIAL IMPACT OF ENCEPHALITIS

The outcome of brain injury is different for each person and can include:

- Difficulty with self-care (e.g., showering, cleaning, shopping, cooking).
- Being unable to return to driving.
- Relationship problems.
- Substance misuse.
- Difficulty returning to education.
- Problems with or being unable to return to work.
- Difficulties with socialising and maintaining a social life.
- Financial difficulties.

The impact of brain injury is multi-faceted and can cause significant changes to an individual's lifestyle and life values.



SECTION 4: RECOVERY AND REHABILITATION

This section describes options for recovery and rehabilitation after encephalitis. It also provides an overview of the services and specialists you may encounter during your recovery.



Key facts

- The brain takes much longer to recover from an injury than other parts of the body such as muscles, bones or skin.
- Unlike other body parts, you cannot see your brain repairing and may assume all is back to normal when this is not the case.
- Timely access to rehabilitation is important for improving long-term outcomes.
- Recovery after encephalitis involves rest initially and then a gradual return to normal activities.
- The aim of rehabilitation is to help the person acquire the knowledge and skills needed for optimal cognitive, psychological, physical and social function.
- Often rehabilitation involves 'compensating for difficulties' as opposed to 'restoring function'.
- Rehabilitation that focuses specifically on returning you to work or other meaningful activity is called 'vocational rehabilitation'.
- People may need various individual assessments and interventions at different stages in their recovery.
- Maximising communication with health and care professionals involved in your recovery is important.



GUIDELINES FOR RECOVERY

The acute phase of the illness (the time of active brain inflammation) can last anything from a few days to a few weeks or maybe longer. It may be followed by a phase of rapid improvement, which may slow down, but recovery can continue over the years to come.

As time passes and you feel better, people, even doctors, will tell you that you are fine, "it's time to get on with life." However, it is very important not to rush the healing process. After an acquired brain injury (ABI), restoring the networks by which the brain functions takes time. Newly established networks need constant maintenance. They may also be slower and less efficient at relaying information.

It is very important when you try to resume your usual activities that you do this very slowly and tentatively. You do not know how much, or how quickly, your brain will recover. A brain that is struggling to cope will let you know by giving you a headache or making you unusually irritable, confused, disoriented or afraid.

These are difficult things to think through. It is not surprising that few of the people you are close to (at home, as friends, in the workplace or education) are able to understand and appreciate your difficulties fully – and it takes time for a person who has had encephalitis as well.

A healthy diet that is high in antioxidants (fresh fruit and vegetables) and high in omega-3 (fish or flaxseed oils) may also aid recovery.

Exercise improves blood flow through the brain, bringing the essential nutrients needed for repair and maintenance. Exercise may even spur the growth of new brain cells and prolong the life of existing ones. A little fresh air can even improve mood. Exercise does not have to be time consuming, expensive or excessive: a short walk three times a day will give your brain the boost it needs. Exercise can also reduce other problems, such as sleep difficulties and being irritable.

WHAT IS REHABILITATION?

The aim of rehabilitation is to support a person with ABI (re) acquire the knowledge and skills to achieve personally relevant goals in relation to social, emotional, work and recreational function. Good rehabilitation involves a holistic approach to take into account the complex cognitive, emotional, behavioural, physical and social challenges faced by people with ABI and their families. It involves a practical and educative approach using the strengths of the person to develop strategies and ways of coping. This might involve restoring skills, compensating for difficulties and adjusting to changes following ABI.

Rehabilitation can continue to be of benefit many years after an ABI as goals and personal needs change. Some people need to be given time to be 'ready' to take on new information and strategies. They may be resistant to help initially, and that in itself may require careful work.

Depending on the nature of the person's problems, rehabilitation may range from receiving help from outpatient and community-based services to attending programmes in specialist residential brain injury units. At times, the individual may need help from only a few key professionals. At other times they may require help from a full multidisciplinary rehabilitation team as well as other medical and health and social care professionals.

Family members are often heavily involved in rehabilitation and are integral to the success of interventions. In fact, it is also important to note that a certain amount of rehabilitation takes place at home, without the formal involvement of professionals. This kind of rehabilitation involves people with encephalitis and their carers using 'self-management' strategies, examples of which are discussed later.



PROFESSIONALS INVOLVED IN RECOVERY AND REHABILITATION

Following is an overview of professionals who may be able to help people following encephalitis, and the kinds of difficulties they provide support with:

Neuropsychologists for:

- Neuropsychological assessment to understand cognitive strengths and weaknesses following brain injury, to provide education and plan rehabilitation interventions.
- Assessment of capacity to make complex decisions (such as management of finances).
- Development of rehabilitation programs to manage changes in thinking and memory; provision of psychotherapy to address emotional changes and support adjustment; development of programmes to manage changes in behaviour.

Occupational therapists for:

- Assessing abilities and supporting an individual to maximise independence in relation to simple (e.g., personal care) and complex (e.g., managing finances) activities of everyday living.
- Helping someone to re-engage with their usual leisure activities or new interests.
- Development of rehabilitation support to allow return to study or work.
- Considering what aids/equipment might be useful for helping someone maximise their independence and fulfil their goals.

Speech and language therapists for:

- Difficulties with understanding or producing speech.
- Problematic understanding or use of language.
- Difficulties with eating, drinking and swallowing.

Neurophysiotherapists for:

- Problems with movement, such as difficulties with mobility and dexterity and/or sensory changes (i.e., numbness, pins and needles).
- Advice regarding pain management.

These professionals often work together in multidisciplinary teams to provide support following ABI both in the community and in outpatient settings. Assessments by multidisciplinary community-based teams can also be useful in determining whether people might require more intense, inpatient multidisciplinary rehabilitation (e.g., in the case of severe and enduring problems that threaten the breakdown of care or when behaviours pose a significant risk). However, in some regions the health professionals listed above work independently of each other (e.g., Neuropsychology department in a hospital).

Depending on where you live, help may be available from local services and/or there may be other services available that you can access for free. The best thing to do is to speak with your family doctor/GP or neurologist in order to obtain a referral to these services. They are best placed to know what kind of support is available in your local area and how to get access to this support.

If there is no local statutory service available, another option is to see clinicians and therapists in private practices who specialise in ABI, particularly if you have private insurance.

Other professionals and specialist services that might be able to help include:

- **Neurologists** – for concerns about symptom relapse, medication advice, management of seizures and if review or further neuroimaging (scans) is required.
- **Neuropsychiatrists** – for management of emotions, behaviour and unexplained symptoms.

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- **Social Services/Mental Health Crisis Teams** – to assist with issues such as arranging care, respite or residential placements, family support, or when there are concerns about risks posed to the service-user or others. These local teams can be a valuable source of support across extended hours.
 - **Epilepsy nurse specialists** – for epilepsy management and follow-up.
 - **Pain management services** – for management of pain.
 - **Continence services** – for advice about continence management.
 - **Psychosexual clinics** – for management of the combined impact of physical and psychological aspects of sexual dysfunction.
 - **Ear, nose and throat specialists/audiologists/ophthalmologists** – for managing sensory problems.
 - **Endocrinologist/neuroendocrinologist** – for management of hormonal irregularities.
 - **Dieticians** – for concerns about a person’s weight (under or overweight) or other nutritional issues (e.g., restricted diet, aversion to certain food textures).
 - **Immunologist** – in the event of problems with underlying immune dysregulation, including immunosuppression.
 - **Sleep clinics/sleep medicine departments at local hospitals** – for management of sleep difficulties.

Complementary therapies include treatments such as osteopathy, acupuncture, homeopathy, massage, reflexology and aromatherapy. We strongly recommend that you discuss with your doctor any alternative therapies, medicines or treatments before using them.

GETTING THE MOST OUT OF THE MEETINGS WITH PROFESSIONALS

Meetings with professionals could involve appointments with your family doctor/GP, consultant, therapist, social worker, someone from the benefits agency or other person providing you with advice. Meeting professionals can be quite daunting and emotionally, especially if you are anxious or upset. Good preparation can help to ensure that the experience is a positive one. Following are some recommendations for assisting you with these interactions.

Arranging the meeting:

- Ask about the options for meeting.
- Ask what the purpose of the meeting is so you can think about it and talk to someone beforehand.
- Ask who will be there and think about having someone with you if appropriate (e.g., friend, relative, advocate or someone from another agency).

Before the meeting:

- Think about what you want to say. Write down your list of problems, what you want achieve from the meeting, and/or how things have been since you last saw them.
- Look at your diary and any other recording systems to help explain how things have improved or got worse.



At the meeting:

- Keep it simple.
- Keep checking your notes.
- Listen to what is said and take notes or ask someone to come with you who can do this.
- Keep a record of all your meetings.
- If you do not understand, do not be afraid to say so and ask for further explanation.
- Ask about the alternatives and/or whether you can have a trial of a particular therapy/medication.
- Do not be afraid to say that you need time to think about recommendations/issues and talk it through with someone else.
- Ask for any decision/information/outcomes from the meeting to be written.

If things go wrong:

- Do not get angry; if you do, take some deep breaths or ask for a short break.
- Do not blame; focus on finding a solution.
- Say you are not comfortable with their decision and ask for a second opinion.

At the end of the meeting:

- Check you have covered all of the points on your list.
- Ask them to repeat what people have agreed to do (i.e., the actions) and by what deadlines, so everyone is clear.

- Ask that another appointment time and/or venue for the next meeting be arranged if necessary.
- Try to end the meeting on a friendly note.


MANAGING COGNITIVE DIFFICULTIES

A neuropsychological assessment (an assessment of thinking skills) is a useful tool for describing the pattern of cognitive strengths and weaknesses following encephalitis. This involves the completion of various paper and pencil tests, as well as collecting information about a person's background and current functioning. Depending on whether a 'brief screen' or a more comprehensive assessment is completed, an assessment of this nature may be very brief (e.g. 30 minutes) or else completed over a number of hours.

Occupational therapists and speech and language therapists may also be involved in undertaking assessments of people's thinking skills by examining their everyday abilities and patterns of language and communication. These assessments allow for an evaluation of different 'domains' of cognitive functioning such as information processing speed, attention and concentration, memory, executive functioning, and perceptual and visuospatial skills. Assessments also help to plan rehabilitation and appropriate support to enable an individual to manage changes to their everyday functioning. Specific strategies and compensatory devices may be suggested that help to compensate for everyday problems. With training and consistent use, these can help an individual to work around their thinking problems to function in everyday life. Below is a list of strategies that may be able to help with specific problems:

Problems with memory

Memory is not like a damaged muscle that, with appropriate exercise, can be made strong again. Memory loss arises because brain cells, connections



and systems have been irreparably damaged and repeated practice or drills do not restore memory function. Instead, it is recommended to teach the person affected strategies for using their remaining memory abilities more effectively.

There are two important things to know:

- Avoiding errors during learning leads to better learning in people with severe memory problems; so, if you are trying to teach a memory-impaired person something, don't let them make errors.
- Repeated practice is helpful to learn new information if this is done over a number of days in a practical manner as opposed to attempting to cram new information.

Practical steps in managing memory problems:

- Maintain a regular routine.
- Organise the environment so it is structured and uncluttered; keep things in the same places as much as possible.
- Use labels, colours and signs on things to make them distinctive or indicate where they are located (e.g., cupboards for crockery, cupboards for food).
- Use a diary, written notes and/or a wall chart to remember dates and future events and to recall what has happened in the recent past.
- Use a flow chart on the wall giving instructions about which places to look for things habitually misplaced (e.g. glasses).
- Display photographs of family and friends prominently and label them with their names.
- Use memory aids (e.g., diaries, calendars, post-it notes, message boards, personal organisers, watches, smart phones and apps, medication boxes, email and computer-based support, voice recorder) to improve everyday memory function.

To help manage difficulties remembering people's names, it can be useful to develop a picture of the person and their name based on a distinct feature of their face or personality. Written notes about that person, their name and the distinct picture can then strengthen this association. Smart phone technology can also help by using 'tagging' (naming people) in photographs on the phone or in social media platforms.

To remember books or magazines, it may be helpful to have a small voice recorder or notebook to make a few key points at the end of each chapter. A bookmark could also serve this purpose. These notes can then be reviewed when the book is next picked up. Many people find reading short stories easier rather than reading longer stories.

Further support and information

Managing memory problems after encephalitis factsheet, available from our website www.encephalitis.info/factsheets or our Support Service support@encephalitis.info | +44(0)1653 699599.

The book ***Coping with memory problems*** by Linda Clare and Barbara Wilson. (available from www.pearsonclinical.co.uk)

Slow thinking speed or difficulties with concentrating and attention

- Allow more time to complete tasks, whilst acknowledging the frustration that may accompany slower processing.
- Keep distraction to a minimum, including a reduction in background noise where possible.
- Take notes to capture key points in order to manage problems with taking in what has been said.
- Attempt one task at a time, during peak energy times.



Problems with communication

- Use different words to communicate the message as opposed to using one (the lost) word.
- Take more time, rely on notes if possible and manage anxiety associated with findings words.

Problems with planning and organising

- Increase structure and routine in daily activities.
- Use compensatory aids such as a diary, message board, smart phone or alarm.
- Write daily activities in a weekly planner (paper-based or smart phone), with a list of steps required to complete tasks, to be crossed off one-by-one; reviewing progress to troubleshoot and learn from experiences forms part of the problem solving process.
- Use alarms (e.g. mobile phone alarms) to help monitor performance and keep a person on track.

Difficulties with 'get up and go'

- Recognise that a lack of initiative is a result of encephalitis as opposed to being 'lazy' or 'not interested'.
- Keep a daily routine to provide structure and manage reduced drive.
- Break activities into smaller steps, with enjoyable rewards once an activity is completed.
- Recognise the individual's achievement, highlight to others and then attempt a more enjoyable task (e.g. music, an outing, a game etc.).

Impulsive or disinhibited behaviour

Increased awareness of impulsive and disinhibited behaviour can help the individual and their family to plan for social situations. It might be helpful to devise a signal to help the person stop, think and respond appropriately. Alternatively, written prompt cards or signs may be useful to curb inappropriate responding (e.g., stop and think!).

Reduced awareness or denial of problems


Both reduced insight and denial of problems pose challenges for family members and the support of the neuro-rehabilitation team is recommended. Direct challenging of a person's beliefs is not recommended. Patience and listening to frustrations can be of help whilst establishing goal-directed rehabilitation programmes to gently test and reveal a person's weaknesses in addition to their strengths.

MANAGING EMOTIONAL AND BEHAVIOURAL DIFFICULTIES

Clinical neuropsychologists or clinical psychologists who have experience working with brain injury can help with managing problematic behaviours and emotions following encephalitis.

Some of the aims of their intervention include:

- Understanding the behaviour to reduce frustration for the individual and their family members.
- Putting measures in place to manage the challenging behaviour, ensure the safety of the individual and maintain relationships.

- 
- Helping the individual and family to obtain an improved understanding of the psychological reaction to encephalitis.
 - Supporting the individual and family by introducing strategies for helping them to cope, and effectively adjust.

Support may be provided to the individual and carer, in the form of couples counselling or within the context of therapy groups.

Other professionals such as occupational therapists, physiotherapists and speech and language therapists may also be involved in helping to understand and manage the impact of encephalitis on behaviour and emotion. This is because difficulties with communication, frustrations with physical problems or difficulties with everyday tasks contribute to problematic behaviour and emotion. There is also a role for a psychiatrist and/ or general practitioner as medication may prove useful.

Further support and information

- Mental health and encephalitis information and animation on our website: <https://www.encephalitis.info/effects-of-encephalitis/mental-health-and-encephalitis/>
- ***Managing anger after encephalitis and Depression after encephalitis*** factsheets.
- ***Responding to challenging behaviour following an acquired brain injury*** booklet, produced by Synapse Australia and reviewed by Encephalitis International.
- Support Service: support@encephalitis.info | +44(0)1653 699599.

The benefits of sharing experiences and connecting with people

Many people also find the support from other people affected by encephalitis and their families invaluable when negotiating behavioural changes and managing emotions following the illness. Peer support through talking to others who have been affected by encephalitis can be a positive way of making sense of feelings and life changes.

For this reason, Encephalitis International has developed the following initiatives for helping people connect with each other and share experiences:

Connection Scheme

www.encephalitis.info/connection-scheme

This has been set up to enable members to make contact with others in a similar situation to themselves.

Virtual Gatherings


We host regular online support groups which connect our community across the world who have experienced encephalitis directly or indirectly. These groups are currently held on zoom, for around 60 minutes and take place monthly.

We aim to keep these calls accessible, friendly, supportive and safe.

To join any of the following online meetings, please visit www.encephalitis.info/online-peer-support-groups/

Sharing lived experiences

Reading the narratives of other people who have experienced encephalitis is also often useful. Other people's narratives can provide hope that there is life after encephalitis, by sharing tips about different ways of coping and finding meaning in the experience.



Some people prefer not to read narratives. There is always a risk that the story may not be what people expect or that people may experience negative feelings about their own recovery as a consequence. Before reading, it is important to consider whether the time is right. Narratives are more likely to be of benefit at a later stage in your recovery than in the immediate aftermath of experiencing encephalitis.

Our website (www.encephalitis.info/recommended-books-2/) has reviews of a wide range of books in which people have written about their personal experience of encephalitis or ABI more generally. For more stories from people affected by encephalitis, please visit: www.encephalitis.info/your-stories/.

Maximising social involvement

Social activities make an important difference to the feelings and confidence of people who have had encephalitis. Social interaction helps to manage stress and feelings of depression and also stimulates brain development. Friendship patterns can change after encephalitis so it is important to consider new avenues for social involvement.

When the time is right, there may be local groups to join, and opportunities to do voluntary work. Some people find going on courses or joining interest groups/clubs helpful but it is important to find a group that you feel comfortable with. For some people, it is beneficial if close friends or family can assist with accessing relevant activities and groups.

MANAGING PHYSICAL DIFFICULTIES

A range of professionals may be involved in managing physical problems after encephalitis, depending on the specific nature of the problem and the specialist knowledge required in order to help. Within the context of multidisciplinary teams, physiotherapists and occupational therapists are

often most commonly involved in evaluating problems with movement and balance and the impact of this on one's ability to complete everyday tasks. However, for many physical problems, and when not undergoing formal rehabilitation, family doctors/GPs and sometimes neurologists are the first port of call for reporting complaints of a physical nature. Below are some additional considerations for managing physical difficulties post-encephalitis.

Fatigue and sleep difficulties

As a general rule, in order to manage fatigue effectively it is important to structure your day with rest periods in between activities. Initially, rest periods should be long and activity periods short. As you improve, spend longer on your activities and take shorter rests, always remembering to stop before you get overtired. Some additional things to consider include:

- Use a diary to record energy levels and identify peak energy times during the day.
- Pace involvement in activity throughout the day.
- A graded approach to involvement in activity so as to improve stamina over time.
- Take breaks within tasks and changing tasks to restore energy.
- Good sleep habits to ensure that a poor sleep pattern does not add to the fatigue.
- Ensure that excessive amounts of caffeine (e.g. coffee or energy drinks) are not being consumed and impacting adversely on sleep.

Further support

Managing fatigue factsheet available from our website

www.encephalitis.info/factsheets or

Support Service: support@encephalitis.info | +44(0)1653 699599.



Epilepsy

Epilepsy is treated with anticonvulsant drugs, of which there are several. The aim of the drugs is either to prevent the spread of abnormal activity within the brain or to raise the threshold at which an attack may occur.

Further support

Seizures and encephalitis factsheet available from our website www.encephalitis.info/factsheets or

Support Service: support@encephalitis.info | +44(0)1653 699599.

Sensory changes and pain

Although sensory problems and pain may first come to the attention of your family doctor/GP, neurologist, physiotherapist or occupational therapist, a range of professionals may be involved in the assessment and subsequent management of sensory changes and pain such as: ear, nose and throat specialists, audiologists or ophthalmologists. In the case of chronic pain, referral to a pain management clinic may be considered.

Sexual changes

Sex is an important part of life and is central to our sense of who we are. If you are experiencing difficulties in this area but haven't sought help, it is important to raise your concerns. You should speak with your family doctor/GP or neurologist in the first instance. They may refer you for medical investigations and/or relationship counselling for support.

Hormonal changes


It is difficult to diagnose problems with hormone function as many of the symptoms overlap with those that typically occur after brain injury without hormones necessarily playing a role. If you suspect problems with hypopituitarism or hormonal function more generally, you should raise this with your family doctor/GP who may feel that referral to an endocrinologist is needed. Endocrinologists specialise in diagnosing and managing problems relating to the glands and hormone production. Treatment may involve hormone replacement therapy to return hormones to normal levels.

VOCATIONAL REHABILITATION: RETURN TO WORK

Vocational rehabilitation supports people to retrain and engage in work or study following ABI. Returning to work can be an important goal for people following ABI. In addition to the economic benefits, engagement in work or other meaningful activities, it can enhance emotional adjustment and build a stronger sense of self post injury.

However, it is very important that people do not attempt to return to work too soon. An unsuccessful return to work can affect negatively on confidence and possibly lead to additional problems such as anxiety and depression.

Following encephalitis, it is important to consider the extent to which any changes in cognitive, psychological and/or physical functioning have affected an individual's ability to work. For this reason, many professionals from the multidisciplinary team may be involved in the process of facilitating a return to work (e.g., neuropsychologists, speech and language therapists, physiotherapists, occupational therapists) depending on the nature of the individual's problems. However, the occupational therapist takes the lead role, usually.



Assessing an individual's ability to return to work may involve observing them 'on the job' so as to evaluate the job role and work environment and identify:

- Whether the individual is able to complete tasks.
- Whether there are risks involved in returning to work and what the nature of these is (e.g., physical harm may be a risk if someone operates machinery and is distractable).
- The kinds of strategies need to be considered to help someone complete their job role (e.g., lists for remembering tasks, keeping organised, strategies for helping them to calm if they become upset).
- Any aids which may benefit the person while performing their job (e.g., whiteboards, checklist, adaptive aids for managing physical problems).
- Whether the job role needs to be changed e.g. certain tasks need to be removed from the job description in order for someone to return to work.
- Whether it is possible for the person to return to their old job or whether they need to consider getting a different job.
- Whether or not a return to work (in any form) is feasible.

Liaising with the employer is also considered important to promote understanding of the longer term effects of encephalitis and the impact of this on an individual's ability to do their job, as well as to provide a justification for, and support with, implementing any recommendations made following a workplace assessment.

In some cases it becomes evident that a return to the pre-injury job is not feasible. Alternative considerations for vocational rehabilitation may then include: modifying the job role so as to enable a return to the pre-injury job in an altered form; considering a new job/form of employment; undertaking training; voluntary work; or structuring the week so as to promote engagement in activity that is meaningful to the individual.

Therefore, professionals involved in vocational rehabilitation may also provide advice about training courses that will help people find employment in the future, and help them access these courses.

This again, may require consideration of how an individual's strengths and weaknesses following encephalitis match the requirements of the course and future profession, and making recommendations about aids and strategies to help support them in completing relevant courses. They may also help the individual to source and manage voluntary work or identify recreational activities of interest.

OBTAINING APPROPRIATE CARE AND SUPPORT

Support requirements differ from one person to the next following encephalitis. Some people will be able to return to living independently as they had done before becoming ill. Some may require assistance with completing certain tasks (e.g., shopping or managing financial responsibilities for a couple of hours per week), and others may require placement in a residential facility where 24 hour support is provided.

If you find difficult to look after yourself, your local authority may be able to carry out an assessment of your care and support needs. They can then decide if you meet the criteria for any of their services:

- Family support.
- Liaison with other agencies.
- Speaking or writing on your behalf.
- Special equipment and home adaptations.
- Short breaks.
- Financial help.

SECTION 5: ADDITIONAL SOCIAL AND LEGAL ISSUES

This section provides an overview of some additional social and legal issues raised by encephalitis. Please check your local services for specific rules for your country.



Key facts

- Encephalitis can affect employment and family's finances.
- It is important to get professional help when applying for benefits.
- It is your responsibility to inform the responsible authority for driving about your illness.
- You may need to surrender your driving license if your driving has become unsafe.
- When planning your holiday you may need to take extra care because of some of the consequences of encephalitis.



CAPACITY TO MAKE DECISIONS

As a result of the impact of encephalitis on cognitive functioning, some individuals lose the capacity (either temporarily or permanently) to make certain important decisions. Examples include the decision about whether to undergo rehabilitation, where to live, manage finances or to instruct a solicitor.

Capacity is regarded as ‘decision-specific’, meaning that an individual may have the capacity to make one decision but not another at any given point in time. In order to demonstrate that an individual does not have capacity it must be evident that:

- There is an impairment in the brain or mind (e.g. brain injury).
- This impairment means that the person is unable to make a specific decision that they need to make. In order to show that they can make a decision, they need to be able to understand relevant information, weigh this in the balance, recognise the reasonably foreseeable consequences of making the decision and be able to communicate the decision effectively.

A person is not to be considered incapable of making a decision purely because the decision would be considered ‘unwise’ by the majority. Also, measures must be taken to ensure that the person is given the best possible chance of demonstrating capacity.

(e.g., written notes, repetition of information, consideration of when is best to undertake the assessment so as to maximise their alertness).

If there is doubt regarding one’s capacity to make a decision then the person must be given the benefit of the doubt. Also, any treatment and care provided to someone that lacks capacity should be the least restrictive of their basic rights and freedoms.

Where an individual lacks capacity, a decision may be made in the individual’s ‘best interest’.

Many professionals are involved in undertaking capacity assessments depending on the extent to which the decision relates to their area of expertise and experience of the patient. For example, a social worker may be best placed to assess an individual's capacity in the decision about where to live, having undertaken many discussions with the individual and family members about housing options. However, when decisions are complex, or when the consequences of making certain decisions are significant, neuropsychologists are often involved in undertaking capacity assessments.

DRIVING AFTER ENCEPHALITIS

After encephalitis, many people see their return to driving as a marker of their recovery. However, driving involves many more complex skills than simply the mechanical ability to drive a vehicle. It requires the ability to observe, sequence events, make quick judgements, plan and react appropriately to complicated situations, often in busy traffic. Unfortunately, encephalitis often affects some of these skills.

Depending where you live, it may be your responsibility to inform the appropriate authority (Driver and Vehicle Licensing Agency DVLA and your insurance company in the UK) about your illness.

Doctors are encouraged to advise people that their condition may affect their ability to drive. Please talk with your family doctor/GP/consultant about how encephalitis affects your ability to drive.

Further information on driving after illness

Encephalitis International has a factsheet '*Driving after encephalitis*' which is available from our website www.encephalitis.info/factsheets or Support Service: support@encephalitis.info | +44(0)1653 699599.



MONEY AND BENEFITS

In the days following encephalitis, money can be a concern.

Encephalitis and associated consequences may affect employment and a family's finances. If the person, who has had encephalitis, was employed before they were ill, their employer should pay them in line with any company sickness package or at least ensure they receive Statutory Sick Pay.

Claiming benefits can also help to ease the pressure. However, the processes involved are often not easy. The system is complex and can be confusing. Applying for benefits can be a frustrating experience, especially for someone who has difficulties with memory and communication. It is important to get professional advice and make applications as soon as possible so that money to which you are entitled is not lost.

HOLIDAYS AND TRAVEL INSURANCE

Holidays usually mean travelling, visiting new and unfamiliar places, spending time with many people, shopping and entertaining. Following encephalitis, some people may experience fatigue or have low tolerance for noise. They may need to have a structured environment in which to function as changes in their environment can quickly make them feel overwhelmed and 'shut down' cognitively and emotionally. Therefore, holidays can be a difficult time for some people.

It is wise to consider potential problems in advance and plan around them in order to enjoy the holiday time.

When planning your holiday, it may be useful to consider the following:

- **Medication**

Make sure you have enough medication for your time away as well as to cover any unexpected delays. Medical supplies may be subject to constraints in some countries and in remote areas.

- **Destination**

Make sure you check with your doctor whether you need any vaccinations before going away (and any additional medications, which may be required following encephalitis).

Be aware of where the medical facilities are at your destination, so that you can access them quickly if necessary.

- **Flight**

Make sure it is safe for you to fly (check with your family doctor/GP if you have any doubts). Inform the travel airline about any special requirements you may have.

- **Insurance Policy**

If you have epilepsy or any other consequences of encephalitis, it is worth taking a closer look at the details of the insurance policy, to see whether chronic illnesses or pre-existing medical conditions are covered. There are companies that specialise in providing cover for people that have a history of a pre-existing medical condition. Sometimes, the insurer requires a letter confirming that the individual is fit to travel. If you do not declare all your medical history, the insurance company may refuse to pay in the case of a claim.

SECTION 6: MANAGING THE IMPACT OF ENCEPHALITIS ON THE FAMILY

This section focuses on the impact that encephalitis has on the family and highlights the main issues for carers and children of a person affected with different options for support.



Key facts

- Encephalitis can affect family relationships.
- Families often go through a process of coming to terms with the illness and the consequences and then finding ways of coping.
- Family members deal with emotions in different ways; strong feelings are understandable.
- Disability following encephalitis can be 'hidden' and those around you may not be aware of how your everyday life has changed.
- Being a carer has a big impact on everyday life, friendship, work or education.
- Children in the family can be affected in many ways depending on their age and family support.
- Carers need their own needs to be acknowledged and addressed.



IMPACT ON THE FAMILY

All families are different, but encephalitis can challenge family relationships. Initially, there may be elation that a loved one has survived. Soon after, feelings can be conflicted with relief and joy on one side and confusion, even anger on the other, both for the person affected and the family members. This usually happens as it becomes evident that the person is unable to care for themselves or carry out their roles as they once did.

Spouses often feel isolated and trapped as the roles are reversed and relationships are put under strain. Children can feel neglected and their needs may be overlooked. Your extended family and friends may not have heard of encephalitis before, so they may not know/understand what you have been through. They may see that your loved one has recovered physically well and think that everything is back to normal. They may not understand your daily concerns and the difficulties being experienced as a result of the illness.

In addition, there may be feelings of shame brought about by the condition and behavioural changes associated with the illness. Your loved one may behave in a socially inappropriate way, such as saying things that upset others. You may feel that your family is being misunderstood or judged.

Accepting your situation can help, however this is not always easy and may be difficult to achieve. Typically, families will go through a process of coming to terms with the consequences of the illness, then finding ways of coping. In many cases, this looks something like the following five steps:

- **Why are they ill?**

The initial reaction of family and friends is usually a mixture of panic as the symptoms are serious and there may be difficulty in diagnosing the illness. When the diagnosis is suspected/confirmed, they might ask 'What is this illness? Why did it happen?'

- **They are getting better/What am I doing in hospital?**

As symptoms subside, family and friends experience relief and delight. This time can be characterised by conflict between the person affected and friends and family. Both family and friends have been through a very traumatic experience and may have been prepared to lose their loved one, who in turn may remember nothing of the illness. Some people recovering from encephalitis may be confused and even angry at finding themselves in hospital.

- **They look normal/I feel terrible.**

A good physical recovery is usual after encephalitis but this external good physical appearance can mislead family and friends into believing that the person affected has completely recovered. In reality, the person may be struggling with even the simplest tasks.

- **Why can't you pull yourself together/I think I'm going mad.**

It is at this stage that it is important to consider referral for assessment by a neuropsychologist and perhaps other rehabilitation professionals (e.g., occupational therapist, speech and language therapist). These assessments can help to identify changes in thinking skills, emotion and behaviour that may be affecting an individual's ability to complete everyday tasks. These assessments can then provide clues about potentially useful strategies for minimising problems.

- **Life is different now/I am different now.**

During this stage, some people realise that some of their limitations are going to be permanent. There is a readjustment of expectations, and roles and relationships are redefined.



SUPPORT FOR CARERS

It is important that you don't overlook your own needs as a carer, both for your own sake and because the right support provides you with the resilience needed for looking after your family.

Social support

Social support refers to the existence and availability of people on whom one can rely and who provide care. Broadly speaking, social support encompasses all the help and care received from friends, family, peers, colleagues, and community-based groups. These sources of support are collectively referred to as your support network.

There are different types of social support including emotional, practical and informational. Emotional support refers to the actions people take to make you feel cared for, such as listening to you and giving you an opportunity to express your feelings. Practical support involves being provided with help with specific tasks, to make your life easier, such as cooking meals for you and your family or collecting your children from school. Informational support means being provided with facts that might help you manage your situation, such being provided with information about the causes of encephalitis and strategies that may help to manage difficulties.

Social support appears to improve people's resilience (the capacity to adapt successfully in the face of difficult life events) and reduce stress. It has even been linked to lower levels of mortality (death). This is achieved by: improving understanding of encephalitis; reducing uncertainty about the future; reducing a tendency to blame yourself for what has happened; increasing your perception of control over the situation; improving your self-esteem; and reaffirming your sense of belonging. For all of these reasons it is important to draw upon the support around you to help you cope with this difficult situation.


The carer's assessment

If you care for your loved one, you may be entitled to having support from your local council. Support may take the form of money to pay for things to make caring easier or practical support such as a replacement care when you need a break.

Replacement/respice care

Respite care may be necessary, as you, as a carer, need time to look after yourself. Replacement/respice care involves someone else, other than you, providing care on a temporary basis. The local authority may arrange for the respite care if this is in the plan as a result of an assessment. If it isn't in the plan, you may need to arrange it yourself. Local carers' groups may be able to recommend suitable places.





Carers may find themselves feeling guilty or anxious about taking a break. It is hard to leave your loved one and have some time for yourself. You have become so used to being there for your loved one that you cannot see your life in any other way, even for a couple of hours. However, spending time apart may be beneficial for both of you: you get some rest and the person you care for has an opportunity to being independent from you. If you find it difficult, try to introduce breaks gradually. It may be very hard the first time, but you may see the benefits further down the line.

Further support and information

Encephalitis International's Connection Scheme and events connect people with similar experiences of encephalitis, helping to relieve feelings of isolation brought up by this condition. www.encephalitis.info/connection-scheme www.encephalitis.info/events-and-activities

CHILDREN AND YOUNG PEOPLE IN THE FAMILY

Encephalitis has a wide ranging impact on other family members, and this certainly includes children, both in the short and longer term. The family day-to-day routine may be changed in that:

- The person who has been ill becomes the focus of attention.
- All talks and plans are about treatments, hospitals and doctors.
- The parent who has been ill may have changed: may need to rely on others to look after them; may no longer show the same interest in the children, speak to them in the same way or behave as they did before the illness.
- There may be no time for activities with children such as support for homework, spending time with them and taking them out.

As a result, children's behaviour and expectations at home may have to change quickly, often well before they understand why this has happened.

Alternatively, some children are born into a family where there already is someone who has had encephalitis. For these children, the impact may develop over the years, particularly as they make friends and go through school, and discover that other people just don't understand why the person with encephalitis acts the way they do.

Children can be affected in many ways depending on their age, their family relationships and many other factors. It is good if close family, neighbours, friends and school staff can be made aware of what is happening in the family. It is important to understand the impact on children of living alongside someone with considerable needs.





Feelings experienced by children may include:

- Loss and bereavement they cannot understand.
- Jealousy and even anger at the attention their relative is getting.
- Guilt because their relative is ill.
- Anxiety that this illness may happen to them as well.
- Confused because of the big changes in their everyday lives.
- Frustration and sadness that someone important to them cannot remember things that matter, is always tired and may be behaving very badly.

The guidance and support that families receive vary greatly. In order to support children it is important to:

- Recognise these feelings, normalise and accept them.
- Reassure the young person that what has happened is not at all their fault.
- Make sure there are opportunities to talk things through.
- Ensure and encourage an atmosphere in which the care of others is respected and no adverse remarks are tolerated.
- Keep school and college staff informed about what is happening, and remember that information might need to be repeated as a child or young person changes their year group, school or post-16 placement.
- Determine if there is support available at school, and if appropriate find out if there is a local support group for children that might help.

Further support

Encephalitis International's Support Service can provide information and support on support@encephalitis.info | +44(0)1653 699599.

Young carers

When a parent has had encephalitis, the children and young people in the family often need to help at home. Most children have a range of natural responses to their parent's illness, but want to play their part. Children become 'young carers' when they are doing what an adult would normally do for the person who needs a great deal of support. This takes time and energy. It demands new skills. It means 'being there' for the parent rather than spending time with others their age. Being a young carer almost always has a big impact on everyday life, friendships and education.



SECTION 7:

ENCEPHALITIS INTERNATIONAL

Encephalitis International is the only resource of its kind providing direct support and information to people affected by all types of encephalitis, raising awareness about the condition, and furthering our understanding of encephalitis through promoting and collaborating with research.

WHO WE ARE

We are an international charity and the only resource of our kind in the world, dedicated to supporting those affected by encephalitis, their families and professionals involved in their care.

Our vision is bold yet simple: A world without death and disability from encephalitis.

Our mission is to rebuild futures around the world by saving lives, accelerate awareness and drive research.

HOW WE CAN HELP YOU

- **Support Service Helpline** support@encephalitis.info
[+44\(0\)1653 699599](tel:+44(0)1653699599) / online chat on our website
- **Website** – Containing factsheets, books, booklets and leaflets which cover various issues regarding encephalitis. www.encephalitis.info
- **Regular newsletter features** Encephalitis International's activities, news, events etc. www.encephalitis.info/keep-in-touch/.
- **In-person and virtual meetings** and events for all the family, details of which can be found on our website. www.encephalitis.info/online-peer-support-groups/
- **Connection Scheme**, which has been set up to enable our members to make contact with others in similar situations to themselves. Further details from our website. www.encephalitis.info/connect-with-others/connection-scheme/
- **Provision of support and information** about encephalitis and its effects to interested parties (e.g. health, social care and education professionals; schools; family doctors/GPs; workplaces etc).

HOW YOU CAN HELP US

- **Join us** - Encephalitis International. It is free and helps us to raise our influence among the general public and medical profession. Call us on [+44\(0\)1653 692583](tel:+44(0)1653692583) or join online at www.encephalitis.info
- **Take part in World Encephalitis Day** – 22nd February each year.
- **Connect with us on social media** – Facebook, Instagram, TikTok, LinkedIn & YouTube.
- **Make a donation or fundraise for us** – Call us on [+44\(0\)1653 692583](tel:+44(0)1653692583), or email our fundraising team on fundraising@encephalitis.info

Can you help us to fund research into encephalitis?

With no statutory funding, Encephalitis International relies on the generous support of a number of philanthropic organisations and the encephalitis community - everyday people like you committed to helping our drive for research into encephalitis to improve recognition, diagnosis and treatment globally.

Could you help by:

- Making a donation
- Taking part in a challenge event
- Seeing if your company offers support for charities
- Seeking support or an introduction to a charitable trust or foundation you know



Encephalitis International
The brain inflammation non-profit

How your donation could make a difference...

£25 helps fund Advances in Encephalitis Research Summary – our go-to guide for professionals working in encephalitis.

£50 contributes towards funding a research day for our seed funding projects.

£150 funds a place for an early career researcher or physician at our international Encephalitis Conference.



Get in touch today

e: fundraising@encephalitis.info

Encephalitis International is a registered Charity and Charitable Company. Our England and Wales Charity No. is 1087843 and our Charitable Company No. is 04189027. Our Charity No. in Scotland is SC048210. Encephalitis International is a Named Fund member of the Chapel & York US Foundation, Inc. The Chapel & York US Foundation, Inc. is a 501(c)(3) tax-exempt organisation



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