Acknowledgements

We are extremely grateful to the Professionals, Regional Representative Volunteers and Supporters who have helped develop this Guide. Your contribution has been invaluable and enabled us to produce this much-needed resource.
About This Guide

We are thrilled to have had the opportunity to review, revise and launch this brand new guide to Encephalitis for adults.

This guide covers everything from descriptions of the condition, its diagnosis and management through to important information and guidance on the stages that follow, such as recovery and the impact on the family.

The guide concludes with some information about our Society and how we can continue to help each other.

We are really proud of the guide – it really is a one-stop shop for people. You can dip in and out of it depending on where you are with your illness and journey of recovery.

We hope it is useful to you and we value any feedback.

Of course our range of publications extends beyond adult, so do please check out our website (www.encephalitis.info) for more detailed information on the different types of Encephalitis and also for information and resources for children, parents, teachers, primary care professionals and so forth.

Please remember we are all here for you at The Encephalitis Society – just get in touch if you need us.
Wishing you all the very best,

Dr Ava Easton
Chief Executive
Disclaimer

Although this information may be useful to people affected by Encephalitis around the world, certain information such as details of organisations and legislation apply only to the UK or some parts of the UK. If you live outside of these areas, you are encouraged to find similar organisations to those referenced and consult local legislation.

After experiencing Encephalitis the long-term prognosis can be very good, with many people experiencing few or no problems in the longer-term. In other cases, a person may be left with considerable difficulties. Therefore, it is important to remember that the consequences of Encephalitis described here may not be reflective of every situation.

Should any of the information contained in this Guide raise issues or cause concern please don’t hesitate to contact The Encephalitis Society via our Support Line on +44 (0)1653 699599 or support@encephalitis.info

References

If you would like more information on the source material and references for this Guide, please contact The Encephalitis Society.

Feedback

We hope you find the Guide useful. Please feel free to share it with your friends, extended family and any services with whom you are involved (e.g. health, social care, education). We are looking forward to receiving your feedback by email at mail@encephalitis.info or by phone at +44 (0) 1653 699599. Your comments and suggestions are very welcome and will help us improve our information resources.
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SECTION I: ENCEPHALITIS: THE ILLNESS

This section provides information about the acute illness: types, causes, 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, gender, nationality or culture.
- There are up to 6,000 new cases each year alone in the UK and many more thousands worldwide.
- Inflammation is usually caused by infection or an inappropriate auto-immune response.
- The variety of causes and presentations, along with the often dramatic and rapid onset may make the management of this condition a challenge.
- It is important to differentiate Encephalitis from other disorders that may cause similar symptoms but have very different treatments.
- Early and adequate treatment improves outcomes.
- Aciclovir is the most frequently used anti-viral drug.
- Encephalitis has a variable mortality (death) rate depending on the underlying cause.
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ENCEPHALITIS: THE ILLNESS

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1. **What is Encephalitis?**

Encephalitis is inflammation of the brain. 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.

2. **Types of Encephalitis**

**Infectious Encephalitis**

Viruses are the most common cause of Infectious Encephalitis. Many of these viruses cause minor infections elsewhere in the body such as tummy upsets, skin rashes or cold sores. Only very rarely do these infections affect the brain, therefore Infectious Encephalitis is often described as a rare complication of common infections.

Known viral causes of Encephalitis:

- Human herpes viruses (e.g. cold sores, glandular fever)
- Rash-causing viruses (e.g. mumps, measles and rubella)
- Throat and chest viruses (e.g. flu, enteroviruses)
- Gut viruses (e.g. enteroviruses, Echo virus)
- Insect-borne viruses (e.g. Japanese Encephalitis virus, West Nile virus)
- Tick-borne viruses (e.g. Tick-borne virus)

Within the British Isles, Herpes Simplex virus (HSV or the Cold Sore virus) is the virus most frequently identified as a cause. The introduction of vaccination for measles, mumps and rubella has greatly lowered the rate of Encephalitis from these diseases.
Bacteria, fungus and parasites can cause Infectious Encephalitis more rarely. Examples include:

- **Bacteria**: mycoplasma, meningococcal, pneumococcal, listeria
- **Fungi**: histoplasma, cryptococcus, candida
- **Parasites**: 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 also 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. This condition is called Post-infectious Encephalitis.

Post-infectious Encephalitis has a variety of other names such as Acute Disseminated Encephalomyelitis (ADEM), Parainfectious Encephalitis and Post-vaccinal Encephalitis. The illness usually follows in the wake of a mild viral infection (such as those that cause rashes in childhood) or immunisations. Typically, there is a delay of days to 2 - 3 weeks between the triggering infection and the development of Encephalitis.

**Autoimmune Encephalitis**

Sometimes the immune system attacks the brain without any infection or vaccination present causing Encephalitis. These forms of Encephalitis are called Autoimmune Encephalitis. Some of these forms are identified by finding a specific antibody in blood and/or cerebrospinal fluid. The trigger for the attack is not known in most cases. Sometimes a systemic tumour may generate the antibody. This tumour may be benign (e.g. ovarian teratoma) or cancerous (e.g. lung cancers).
Patients with Autoimmune Encephalitis are often classified by the target of the antibody, which includes:

- LGI1
- CASPR2
- VGKC-complex
- NMDA-receptor
- AMPA-receptor
- GABAA/B receptor
- Glycine receptor

The above examples are not an exhaustive list. The Encephalitis Society has developed factsheets for most types of Encephalitis. You can find them on our website at [www.encephalitis.info/information](http://www.encephalitis.info/information) or request copies of them from our office on +44 (0)1653 699599.

3. Symptoms

The symptoms of Encephalitis are varied. They may reflect the specific areas of the brain affected by the inflammation and the type of Encephalitis.

**Infectious Encephalitis** frequently begins with a flu-like illness or headache. 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 a high temperature, seizures (fits), aversion to bright lights, inability to speak or control movement, sensory changes, neck stiffness or uncharacteristic (bizarre) behaviour.

**Autoimmune Encephalitis** often has a longer onset. Symptoms vary depending on the cause but may include confusion, altered personality or behaviour, psychosis, movement disorders, seizures, hallucinations, memory loss or sleep disturbances.
4. Diagnosis

Encephalitis is difficult to diagnose most of the time. Symptoms alone often do not allow a doctor to distinguish between the many diseases that can mimic Encephalitis such as:

- bacterial meningitis (inflammation of the membranes that surround and protect the brain and spinal cord caused by bacteria).
- stroke (medical condition in which the blood supply to part of the brain is cut off).
- brain tumours.
- drug reactions.
- metabolic encephalopathy (neurological disorders caused by systemic illnesses such as diabetes and renal or heart failure).

Tests, which can help confirm the diagnosis and rule out other disorders, include:

**Brain scans**

Computerized Tomography (CT) or Magnetic Resonance Imaging (MRI) scans which may also 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 can detect the electrical pattern of brainwaves. Abnormal patterns found in Encephalitis include slowing of brain activity as well as epileptic seizures. These findings can occur in a number of diseases other than Encephalitis but occasionally there are features specific to some types of Encephalitis.

**Lumbar puncture (LP)**

This is a mandatory test if a doctor is planning to diagnose or exclude Encephalitis. It allows a doctor to sample the cerebrospinal fluid (CSF). CSF is produced within the brain and flows out at the base of the brain to surround and cushion the brain and spinal cord. It contains substances essential for normal activity of the brain but also takes waste products back to the blood.
A LP involves passing a needle, under local anaesthetic, between two of the backbones at the base of the spine. It is a simple procedure when performed by an experienced doctor. In an adult, several tablespoons full of fluid can be collected safely. Blood tests are often taken at the same time as the LP in order to compare blood contents with that in the CSF. Approximately 10% of adult patients suffer a headache after a LP. This headache is typically mild and worse upon being upright and better lying flat. It usually improves with simple painkillers and good hydration. Some doctors also recommend caffeine, from drinking tea or coffee.

A variety of laboratory tests are performed on CSF. Some tests give results within hours whereas for others it can often take days to obtain results. 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). The types of white blood cell found help differentiate between causes of Encephalitis. Other CSF tests are more complicated and include culture for microbes, antibody studies, or molecular tests to detect the genetic footprint of viruses or bacteria. The latter molecular tests include the polymerase chain reaction (PCR), which when applied to CSF is used most frequently to identify genetic material from Herpes Simplex virus, Varicella Zoster virus (Chickenpox virus) and enteroviruses. PCR has significantly advanced the ability to diagnose Viral Encephalitis. LPs may often have to be repeated during an individual’s illness.

**Other laboratory screening**

Blood and urine, as well as other body fluids can help detect and identify brain and/or spinal cord infection, autoantibodies associated with Autoimmune Encephalitis or exclude other causes of Encephalitis mimics.

Research suggests that despite extensive testing, the infectious causes of Encephalitis cannot be determined in approximately 60% of cases. For some individuals, their diagnosis of Encephalitis will be a diagnosis of ‘exclusion’ based upon other diseases having been dismissed because of laboratory test results. In most cases the type, either infectious or autoimmune/post-infectious, will have been determined.
Some people may have a descriptive diagnosis based on:

- The cause of the infection if known (e.g. Herpes Simplex virus, West Nile virus, enterovirus, or Japanese Encephalitis virus).
- The target of the autoantibody (e.g. LGI1-antibody or NMDAR-antibody Encephalitis).
- The area of the brain affected (e.g. Brainstem Encephalitis or Limbic Encephalitis).
- The type of inflammation, when not caused directly by an infection (e.g. Rasmussen’s Encephalitis, Hashimoto’s Encephalitis, or Acute Disseminated Encephalomyelitis).

In the UK, if a doctor suspects a diagnosis of Encephalitis, they are legally obliged to report this to the local Public Health England centre for the purpose of research (www.gov.uk/contacts-phe-regions-and-local-centres).
5. Treatment

Treatment of patients with Encephalitis has two objectives:

a) To ensure the patient receives specific treatment for the cause of their Encephalitis.

It is important that these drugs be started promptly and often, particularly in the case of HSV-Encephalitis, before a definite cause is found. Therefore, patients are frequently given several different drugs at once.

In cases of Viral Encephalitis, patients are treated with anti-viral drugs. Aciclovir is the most frequently used anti-viral drug. It is effective against Herpes Simplex and Varicella Zoster viruses. It is given into a vein. Unfortunately, there are no specific treatments at present for many other viral causes of Encephalitis.

For bacterial causes of Encephalitis, there are a range of specific treatments available. Patients are usually started on antibiotics, which treat a broad spectrum of bacterial causes, and then given more specific types of antibiotic if the bacteria causing the illness can be identified.

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 (when some of a person’s blood is taken out from a vein, washed and then put back into the vein in a drip)

Steroids have potential side effects but also important benefits as they reduce the inflammation of the brain. The risks of harm from any of these side effects are minor compared to the good that they do in patients with Autoimmune Encephalitis. However, in each patient the risk-benefit balance may vary.
b) 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 or high dependency unit. Interventions vary including controlling seizures (with antiepileptic drugs), sedation, supplying fluids, treating hospital-acquired infections and ventilation (breathing for the patient with a machine).

Guidelines for management of suspected Viral Encephalitis

Treatment of Encephalitis is effective if started promptly and delays in treatment can have a devastating impact. The National Encephalitis Guidelines Development Group and The Encephalitis Society developed guidelines for the diagnosis and management of adults with suspected Viral Encephalitis (i.e. The management of adults with suspected Viral Encephalitis, diagnosis and early treatment). The Guidelines are a ‘ready reference’ for clinicians encountering the more common causes of Encephalitis. Both versions of these, one for professionals and one for those affected by Encephalitis, can be found at www.encephalitis.info/information.
6. Relapse

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 unusual patients in whom there is a recurrence of 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, rarely in some patients, there may be an early recurrence of Encephalitis after stopping treatment that is due to inflammation even after the virus has cleared.

In some types of Autoimmune Encephalitis there is a recognised risk of recurrence. For example recurrence risk is in the order of 15% in patients with NMDAR-Antibody Associated Encephalitis. It is difficult to accurately predict who will relapse but if the risk of relapse is considered to be significant, treatment is often offered over a longer period of time. 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 quickly reported to the patient’s neurologist. Relapses are more rarely seen in patients with LGI1-antibody Encephalitis.

7. Death and bereavement

Encephalitis is a serious disorder. Unfortunately, despite improvements in specific and more supportive treatments (i.e. intensive care management), it still has a high mortality rate. When death happens it is usually because of severe brain 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 pressure it stops functioning.
The rapid course of Encephalitis can be overwhelming. The realisation that today’s drugs, medical management and sophisticated equipment are sometimes unable to treat the disease successfully is frightening. Families who suffer a bereavement are often left feeling shocked and traumatised. Death is always difficult for those who are left behind, but even more so when it is completely unexpected.

There are staff at The Encephalitis Society who can talk through issues with family members and friends and, if appropriate, put bereaved families in touch with each other. Sharing difficult experiences can help with the grieving process. If you feel this would be beneficial please get in touch with us on +44 (0)1653 699599 or at support@encephalitis.info.

We have also produced two factsheets, *Death from Encephalitis* and *Loss of a loved one* which feature various sources of help for families in grief. They are available from our website [www.encephalitis.info/information](http://www.encephalitis.info/information) or our office.
SECTION II: BEING IN HOSPITAL

Being in hospital is a confusing and stressful time for everyone, both the person affected and their family. This section provides some ideas about how you and your family members can wade through the labyrinth of specialists, medication, tests and diagnosis.

KEY FACTS

- Being in hospital can be a very traumatic experience for all involved.

- 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.

- 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.

- When the inflammation begins to resolve the person affected may not remember anything about being ill.

- Remember your own needs as a family member when supporting your loved one as you can’t help them if you don’t take care of yourself.

- 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.
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BEING IN HOSPITAL

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1. **At the bedside**

**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’. Scores are monitored over time and a deterioration is reported to doctors by nursing staff.

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

During and after the acute phase of Encephalitis the patient may be uncharacteristically uncooperative, aggressive and even violent. They may attempt to abscond. This is due to the impact of swelling in the brain on emotion and behaviour both during the illness and soon after, referred to as an acute confusional state. This state can persist in the early stages of recovery. During this time, the patient is not aware of their behaviour or able to control it. They are also oblivious to the impact their behaviour is having on those around them. This is in direct contrast to the myth often portrayed in the media, when the patient emerges from a coma calm and serene.

Observing a loved one in this state is distressing for family members and can make it difficult for those trying to care for them. When in this state, patients benefit from a ‘low stimulation’ environment. This means a quiet environment in which noise (e.g. from the television or telephone), and visits from others are minimised.

If you have concerns about risk associated with behaviours being exhibited by your loved one you should discuss these with nursing staff. They may be able to suggest strategies for minimising risk. For example, bedrails are sometimes used to prevent injury, especially when a patient is experiencing seizures. Alternatively, it may be appropriate for a specially adapted bed to be used that lowers to the floor so as to reduce the risk of falls.

Understanding Encephalitis in the acute stage

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.

So as to maximise the effectiveness of communication:

- Get to know the key staff involved in your loved one’s care.
- Write down what you want to ask and take any opportunity to ask questions.
Also, contact The Encephalitis Society. You can talk with an experienced professional by phone or email. They may have a Regional Representative in your area who can provide information and support. Regional Representatives are volunteers who have first-hand experience of Encephalitis so are well placed to help.

**Remember your own needs as a family member**

In addition to the stress associated with a loved one being unwell, practical issues such as lack of sleep, no time to eat, no appetite and losing touch with family and friends can all add to the impact of the illness. At times family members may feel helpless, isolated and confused.

Acknowledge your emotions and be aware that other family members may react differently. 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.

Involve your extended network of family and friends in providing you with practical support. Take them up on their offers of help. If they have not offered, ask them to prepare some food, do some washing, shopping or look after your children. The likelihood is that they want to help but don’t know what to do for the best.

### 2. Discharge from hospital

Most people affected by Encephalitis are left with some form of Acquired Brain Injury (ABI) and therefore discharge planning is considered ‘Complex’ requiring the involvement of other professionals for assessing the likely long-term issues. 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 Planning Meeting to ensure that support and care will be provided to meet your needs. You and/or your carer should be involved in this discussion so that the discharge plan is as realistic and achievable as possible.
If you are likely to have continuing health and social care needs, a care plan will be produced. This will identify who will provide the care and support for you at home. You and the person who will be your main carer (with your consent where possible) should be consulted and satisfied with the plans that are put in place. All plans such as Care assistance, Respite facilities, Day Care, as well as referrals for Neurology, Neuropsychology, Speech and Language Therapy, Occupational Therapy or Physiotherapy need to be in place before you return home.

In a few cases, a return home will not be possible and residential rehabilitation or long-term residential placement may be required. The majority of people will be managed in local units although it may be appropriate for the person affected to be referred to a specialist centre for assessment and care planning that is out of area, even if the implementation of the care plan is to be followed up by local professionals. This might include, for example, centres for managing brain injury or epilepsy that have interdisciplinary teams with specialist skills in brain injury rehabilitation.

You have the right to choose what care and support you want after being provided with all the information necessary to help you make informed decisions (e.g. financial implications). If you do not have capacity to make decisions about your care, your carers should be consulted about their views on what is best for you.

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 if there are problems following discharge, as well as details of the services that you are being referred to so you can call them to discuss relevant issues (e.g. occupational therapy, physiotherapy, neuropsychology, speech and language therapy).

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 and/or the Patient Advice and Liaison Service (PALS).
3. Problems during the hospital stay

Patient Advice and Liaison Service (PALS)

If you have any concerns about the care of your loved one that cannot be resolved through discussion with the staff involved you can seek advice from PALS.

PALS can provide confidential information and support on health related matters while you or your loved one is in hospital. They liaise with staff, managers and, where appropriate, other relevant organisations to negotiate speedy solutions. They also help bring about changes to the way that services are delivered.

They can also:

- Provide information about support groups available outside of the NHS.
- Find an advocate for you.
- Provide information and advice regarding the complaints procedure, but they cannot take up any formal complaints.

You can find PALS officers at your local hospital. Ask a member of staff or alternatively visit the NHS website to find the nearest PALS at [www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-(PALS)/LocationSearch/363](http://www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-(PALS)/LocationSearch/363)
Making a complaint

If you are unhappy with the hospital or any other NHS service you are involved with, you can make a complaint. Each hospital or service has a policy regarding the complaints procedure. Local PALS can provide more information about it. Alternatively, you can complain directly to the commissioner of the specific service: NHS England if your complaint relates to a GP and the Care Quality Commission (CQC) if your complaint relates to hospitals or community services. The time limit for registering complaints is usually 12 months from the date of the incident or from the date you first became aware of it. The time limit can be extended in cases in which it would be unreasonable to expect you to have registered a complaint sooner, for example, because of grief or trauma.

The following organisations may help if you want to pursue a complaint:

- **The Encephalitis Society** can provide support and direct you to those best placed to address your concerns. Contact details: email support@encephalitis.info or tel 01653 699599.

- **The Patients Association** ([www.patients-association.com](http://www.patients-association.com)) provides information to patients and their families about the healthcare system.

- **Local Health Watch** ([www.healthwatch.co.uk](http://www.healthwatch.co.uk)) provides general advice and support regarding complaints about the NHS and social care. They may act as your advocate when you make a formal complaint. Each local Health Watch works in partnership with other local organisations. An online search facility for your local Health Watch is available on their website.
SECTION III: THE IMPACT OF ENCEPHALITIS

This section covers information about the 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 virtually no problems after Encephalitis and others will experience severe, lifelong difficulties.

KEY FACTS

- The effects of Encephalitis vary greatly from one person to the next.
- In some people, Encephalitis may cause 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 the success of treatments received.
- There may be changes in thinking skills, emotion, behaviour and physical functioning.
- Following Encephalitis, these problems can range from mild to very severe.
- Although physical changes are easy to spot, changes in thinking skills can be subtle and difficult to recognise.
SECTION III: THE IMPACT OF ENCEPHALITIS

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1. The effects of Encephalitis on the brain

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 we 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 neurons. 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 of a main road with tarmac allowing traffic to flow more freely.

The complexity of the brain is due in part to the system of interconnections between neurons in the different parts of the brain. Neurons communicate with one another via specialised chemicals called neurotransmitters. The brain is composed of numerous structures, each made up of neurons and supporting cells called glia. Neurons transmit electrical and chemical signals, and this transmission of signals between neurons is how the brain functions.

Three basic types of glia exist in the brain:

- Oligodendroglia cells wrap axons with myelin. The myelin thus forms a sheath around the axon, facilitating the transmission of electrical signals along a neuron.

- Astroglia cells (astrocytes) are found throughout the brain. They play many different ‘housekeeping’ roles: provide nourishment and protection for the neurons and structural support or ‘scaffolding’ for the brain. They also play an important role in the immune system.
Microglial cells are important in the brain’s injury response as they search cellular debris and help to clean up damage.

The brain is protected by a blood-brain barrier, which prevents any large molecules passing from the blood into the brain. The barrier is the result of the cells lining blood vessels in the brain. Blood vessels in the rest of the body are lined by cells which fit together very loosely allowing easy movement by quite large bodies to and from the blood. Cells lining blood vessels in the brain fit together very tightly and most substances have to be actively transported through the cells rather than passing between them. 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. When the immune response is either inadequate or inappropriate, an infection of the brain can cause Encephalitis.

The immune response evolved to protect organisms against injury and infection. Following an injury or infection, a complex cascade of events leads to the delivery of 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 (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.
2. **The after-effects of Encephalitis**

Nerve cells may be damaged or destroyed by both the infection and inflammation. The resulting damage is termed an ABI. The loss of brain function from ABI can range from minor, to more significant, impairments. The degree and type of damage will vary according to the cause and the severity of the inflammation, the parts of the brain affected and any delay in treatment. Coming to terms with the resulting problems can be very distressing and challenging for everyone concerned. The person you knew, or who was you, may have changed and the person they have become, or you have become, may present with a number of problems. There may be cognitive, physical, emotional and/or behavioural difficulties. Encephalitis affects each person differently depending on the brain system affected and the type of Encephalitis, in addition to a range of other factors including an individual’s support system and access to treatment.

### 2.1 Cognitive changes

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 ability to complete everyday activities, from running a household to maintaining friendships, working, driving and studying. Following Encephalitis, an individual may experience changes in these cognitive abilities to varying degrees and, in turn, have trouble with everyday activities.

No single cognitive skill contributes alone to the success of completing each everyday task. 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.

**Attention and concentration**

Following Encephalitis a person may be more distracted or find it hard to concentrate. Fatigue may 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 when answering 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.

**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:

- It may be difficult to remember recent events, such as what happened last week, conversations or what has been read from chapter to chapter.
- It may be hard to learn a new skill, a lesson at school or how to use technology (e.g. a new mobile phone).
- It may be difficult to recall events and people from life before Encephalitis.
- Problems can also occur in remembering plans and what has to be done at some time in the future, such as appointments or paying a bill.

**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 or people. 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 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 such
that they experience 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.

**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 & problem solving**

Following Encephalitis people may have difficulty solving problems, planning and organising things. They may be inflexible in their thinking, becoming fixed on one particular thought and unable to consider alternatives.

**Lack of initiative**

After 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.

**Impulsivity**

Individuals affected by Encephalitis may experience changes to the cognitive control system that makes them stop and think before acting or speaking. This may lead to difficulty judging situations and socially awkward, unpredictable behaviour, which can have a negative impact upon everyday functioning including relationships.
2.2 Behavioural and emotional changes

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 people may appear to be self-centred 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 others, 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 changes in their thinking or behaviour and the effects they have on everyday life, including driving and working. 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 associated with cognitive, motor or behavioural changes. For example, it can be frustrating to misplace belongings or not be able to get 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 have 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.

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 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. Others may experience anxiety in the form of panic attacks, associated with a reduction in their usual activities. Some 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.

**Depression**

Depression is a common response to the numerous life changes that may occur following Encephalitis as a result of the functional limitations imposed by cognitive, behavioural and emotional difficulties. Mood changes may reflect a growing realisation of the discrepancy between who one was before Encephalitis and how they see themselves now. This might be particularly evident following losses or changes in the person’s social roles. A person may mourn the end of a relationship, the inability to pursue a former active social life or chosen career, or changes to family and capabilities.
2.3 Physical changes

Fatigue

Fatigue is one of the most common problems people experience after ABI. 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.

Fatigue is the brain’s way of ‘shutting down’ in order to carry out repairs. In a world where everything moves so fast it is often difficult to adjust to the fact that you may now need to slow down. However, it is important to rest before becoming overtired; doing too much on a ‘good’ day often results in days of extreme fatigue.

Movement, balance and coordination

The brain controls our ability to coordinate movement and balance. Following Encephalitis people may experience weakness and/or difficulty controlling their movement. They may appear to be clumsy or unstable on their feet.

Epilepsy and seizures

Seizures (fits) are the result of abnormal electrical activity in the brain. Encephalitis results in brain damage increasing the likelihood of seizures. Seizures may occur during the acute illness and/or develop weeks, months, or even in very rare cases, years afterwards.

Seizures may be classified into different types:

- In the case of primary generalised seizures the entire brain is rapidly involved right from the beginning of the seizure.
- Focal (partial) seizures occur when abnormal electrical activity begins in one localised area of the brain. These seizures can often be subtle or unusual, and may go unnoticed or be mistaken for anything from ‘intoxication’ to ‘daydreaming’. As the seizure evolves, it may either remain in that area or spread to involve other nearby areas on the same side of the brain (regional spread), or it may spread more widely to involve both sides of the brain (secondary generalised seizure).
• 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’.

Most people who develop epilepsy after Encephalitis have focal or secondary generalised seizures. Because Encephalitis is commonly a diffuse process involving both sides of the brain, seizures may sometimes arise from several different locations and this is referred to as multifocal epilepsy. Focal epilepsy is often classified according to the region or lobe of the brain where the abnormal electrical activity starts at the beginning of the seizure. Therefore, it is common to refer to frontal lobe epilepsy, temporal lobe epilepsy, parietal lobe epilepsy and occipital lobe epilepsy, when the seizures have their origin in those particular lobes of the brain.

**Sensory changes and pain**

Vision, hearing, smell, taste and tactile sensation can all be affected differentially 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’. They may also experience pain including headaches. These problems may be apparent only within the context of the acute illness or may persist in the longer term.

**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. The nature of sexual problems are many and varied.

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. They may experience heightened feelings of vulnerability and anxiety.

Sexual problems may be a side effect of taking particular drugs. Alternatively, life circumstances such as relationship problems following brain injury can also lead to sexual dysfunction. Clearly, problems with sex affect not only the person with Encephalitis but also the sexual partner. Couples may argue and single people with Encephalitis may lack confidence in forming new relationships.

**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). If brain injury leads to a reduction in hormones being produced, this results in a condition called ‘hypopituitarism’.

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.
SECTION IV: RECOVERY AND REHABILITATION

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

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.

- Recovery after Encephalitis involves rest initially and 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’.

- Timely access to rehabilitation is important for improving longer term outcomes.

- One of the aims of rehabilitation is to help identify the nature and degree of structure and support required after Encephalitis.

- People may need different assessments and interventions at different stages in their recovery.

- Maximising communication with health and social care professionals involved in your recovery is important.
SECTION IV: RECOVERY AND REHABILITATION

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1. 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 slows down, but recovery can continue over the years to come.

As time passes and you feel better, you may hear people say ‘it’s time to get on with life’. However, it is very important to try not to rush the healing process. After ABI, restoring the networks by which the brain functions takes time. Newly established brain networks need constant maintenance, and research has shown that these repair phases occur in sleep. Your brain 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, making you unusually irritable, confused, disoriented and/or afraid. Be prepared for a long period of convalescence. Initial recovery may be rapid but usually falls short of complete recovery. Further recovery takes place more slowly over a period of months and even years. 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.

2. Managing the after-effects of Encephalitis

2.1 What is rehabilitation?

Rehabilitation involves treatment designed to facilitate recovery from illness. The aim of rehabilitation is to help the person acquire the knowledge and skills needed for optimal cognitive, psychological, physical and social function. Good rehabilitation involves a holistic approach. It recognises the complex problems 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, or where this is not possible, compensating for difficulties.
Rehabilitation can be a very long journey and some people can benefit from rehabilitation many years later. Some 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 and 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.

2.2 Key professionals

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

**Neuropsychologists** are trained in understanding brain-behaviour problems. Referral to a neuropsychologist may be useful for:

- An assessment of thinking skills with a view to managing cognitive problems (e.g. difficulties with attention and memory).
- An assessment of an individual’s capacity to make complex decisions (such as where to live).
- Therapy and other interventions for managing problems with emotion and behaviour.
**Occupational therapists (OT)** support people to engage in activities that are important to them. Referral to an occupational therapist may be useful 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 become involved in leisure-based activity.
- Supporting people to go to college or return to work.
- Considering what aids/equipment might be useful for helping someone maximise their independence and fulfil their goals.

**Speech and language therapists** specialise in assessment and management of problems with communication, eating, drinking and swallowing. Referral may be useful for assessing and managing:

- Difficulties with understanding or producing speech.
- Difficulties understanding or using language.
- Difficulties with eating, drinking and swallowing.

**Dieticians** assess nutritional needs and recommend appropriate nutritional treatment for patients. Referral may be appropriate when:

- There are concerns about a person’s weight (under or overweight).
- There are concerns about other nutritional issues (e.g. restricted diet, aversion to certain food textures).

**Neurophysiotherapists** help and treat people with physical problems secondary to neurological conditions. Referral to a neurophysiotherapist is useful for assessing and addressing:

- 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 (e.g. NHS Community Neurology Rehabilitation Teams, NHS Community Brain Injury Teams). Assessments by NHS 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 an NHS Hospital).

Depending on where you live, help may be available from local NHS services (e.g. statutory services) and/or there may be other services available that you can access for free. The best thing to do is speak with your 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.

**The Encephalitis Society Neuropsychology Service:** This service prioritises access to neuropsychological support for adults with Encephalitis across the UK who are unable to obtain the help they need from local statutory services. You can gain access to this service by asking your GP to refer, making a self-referral or referring your loved one. A referral form for the service can be found at [www.encephalitis.info/files/1614/2849/9043/Referral_Form_-_ESNS_25_2_15.pdf](http://www.encephalitis.info/files/1614/2849/9043/Referral_Form_-_ESNS_25_2_15.pdf) Tel: 01653 699 599.
If there is no local statutory service available, another option is to pay to see professionals on a private or ‘fee-paying’ basis. Information about private practitioners can be found on the following websites:

- **The College of Occupational Therapists**: [www.cotss-ip.org.uk](http://www.cotss-ip.org.uk)
- **Royal College of Speech and Language Therapists**: [www.rcslt.org](http://www.rcslt.org)
- **British Dietetics Association (BDA)**: [www.bda.uk.com](http://www.bda.uk.com)
- **The Chartered Society of Physiotherapy**: [www.csp.org.uk](http://www.csp.org.uk)
- **The British Psychological Society**: [www.bps.org.uk](http://www.bps.org.uk)

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

**Neurologists** are doctors specially trained to diagnose disorders of the brain, spinal cord and nerves, and to treat them with medical interventions if appropriate. A neurologist should have seen everyone who has been ill with Encephalitis in the acute phase. In practice, this is not always the case. Following the illness, you only need regular follow-ups by a neurologist if you have medical problems that require medication such as epilepsy and headaches. However, your neurologist can refer you to other appropriate services.

**Neuropsychiatrists** are medical doctors who help people manage mental health problems that might occur following a brain injury. A neuropsychiatrist can prescribe medication and arrange for other forms of support as needed.

**Social workers** assist with social issues such as arranging respite, residential care or safeguarding.

**Epilepsy nurse specialists** are trained nurses with extra qualifications in neurology, care of a patient with epilepsy and nurse prescribing. Their role includes various clinical interventions such as medication review and clinical assessment, as well as providing counselling and social support to patients and their families.

**Pain management services/pain clinics** are multidisciplinary services specialising in helping patients managing their pain via physiotherapy, psychological support and/or medication.
Continence services are nurse-led services that provide specialist continence assessment, investigations, treatment and support to those who have bladder, bowel or pelvic floor dysfunction.

Psychosexual clinics consist of qualified therapists that specialise in managing the combined physical and psychological aspects of sexual dysfunction. Private sexual and relationship therapists can be found on the College of Sexual and Relationship Therapists website www.cosrt.org.uk

Ear, nose and throat specialists are specialists in managing diseases of the ears, nose, throat and related structures of the head and neck.

Audiologists specialise in problems with hearing, balance and tinnitus.

Ophthalmologists manage medical and surgical eye conditions.

Endocrinologists specialise in managing the illnesses related to hormones.

Immunologists investigate the functions of the body’s immune system and apply this knowledge in order to diagnose and monitor a range of diseases and disorders.

2.3 Managing cognitive changes

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:

**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 with clarification that the information is correct in order to manage problems with taking in what has been said.
- Attempting one task at a time, during peak energy times, can also help reduce distractibility and get things done.

**Problems with memory**

There are various external memory aids to compensate for these problems such as:

- diaries
- calendars
- post-it notes
- smart phones and apps
- email and computer-based supports
- message boards
- medication boxes
To help manage **difficulty 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.

**Difficulties with perceptual or visuospatial skills:**

- Taking note of key landmarks and repetition so as to navigate familiar routes.

**Problems with communication:**

- To lessen the frustration of word finding difficulties, use different words to communicate the message as opposed to using one (the lost) word.
- Taking more time, relying on notes if possible and managing anxiety associated with finding words may also help to make conversation more fluent.

**Problems with planning and organising:**

- Increased structure and routine in daily activities.
- The use of compensatory aids such as a diary, message board, smart phone or alarm.

With the help of family and the rehabilitation team, a structured approach to planning everyday tasks can be adopted. Daily activities can be written 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. Alarms (e.g. mobile phone alarms) can be used to help monitor performance and keep a person on track.
**Difficulties with ‘get up and go’**

- Recognising that a lack of initiative is a result of Encephalitis as opposed to being ‘lazy’ or ‘not interested’.
- Keeping a daily routine to provide structure and manage reduced drive.
- Breaking activities into smaller steps, with enjoyable rewards once an activity is completed.
- Recognising the individual’s achievement, highlighting to others and then attempting 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.
You may also find the following resources useful for understanding and managing cognitive changes:

- The Encephalitis Society has a detailed factsheet on Cognitive and Behavioural Changes after Encephalitis available to download from our website [www.encephalitis.info/information](http://www.encephalitis.info/information) or as a paper copy from our office.
- The Encephalitis Society has a detailed factsheet on Memory Problems available to download from our website [www.encephalitis.info/information](http://www.encephalitis.info/information) or as a paper copy from our office.
- The book Coping with Memory Problems by Linda Clare and Barbara Wilson (available from [www.pearsonclinical.co.uk](http://www.pearsonclinical.co.uk)) contains useful information about managing memory problems.

### 2.4 Managing behavioural and emotional changes

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, or 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.

You may also find the following resources helpful:

- A detailed factsheet on Managing Anger after Encephalitis is available to download from our website [www.encephalitis.info/information](http://www.encephalitis.info/information) or as a paper copy from our office.
- A booklet, ‘Responding to Challenging Behaviour Following an Acquired Brain Injury’, produced by Synapse (formally the Brain Injury Association of Queensland Inc) is available to order from our online shop at [www.encephalitisshop.com](http://www.encephalitisshop.com) or our office.
- A detailed factsheet on Depression is available to download from our website [www.encephalitis.info/information](http://www.encephalitis.info/information) or as a paper copy from our office.

**The benefits of sharing experiences**

Many people also find 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, The Encephalitis Society has developed the following initiatives for helping people connect with each other and share experiences:

- **Connections Scheme:** This has been set up to enable members to make contact with others in a similar situation to themselves ([www.encephalitis.info/support/support-services/connections-scheme/](http://www.encephalitis.info/support/support-services/connections-scheme/)).
- **Support Volunteers:** As people usually affected by Encephalitis themselves, they offer their time to help people understand Encephalitis and its consequences, as well as help to find local services that may be of benefit ([www.encephalitis.info/support](http://www.encephalitis.info/support)).
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 providing 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/information) recommends and reviews a wide range of books in which people have written about their personal experience of Encephalitis or ABI more generally. Some examples include:

**Books (people’s stories) specifically relating to Encephalitis:**

- **Brain On Fire** by Susannah Cahalan
- **One Million Lovely Letters** by Jodi Ann Bickley
- **Out of It** by Simon Hattenstone
- **Emma’s Story** by Ian and Margaret Shaw
- **Healing Lazarus** by Lewis Richmond
- **In the Shadow of Memory** by Floyd Skloot
- **Awakenings** by Oliver Sacks
- **Forever Today** by Deborah Wearing
- **Rachel’s Story** by Rita O’Dwyer
- **God’s Humour. My Life After Encephalitis** by Marius Van Welie
- **Brain Wreck** by Becky Dennis
Books (people’s stories) specifically relating to Acquired Brain Injury

- Our Time of Day. My Life with Corin Redgrave by Kika Markham
- Where is the Mango Princess? by Cathy Crimmins
- Over My Head by Claudia L Osborn
- Time Out of Mind by Jane Lapotaire
- Doing up Buttons by Christine Durham
- On the Edge: My Story by Richard Hammond
- Touching Distance by James Cracknell and Beverley Turner

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, such as Headway groups (website: www.headway.org.uk; helpline: 0808 800 2244), 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.

2.5 Managing physical changes

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, 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

As a general rule, in order to manage fatigue effectively it is important to structure your day with rest periods in-between activities. Recovery is aided by a structured timetable of graded mental activity followed by rest; followed by graded physical activity followed by rest. 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.

The following resources may also be useful:

- **The Encephalitis Society** has a detailed factsheet on Fatigue available to download from our website [www.encephalitis.info/information](http://www.encephalitis.info/information) or as a paper copy from our office.
- **Managing fatigue after brain injury** by Jacqui Cooper and Donna Malley available from Headway website: [www.headway.org.uk](http://www.headway.org.uk) or helpline: 0808 800 2244.
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. The following resources may provide useful additional information:

- **The Encephalitis Society** has a detailed factsheet on *Seizures and Encephalitis* available to download from our website [www.encephalitis.info/information](http://www.encephalitis.info/information) or as a paper copy from our office.

- **Epilepsy Action**: website: [www.epilepsy.org.uk](http://www.epilepsy.org.uk) Tel: 0808 800 5050 and **The Epilepsy Society** website: [www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk) Tel: 01494 601400 provide information and support for people affected by epilepsy and their families.

Sensory changes and pain

Although sensory problems and pain may first come to the attention of your 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, ophthalmologists (see ‘**Key Professionals**’ above). In the case of chronic pain, referral to a pain management clinic may be considered.

Further support and information:

- **Fifth Sense** provides support and information on anosmia, smell and taste-related disorders via website, email or a regional hub network. Website: [www.fifthsense.org.uk](http://www.fifthsense.org.uk) Email: Info@FifthSense.org.uk

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 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 hormonal 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 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. The following resource may also be useful:

- **The Pituitary Foundation** provides information and support on conditions related to a dysfunction of the pituitary gland. Website: [www.pituitary.org.uk](http://www.pituitary.org.uk) Tel: 0117 370 1320.

Diet and exercise

A healthy diet that is high in antioxidants (fresh fruit and vegetables) and high in omega-3 (fish or flaxseed oils) will also aid recovery. Antioxidants protect nerves from destructive elements. The recommendation to eat five portions of fruit and vegetables each day should be taken seriously. Omega-3 is an essential ingredient of myelin, the covering of nerves in the brain. Covering nerves with myelin can be likened to covering a road with tarmac, traffic flows much easier and quicker down a tarmac covered road. Omega-3 is found in fatty fish (such as salmon, tuna and sardines), flax (linseed) oil and can be taken as an oil capsule.

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 round the block 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.
2.6 Vocational rehabilitation: a return to work

Vocational rehabilitation is a process that enables people with functional, psychological, developmental, cognitive and emotional impairments or health conditions to overcome barriers to accessing, maintaining or returning to employment or other useful occupation. The focus of vocational rehabilitation is to help people retain or regain the ability to participate in meaningful activity, rather than to treat any illness or injury itself.

Work can play an important role in helping people recover from Encephalitis. However it is very important that people do not attempt to return to work too soon. An unsuccessful return can have a negative impact 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 impacted on 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, it is usually the occupational therapist that takes the lead role.

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 may be (e.g. physical harm may be a risk if someone operates machinery and is distractible).
- The kinds of strategies that might be useful to help someone complete their job role (e.g. lists for remembering tasks and keeping organised, strategies for helping them to calm down if they become upset).
- Any aids that may be of benefit for performing work tasks (e.g. whiteboards, checklists, adaptive aids for managing physical problems).
- Whether the job role needs to be changed such that certain tasks are 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 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 people 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.
Services that can assist with vocational rehabilitation

Whilst negotiating a return to work through vocational rehabilitation you should ask your GP to write a Fit Note (or Statement of Fitness for Work) which gives you more information on how your condition affects your ability to work. This will also help your employer understand how they might help you return to work sooner or stay in work.

For assistance with return to work, study, or to gain support with engaging in activity more generally, it is best for you to request referral for vocational rehabilitation through your GP (or neurologist if you are still under their care). You may be referred to an NHS Community Neurology Team if one exists in your local area, or else to an occupational therapist in another service that is able to provide help.

Alternatively, assistance with return to work can be sought from a Disability Employment Adviser (DEA) at the local Job Centre. DEAs can discuss the current employment situation and assist with planning the best way back into work. A DEA can help with work preparation, advocacy, recruitment and confidence building. They can complete an employment assessment to identify what work or training suits best. This can result in a Plan of Action to help you meet your employment goals which may include:

- Training
- Taking part in a programme such as Access to Work or Work Choice.

Further support

- **Momentum Skills** ([www.momentumskills.org.uk](http://www.momentumskills.org.uk)) provides training and employability services to people with disabilities and those who are excluded.
- **Shaw Trust** ([www.shaw-trust.org.uk](http://www.shaw-trust.org.uk)) runs employment services for disabled and disadvantaged people.
2.7 Obtaining appropriate care, support and placement

Rehabilitation helps to provide information about the nature and degree of support an individual requires in order to maximise their ability to complete everyday tasks after experiencing Encephalitis. Support requirements differ markedly 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 it 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

If you need care urgently, the local authority may be able to meet these needs without carrying out the assessment. You will need to contact your local council/social care department as exact details regarding the assessment process and services available vary according to area. Some areas have social workers who are specialists in brain injury. Details of the local authority’s adult social service department are on the Government website at www.gov.uk/help-care-support. Try to prepare for this assessment. Make sure you provide information about all your needs, write things down and keep notes and copies of letters and appointments.

If after the assessment the local authority decides you are eligible for support, they will draw up a care and support plan detailing how your needs will be met. Social care is not free and you may have to contribute towards the cost of meeting your needs. Local authorities will complete an assessment to see if you have to contribute
and if so, how much. Following the care plan, you will also receive a personal budget, which allows you to choose one of the following options:

- Care and support services provided by the council.
- Direct Payments. These payments give you a greater flexibility in choosing your care and support, by being paid to you by the council so that you can decide how you want to meet your care and support needs.
- A mixed package, which includes Direct Payments and care and support provided by the council.

If after the assessment you are not eligible for support from the local authorities, you should be provided with information and advice on what other forms of support are available in your local community.
3. Managing the process of recovery and rehabilitation

3.1 Meeting with professionals

Meetings with professionals could involve appointments with your GP, consultant, therapist, social worker, someone from the benefits agency or other person providing you with advice. Meeting professionals can be quite daunting, 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 where to meet.
- 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 (a 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 to 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 become 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 them through with someone else.
- Ask for any decision/information/outcome from the meeting in writing.

If things go wrong:

- Do not get angry; if you do, take some deep breaths or ask for a short break.
- Do not blame anyone; 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.

The Encephalitis Society has produced a factsheet, *Meeting with Professionals*, which is available on our website [www.encephalitis.info/information](http://www.encephalitis.info/information) or from our office, and may be of further benefit.
3.2 Obtaining a second opinion

Your GP or any healthcare doctor can refer you to a different doctor for another opinion but they don’t have to do this if they don’t agree that it is necessary. Before asking for a second opinion, if you are unhappy with the diagnosis or the treatment, you may want to discuss this with the doctor.

If you would like a second opinion after receiving advice from your GP, you can ask them to refer you to another GP. If you would like a second opinion after seeing a consultant, or any other health professional you need to go back to your GP and ask them to refer you again to an alternative consultant. If your GP agrees to refer you to a new consultant, this consultant will be told that you are seeking a second opinion.

If the GP refuses to arrange a second opinion, you may want to change your GP. Sometimes a GP or consultant may ask colleagues to provide a second opinion of their own initiative. This might happen when the presentation of your symptoms is complex or if they feel they are being asked to comment on issues outside of their area of expertise.
SECTION V: ADDITIONAL SOCIAL AND LEGAL ISSUES

This section provides an overview of some additional social and legal issues raised by Encephalitis. It also signposts you to various organisations who may be able to provide further information and advice.

**KEY FACTS**

- Encephalitis can affect an individual’s ability to make decisions, and in some cases decisions need to be made in their ‘best interest’ as an alternative.

- It is your responsibility to inform the DVLA if Encephalitis has affected your ability to drive.

- You may need to surrender your driving licence if your driving has become unsafe.

- Encephalitis can affect employment and a family’s finances.

- It is important to get professional help when applying for benefits.

- When planning your holiday you may need to take extra care due to some of the consequences of Encephalitis.

- You may be entitled to financial compensation through a clinical negligence claim if you received a poor standard of treatment, which can be of great practical importance to both the person affected and their family.
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ADDITIONAL SOCIAL AND LEGAL ISSUES

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Know Your Rights
1. 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.

The Mental Capacity Act (MCA) is designed to protect and empower individuals who may lack the mental capacity to make their own decisions about their care and treatment. It is a law that applies to individuals aged 16 and over.

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’. Consulting with others is an important part of the decision-making
process. People who should be consulted include anyone previously named by the person concerned, anyone engaged in caring for them, close relatives, friends or others who take an interest in their welfare, any attorney appointed under a Lasting Power of Attorney or Enduring Power of Attorney, and any deputy appointed by the Court of Protection to make decisions for the person. In certain instances, such as where there is not a family member available to represent a patient’s views, an Independent Mental Advocate may be appointed to aid in determining the ‘Best Interest Decision’.

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.

2. Driving

After Encephalitis, many people see a 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.

You need to inform The Driving and Vehicle Licensing Agency (DVLA) that you have been ill with Encephalitis. You have to inform the DVLA if you experience some of the after-effects that may affect your driving ability such as memory problems, epilepsy, dizziness and deafness (this list is not exhaustive - please check the DVLA website for a full list of notifiable illnesses and treatments). The DVLA has specific guidelines regarding driving and epilepsy, which vary depending on several things such as when you tend to have seizures, how controlled by medication they are and when you had your last seizure. You can find out more about these guidelines via the following link:

www.gov.uk/epilepsy-and-driving
The responsibility for informing the DVLA lies firmly with you, the licence holder. You should also inform your insurance company of your recent illness and any associated change in circumstances, and tell them that you have informed the DVLA. It is illegal to drive on the highways without a valid licence and you also risk prosecution if you do not inform the DVLA of any illness or injury that could affect your driving. Your insurance is invalidated in both of these circumstances.

Doctors are encouraged to advise people that their condition may affect their ability to drive. Be aware that the GP has a responsibility to alert the DVLA if they feel that you are unable to drive safely, but you are unwilling to inform the DVLA. In circumstances where your driving likely poses a risk to yourself and/or others, the GP does not need to obtain your consent to contact the DVLA about this.

Further information on driving after illness:

- **DVLA** for England, Scotland and Wales: Address: Drivers’ Medical Enquiries: DVLA, Swansea, SA99 1TU Telephone: **0300 790 6806**

- **DVA** for Northern Ireland: Address: County Hall, Castlerock Road, Coleraine, CO. Londonderry, BT51 3TB; Telephone: **08454024000**/Minicom **02870341380**

- **The Encephalitis Society** produces a factsheet *Driving after Encephalitis* which can be downloaded from our website [www.encephalitis.info](http://www.encephalitis.info) or requested from our office on **01653 699 599**
3. 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. This can be paid for the first 28 weeks of an illness.

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 or communication (e.g. understanding, talking). 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.

The following organisations can help with benefits:

- **Citizens Advice Bureau** (CAB) provides information about benefits on their website at [www.citizensadvice.org.uk/benefits](http://www.citizensadvice.org.uk/benefits). Local Citizens Advice centres provide advice regarding individual cases by phone and in person. A directory of local offices can be found at [www.citizensadvice.org.uk/about-us/how-we-provide-advice/advice/](http://www.citizensadvice.org.uk/about-us/how-we-provide-advice/advice/)

- **The Government** provides information about benefits on their website at [www.gov.uk/browse/benefits](http://www.gov.uk/browse/benefits)

- **The NHS** provides detailed information on Direct Payments on their website at [www.nhs.uk/Conditions/social-care-and-support-guide/Pages/direct-payments-personal-budgets.aspx](http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/direct-payments-personal-budgets.aspx)

- **Headway** produces various factsheets on different types of benefits you may be entitled to and provides advice about filling in the forms. Website [www.headway.org.uk](http://www.headway.org.uk) or Helpline 0808 800 2244. Headway Emergency Fund helps families and individuals cope with the practical implications of a sudden catastrophic brain injury. More information can be found at [www.headway.org.uk/emergency-fund.aspx](http://www.headway.org.uk/emergency-fund.aspx)

- **Disability Rights UK** produces factsheets providing basic information about benefits, tax credits, social care and other disability related issues. Website: [www.disabilityrightsuk.org/](http://www.disabilityrightsuk.org/)


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Section V

- Debt Advice Foundation offers free, confidential support and advice to anyone concerned about loans, credit and debt. Website: [www.debtadvicefoundation.org/](http://www.debtadvicefoundation.org/) Telephone: 0800 0434 050
- Turn2us offers a free service that helps people in financial need access welfare benefits, charitable grants and other financial help. Their website ([www.turn2us.org.uk/](http://www.turn2us.org.uk/)) features an Online Benefits Calculator that can assist you to check what you are entitled to.
- Shelter gives practical housing advice and support online, in person and by phone, helping with everything from mortgage arrears to finding a place to sleep. Website: [www.england.shelter.org.uk](http://www.england.shelter.org.uk) Helpline: 0808 800 4444.

4. Holidays and travel insurance

Holidays usually mean travelling, visiting new and unfamiliar places, spending time with multiple 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 they may ‘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.
**Flights**

Make sure it is safe for you to fly (check with your 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 problems as a consequence 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 pre-existing medical conditions. 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.

**European Health Insurance Card**

If you are travelling within the European Economic Area, you can get a European Health Insurance Card to enable free or reduced emergency care. This does not replace the travel insurance, which covers things such as private medical health care, the flight back to the UK or lost property.

Further information about holidays and travel abroad:

- **The Encephalitis Society** produces a factsheet, *Holiday and Travel Insurance*, which can be downloaded from our website [www.encephalitis.info/information](http://www.encephalitis.info/information) or requested from our office on 01653 699599.
The Government website (www.gov.uk/knowbeforeyougo) provides information about how to stay safe and healthy abroad.

Headway produces a booklet called Holiday & Travel after Brain Injury which provides details of companies that cover travellers with a disability. Website: www.headway.org.uk Helpline: 0808 800 224.

Epilepsy Action works with Insure & Go Insurance Services Ltd to offer a quality travel insurance policy for people with epilepsy, which includes cover for epilepsy related incidents. Website: www.epilepsy.org.uk Helpline: 0808 800 5050.

Tourism For All UK provides information to people with disabilities and older people in relation to accessible accommodation. Website: www.tourismforall.org.uk Tel: 0845 124 9971.

5. Pathways through medico-legal investigation

Most people receive a good standard of treatment when they become ill with Encephalitis. For a few people the long-term consequences of a very serious illness are made significantly worse by a poor standard of treatment. The most common problem is a delay in recognising Encephalitis as a possible diagnosis leading to a delay in giving effective drugs, but unfortunately other failures in this condition’s management can also occur. In those cases, there will be an entitlement to financial compensation through a clinical negligence claim. Because Encephalitis can be such a serious illness, this entitlement can be of great practical importance to both the person affected and their family.

If you want to start a medico-legal investigation, you need to contact a specialised solicitor who should be able to give you preliminary advice without any charge or obligation.

You will also need:

- Medical records which show what the medical staff thought and did.
- Your recording of what happened.
- Any notes/statements/reports generated by the operation of the complaints procedure if available.
To succeed in a claim you need to prove a departure from proper standards of medical care. You also need to prove that the consequences of Encephalitis are worse than would have been the case with proper treatment. Most commonly, you need to show that any competent medical team would have recognised the possibility of Encephalitis earlier and that the outcome would have been significantly better with earlier treatment.

Once your legal team has established that you have a valid claim by obtaining supportive independent medical expert evidence, the process is essentially one of exchanging information, according to a timetable set by the Court, so that both sides can assess the strengths and weaknesses of their position and think about whether they should make or accept a settlement offer.

Many people are very nervous about legal costs, which is understandable but unnecessary. A solicitor will discuss funding issues with you in detail. It is part of your solicitor’s job to make sure the investigation and any claim are dealt with cost-effectively, that you are kept fully informed and you are protected from financial risk.

For further information and support:

- Contact The Encephalitis Society Support Team on 01653 699599 or email support@encephalitis.info
- Download a copy of the factsheet *Pathways Through A Medico-Legal Investigation* from our website www.encephalitis.info or request a copy from our office on 01653 699 599.
- Visit the Law Society’s website at www.lawsociety.org.uk
SECTION VI:
MANAGING THE IMPACT
OF ENCEPHALITIS ON THE
FAMILY

This section focuses on the different ways Encephalitis may affect families and highlights the main issues for carers and children in the family, with different options for support.

KEY FACTS

- Encephalitis may affect family relationships.

- Families often go through a process of coming to terms with 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 both as the person affected and as a family member.

- Being a carer has a big impact on everyday life, friendships, work and 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.
SECTION VI:
MANAGING THE IMPACT OF ENCEPHALITIS ON THE FAMILY

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1. Impact on the family

All families are different, but Encephalitis can herald the start of major family challenges. 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. 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. A family’s coping strategies can be tested.

Your extended family and friends may not have heard of Encephalitis before, so they do not know what you have been through. They may see that your loved one has recovered well physically 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.

Alternatively, 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. Children and siblings may also experience emotional problems if their needs are overlooked. Spouses often feel isolated and trapped as the nature of their role becomes unclear. Extended family and friends often want to help but don’t know how.

Accepting your situation can help, however this is not always easy and may be difficult to achieve. Inevitably not all families have good relationships and sometimes the sudden impact of Encephalitis adds to already strained relations. 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 and disbelief as the difficulty in diagnosing the illness becomes apparent. They might ask ‘Why are they ill, when all the tests are normal?’ Some of the initial tests are conducted to exclude other conditions. When the initial tests show no abnormalities a diagnosis
of Encephalitis becomes more probable. Often Encephalitis is diagnosed because all other possible conditions have been excluded.

**You 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. 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 not even feel ill, and be confused and even angry at finding themselves in hospital.

**You look normal/I feel terrible**

A good physical recovery is usual after Encephalitis but this external 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 of tasks.

**Why can’t you pull yourself together?/I think I am 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). The assessment can help to identify changes in thinking skills, emotion and behaviour that may be impacting adversely on an individual’s ability to complete everyday tasks. The assessment 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.
2. 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 so as 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.

Local authorities have a duty to assess your needs as a carer. The Carer’s Assessment involves a meeting or a discussion with a social worker looking at the support you provide to your loved one and the impact this has on your life. Following this assessment, the local authority will decide if you are entitled to any kind of support. If you are entitled, you will receive a written care plan, which identifies your needs and includes any information, support or services that could be provided together with a personal budget showing the costs of meeting your needs.

Replacement/Respite care

Respite care may be necessary, as you, as a carer, need time to relax and look after yourself. Replacement/Respite 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 may have become so used to being there for them 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 your loved one has an opportunity to be independent from you. If you find it difficult, try to introduce breaks gradually. It may be very hard the first time, but you are likely to see the benefits further down the line.
You may find the following services useful for helping you to cope:

- **Relate** is a UK charity specialised in providing relationship counselling. Website: [www.relate.org.uk](http://www.relate.org.uk) Tel: 0300 100 1234.

- **MIND**, a UK mental health charity provides support, information and tips for everyday living for people who find it difficult dealing with the stress. Website: [www.mind.org.uk](http://www.mind.org.uk) Tel: 0300 123 3393.

- **The British Association for Counselling and Psychotherapy** provides a list of local member counsellors. Website: [www.bacp.co.uk](http://www.bacp.co.uk) Tel: 01455 88 3300.

- **The Encephalitis Society’s Connection Scheme** connects people with similar experiences of Encephalitis, helping to relieve feelings of isolation brought up by this condition. The Retreat, the Annual Members Meeting and other Society events can provide opportunities for networking and taking part in relaxing activities. For more information please visit our website at [www.encephalitis.info](http://www.encephalitis.info) or become a **Member** and keep-up-to-date with all our activities.

- **The Encephalitis Society Neuropsychology Service** provides support to carers struggling to cope after Encephalitis. A referral form for the service can be found at [www.encephalitis.info/files/1614/2849/9043/Referral_Form_-_ESNS_25_2_15.pdf](http://www.encephalitis.info/files/1614/2849/9043/Referral_Form_-_ESNS_25_2_15.pdf) Tel: 01653 699 599.

- **Carers Service** may run local support groups which you can attend: **Carers Trust**: Website: [www.carers.org](http://www.carers.org) Tel: 0844 800 4361. **Carers UK** produces the **Carers Rights Guide** to outline carers’ essential rights and signpost what financial and practical help is available. The Guide is available in 4 versions for England, Wales, Scotland and Northern Ireland. Website [www.carersuk.org](http://www.carersuk.org) Tel: 0808 808 7777

- **Headway Ireland** produces a **Carer and Family Guide – Coping with Acquired Brain Injury**. This guide addresses the concerns of families looking after someone with a moderate or severe brain injury, following their discharge from hospital or rehabilitation. It is available from our online shop at [www.encephalitisshop.com](http://www.encephalitisshop.com)

- **The Selfish Pig’s Guide to Caring. How to cope with the emotional and practical aspects of caring for someone** by Hugh Marriott available from Amazon ([www.amazon.co.uk](http://www.amazon.co.uk))
3. **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’s 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. They 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.
- There may be no time for activities with the children such as support with 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 is already 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 and the support around them. Close family, friends and school staff should be made aware of what is happening in the family. This is because it is important to understand the impact on children of living with 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.
- Confusion 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 is very variable. 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**

- **The Encephalitis Society’s Support Service** can provide information and support on +44 (0) 1653 699599 or email support@encephalitis.info
- **BrainLine** offers information and resources on helping children cope with a brain injury in the family. Website: www.brainline.org
- **Books** by Jo Johnson, a consultant neuropsychologist with an interest in brain injury explaining parental brain injury to children and young people: ‘My parent has a brain injury’, ‘My dad makes the best boats’ and ‘My mum makes the best cakes’. All books are available from Amazon (www.amazon.co.uk).

**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.
Sources of support for young carers:

- **NHS** website provides information about young carers’ rights and help available:  
  www.nhs.uk/CarersDirect/young/Pages/Youngcarershome.aspx

- **Babble** has been created by the Carers Trust as an online space where those aged under 18 who are caring for a family member or friend can chat, share their experiences and access information and advice. Website: www.babble.carers.org.

- **Action for Children** is a UK charity that provides support to young carers. Website: www.actionforchildren.org.uk Tel: 01923 361 500.

- **Barnardos** runs services across the UK which work to support young carers and their families in a variety of ways. Website: www.barnardos.org.uk Tel: 0208 550 8822.

- **ChildLine** is a private and confidential service for children and young people up to the age of 19. You can contact a ChildLine counsellor on 0800 1111.
The Encephalitis Society

1. Who we are

We are an international charity and the only resource of our kind in the world, dedicated to supporting adults and children affected by Encephalitis and their families. Broadly speaking, our work involves:

- Supporting adults, children, families and carers of those affected by Encephalitis.
- Producing evidence-based, quality information about Encephalitis accredited by the NHS England Information Standard.
- Raising awareness about Encephalitis, its consequences and the need for improved services.
- Conducting research and working in partnership with other researchers. This includes appointing leading medical and healthcare professionals to our Professional Advisory Panel, awarding grants for research into Encephalitis, holding annual competitions for medical and neuropsychology students and organising the Annual Professional Seminar, which debates current issues related to Encephalitis.

2. How we can help you

- **Support Service**
  Tel: +44(0) 1653 699599; Email: support@encephalitis.info
  We provide information and advice about Encephalitis to people affected, families and professionals. This includes signposting to other services who may be able to help.

- **Information Service**
  We produce factsheets, books, booklets and leaflets aimed at adults, children, parents and/or professionals covering various issues from what is Encephalitis, diagnosis, types, treatment, recovery, social care, legal issues, education, work and entitlements. Four times a year we are publish The Connect Newsletter, which features our activities, news, events, members fundraising efforts and people’s stories. Most of the information resources are available electronically on our website www.encephalitis.info or as a paper copy from our office.
• The Encephalitis Society Neuropsychology Service
Where possible, this service prioritises access to neuropsychological support for people across the UK who are unable to obtain the help they need from local statutory services. A referral form for the service can be found at www.encephalitis.info/files/1614/2849/9043/Referral_Form_-ESNS_25_2_15.pdf Tel: 01653 699 599.

• Local Support via the Volunteer Scheme
Support volunteers are trained volunteers who provide support to people with Encephalitis in their geographical region.

• Residential weekends, meetings and events for all the family. Details can be found on our website at www.encephalitis.info/events

• Connections 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 at www.encephalitis.info/support or from our Support Service (please see contact details above).

• Providing training and education about Encephalitis to interested parties (e.g. health, social care and education professionals; schools; GPs; workplaces; residential facilities; the community more generally).

3. How you can help us

• Become a Member of The Society. Membership is free and enables you to influence the future development of the organisation. Call us on +44 (0) 1653 699599 or do it online at www.encephalitis.info

• Provide feedback about our services at mail@encephalitis.info or complete the Feedback Questionnaire online at www.encephalitis.info

• Be part of our User Feedback Group and provide feedback about our factsheets, books and booklets at support@encephalitis.info

• Take part in World Encephalitis Day - 22nd February. Register your interest at www.encephalitis.info/awareness/world-encephalitis-day/

• Connect with us on social media: Facebook and Twitter.

• Fundraise for us. Visit our website www.encephalitis.info/get-involved/fundraising-home/ or give us a ring on +44 (0) 1653 699599.