



ENCEPHALITIS
SOCIETY

The brain inflammation charity



Encephalitis in adults

A GUIDE

ACKNOWLEDGEMENTS

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



INSTITUTE OF INFECTION
AND GLOBAL HEALTH

ENCEPHALITIS IN ADULTS. A GUIDE

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CONTENTS

ABOUT THIS GUIDE5

Section 1. Encephalitis the illness

▶ What is encephalitis?9

▶ Types of encephalitis9

▶ Symptoms of encephalitis 12

▶ Diagnosis of encephalitis 13

▶ Treatment of encephalitis 15

▶ Relapses 17

▶ Death from encephalitis18

Section 2. Being in hospital

▶ Medical management of the patient 21

▶ Advice for family and friends 23

▶ Discharge from hospital 26

▶ Problems during the hospital stay28

Section 3. The effects of encephalitis

▶ How the brain works 33

▶ Cognitive difficulties 36

▶ Emotional and behavioural difficulties 39

▶ Physical difficulties 43

▶ Social impact of encephalitis46



Section 4.

Recovery and rehabilitation after encephalitis

▶ Guidelines for recovery	49
▶ What is rehabilitation?.....	51
▶ Professionals involved in recovery and rehabilitation	52
▶ Getting the most out of the meetings with professionals	57
▶ Managing cognitive difficulties	60
▶ Managing emotional and behavioural difficulties	64
▶ Managing physical difficulties	68
▶ Vocational rehabilitation: a return to work	72
▶ Obtaining the appropriate care, support and placement	75

Section 5. Additional social and legal issues

▶ Capacity to make decisions	79
▶ Driving after encephalitis	81
▶ Money and benefits	82
▶ Holiday and travel insurance	84
▶ Pathways through a medico-legal investigation	86

Section 6. Managing the impact of encephalitis on the family

▶ Impact on the family	91
▶ Support for carers	93
▶ Children and young people in the family	97

Section 7. Encephalitis Society

▶ Who we are	102
▶ How we can help you	103
▶ How you can help us	103

Notes section	104
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ABOUT THIS GUIDE

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

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

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

We hope you find this guide useful. If you have any questions or feedback please get in touch with our Support Service:

support@encephalitis.info or +44(0)1653 699599.

“After accessing this book, I feel a sense of relief. Feel at last somebody relates to my symptoms and not being dismissed as it is not an illness that visible to the eye.” (Person affected)

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

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

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Disclaimer

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

Some information in this guide, such as details of organisations and legislation, apply only to the UK or some parts of the UK. If you live outside these areas, you are encouraged to find similar organisations to those referenced and consult the legislation that is applicable to the area you live in.

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

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



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SECTION 1

ENCEPHALITIS

THE ILLNESS

1



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

KEY FACTS



Encephalitis is inflammation (swelling) of the brain.



Anyone can get encephalitis irrespective of age, gender, nationality or culture.



There are up to 6,000 new cases each year alone in the UK and many more thousands worldwide.



Encephalitis can be caused by an infection (e.g., virus, bacteria, fungus) or an inappropriate immune response directed against oneself. In some cases, a specific cause is not found despite extensive testing.



The variety of causes and presentations, along with the rapid onset (often dramatic) may make the management of this condition a challenge for doctors.



Early and adequate diagnosis and treatment improve the outcomes.



The length of time spent in hospital (acute illness) can vary from days and weeks in some cases to months in others.



Encephalitis has a variable mortality (death) rate depending on the underlying cause.



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Contents

- ▶ What is encephalitis?9
- ▶ Types of encephalitis9
- ▶ Symptoms of encephalitis 12
- ▶ Diagnosis of encephalitis 13
- ▶ Treatment of encephalitis 15
- ▶ Relapses 17
- ▶ Death from encephalitis 18

WHAT IS ENCEPHALITIS?

Encephalitis is inflammation of the brain. Anyone at any age can get encephalitis. The inflammation is caused either by an infection invading the brain (infectious encephalitis) or through the immune system attacking the brain in error (post-infectious/autoimmune encephalitis). Encephalitis is different from meningitis. Meningitis means inflammation of the meninges (protective layers that cover the brain). Sometimes patients have both meningitis and encephalitis and this is called meningoencephalitis. In some patients, the cause cannot be found despite extensive laboratory testing.

TYPES OF ENCEPHALITIS

INFECTIOUS ENCEPHALITIS

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



Some of the viruses that can cause encephalitis are:

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

The introduction of vaccination for others viruses (e.g., measles, mumps and rubella) has greatly lowered the rate of encephalitis from these diseases. Bacteria, fungus and parasites can cause infectious encephalitis more rarely.

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

POST-INFECTIOUS ENCEPHALITIS

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

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



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AUTOIMMUNE ENCEPHALITIS

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

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

- ▶ VGKC-complex (LGI1 and Caspr2).
- ▶ NMDA-receptor.
- ▶ AMPA-receptor.
- ▶ GABA_{A/B} receptor.
- ▶ GAD.

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



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SYMPTOMS OF ENCEPHALITIS

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

Infectious encephalitis frequently begins with a flu-like illness (e.g., headache, high temperature). Typically, more serious symptoms follow hours to days, or sometimes weeks, later. The most serious finding is an alteration in the level of consciousness. This can range from mild confusion or drowsiness to loss of consciousness and coma. Other symptoms include seizures (fits), aversion to bright lights, inability to speak or control movement, sensory changes, neck stiffness or uncharacteristic behaviour.

Autoimmune encephalitis often has a longer onset. Symptoms vary depending on the type but may include confusion, altered personality or behaviour, severe psychiatric symptoms including psychosis, movements that the person cannot control, clumsiness, difficulty walking, seizures, hallucinations, memory loss or sleep disturbances.

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



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DIAGNOSIS OF ENCEPHALITIS

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

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

Tests, which can help confirm the diagnosis:

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

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

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

Various laboratory tests are performed on CSF. Some tests give results within hours whereas others often take days. Immediate tests performed on CSF include analysis under the microscope to assess the number and type of white blood

cells present. A raised number of white blood cells in CSF is indicative of inflammation within the brain, spinal cord or lining of the brain (meninges).

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

► **Brain scans**

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

► **Electroencephalogram (EEG)**

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

► **Antibody screening**

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

► **Other laboratory screening**

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

It should be noted that the results of the tests may depend on the time they were performed and are correlated with the evolution of the illness. It is not unusual for the results of some tests to be 'normal' at the beginning of the illness, but then change during the illness.



TREATMENT OF ENCEPHALITIS

Treatment of patients with encephalitis has two objectives:

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

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

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

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

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

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

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

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

GUIDELINES FOR MANAGEMENT OF SUSPECTED VIRAL ENCEPHALITIS

Treatment of encephalitis is effective if started promptly; in contrast, delays in treatment can be devastating. The National Encephalitis Guidelines Development Group and the Encephalitis Society developed guidelines to cover the management (diagnosis and early treatment) of adults with suspected viral encephalitis. These guidelines intend to be a ready reference for clinicians encountering cases of encephalitis. They are available from the Encephalitis Society's website (www.encephalitis.info/management-of-viral-encephalitis-guidelines) or Support Service: support@encephalitis.info or +44(0)1653 699599.



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RELAPSES

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

In some types of autoimmune encephalitis there is a recognised risk of recurrence, 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 relapses is considered to be significant, treatment is often offered over a longer period of time. However, despite treatment a number of patients will still relapse. Recognition of potential relapses requires ongoing vigilance from the patient and their relatives and should be reported to the patient's neurologist quickly.

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

DEATH AND BEREAVEMENT

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

The rapid course of encephalitis can be traumatic and overwhelming. The fact that today's drugs, medical management and sophisticated equipment are sometimes unable to treat the disease successfully is frightening. Families who suffer a bereavement are often left feeling shocked and traumatised. Death is always difficult for those who are left behind, but even more difficult when it is totally unexpected.

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

FURTHER INFORMATION

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



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SECTION 2

BEING IN HOSPITAL

2



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

KEY FACTS



Being in hospital can be a challenging experience for the whole family.



The person affected may be seriously ill and even in a coma.



Brain injury can be a consequence of encephalitis and it is difficult to appreciate the extent of this in the early stages.



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



The patient's behaviour may be bizarre. This is common and called an acute confusional state.



During an acute confusional state, the patient benefits from being in a quiet environment and visitation should be minimised.



It is good practice to have everything in place at home before discharge from hospital (e.g. care, adaptive equipment).



Any concerns you have about the hospital stay need to be raised with the hospital staff in the first instance.



If you care for a person affected by encephalitis, remember your own needs as you can't help them if you don't take care of yourself.



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Contents

- ▶ Medical management of the patient 21
- ▶ Advice for family and friends 23
- ▶ Discharge from hospital 26
- ▶ Problems during the hospital stay 28

MEDICAL MANAGEMENT

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

The patient may also need:

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

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

Sometimes a patient may be placed in an **induced coma**.

An induced coma is a temporary coma brought upon by a controlled dose of drugs to shut down the brain and give time to recover from the swelling caused by encephalitis. The doctors decide the length of coma depending on the extent of injury and the way the patient reacts.

During and after the acute phase of encephalitis the patient may be uncharacteristically uncooperative, aggressive and even violent. This may be due to the impact of swelling and inflammation in the brain on emotion and behaviour both during the illness and soon after, resulting in a **post-acute confusional state**. This state can persist in the early stages of recovery. The family must realise that this behaviour is not within their relative’s control. They are not aware of their behaviour or the impact it is having on those around them. The image of a patient who experiences injury to the brain and perhaps coma, who is subsequently calm, awake and serene to the delight of their family is a myth perpetuated by television and other media. The patient is more likely to be confused, disoriented, aggressive and rude. It is not unusual for patients to run away from their bed during these stages of agitation.

These experiences are distressing for all and can present a number of management problems for those trying to care for these patients. If you feel somebody is at risk, discuss your concerns with the nursing staff. They may be able to reassure and show you strategies or interventions they have in place to minimise



risk. Sometimes nursing staff use bedrails to prevent injury, especially where there is concern about seizures. However, if patients are very agitated, it may be necessary to nurse them on a specially adapted bed that lowers to the floor. This prevents any secondary injuries caused by falling. If you have any concerns about the care of a patient that cannot be resolved through discussion with the staff involved, please contact the Patient Advice and Liaison Service (PALS) at the hospital.

ADVICE FOR FAMILY AND FRIENDS

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

Friends and family will have feelings of relief and joy that their loved one has survived. However, the person who has been affected may remember nothing of the illness. They may be confused and even angry at finding themselves in hospital. This can be a testing time for all.

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

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

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

BELOW THERE IS A LIST OF THINGS WHICH MAY HELP

- ▶ Create a quiet and familiar environment around your family member/friend. They will probably benefit from having lots of rest. It is best not to encourage many visitors and additional noise such as television, telephone conversations or other stimuli.
- ▶ Try and talk to your loved one and explain what has happened if possible. Reassure them that you are there for them.
- ▶ Get to know the key staff involved in their care.
- ▶ Communicate with health care staff. Write down what you want to ask and take any opportunity to ask questions.
- ▶ Some hospitals provide Family Therapy, which may help you deal with the stress and emotions at this difficult time. Ask a member of staff if this is available in your hospital.
- ▶ Acknowledge your emotions and be aware that other family members may react differently.



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- ▶ Contact the Encephalitis Society's Support Service. They may be able to answer your questions and provide information to help you understand the illness and know what to expect in the future.
- ▶ Get your family and friends to do some research and bring to the hospital some information about the illness and its consequences.
- ▶ Involve your friends and family in doing some chores for you. Take them up on their offer of help. If they have not offered, ask them to prepare some food, do some washing, shopping or look after your children. Some of them probably want to help but do not know how.



DISCHARGE FROM HOSPITAL

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

Each hospital has its own policies and arrangements regarding discharge. If you have any concerns regarding your discharge please raise them with the hospital staff and/or PALS (please see p28 Problems during your stay).

CONSIDERATIONS REGARDING ENCEPHALITIS

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

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

- ▶ The name and contact details of the doctor that treated you in hospital.
- ▶ Who you should contact in case there are problems following discharge.



- The services that you are being referred to so you can call them to discuss any problems (e.g., occupational therapy, physiotherapy, neuropsychology, speech and language therapy).

CONTINUING HEALTH AND SOCIAL CARE NEEDS

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) should be consulted about it and happy 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 comprehensive residential rehabilitation or longer-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, specialist centres for managing brain injury or epilepsy that have interdisciplinary teams with specialist skills in brain injury rehabilitation. Referrals to other agencies and plans for your future requires your consent.

You have the right to choose what care and support you want after having all necessary information, including details about any financial implications, to help you make informed decisions. 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.

PROBLEMS DURING THE HOSPITAL STAY

PATIENT ADVICE AND LIAISON SERVICE (PALS)

The Patient Advice and Liaison Service (PALS) can provide confidential information and support on health related matters while you or your family member is in hospital. They liaise with staff, managers and, where appropriate, other relevant organisations to negotiate speedy solutions. 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 NHS website to find the nearest PALS [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)



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MAKING A COMPLAINT

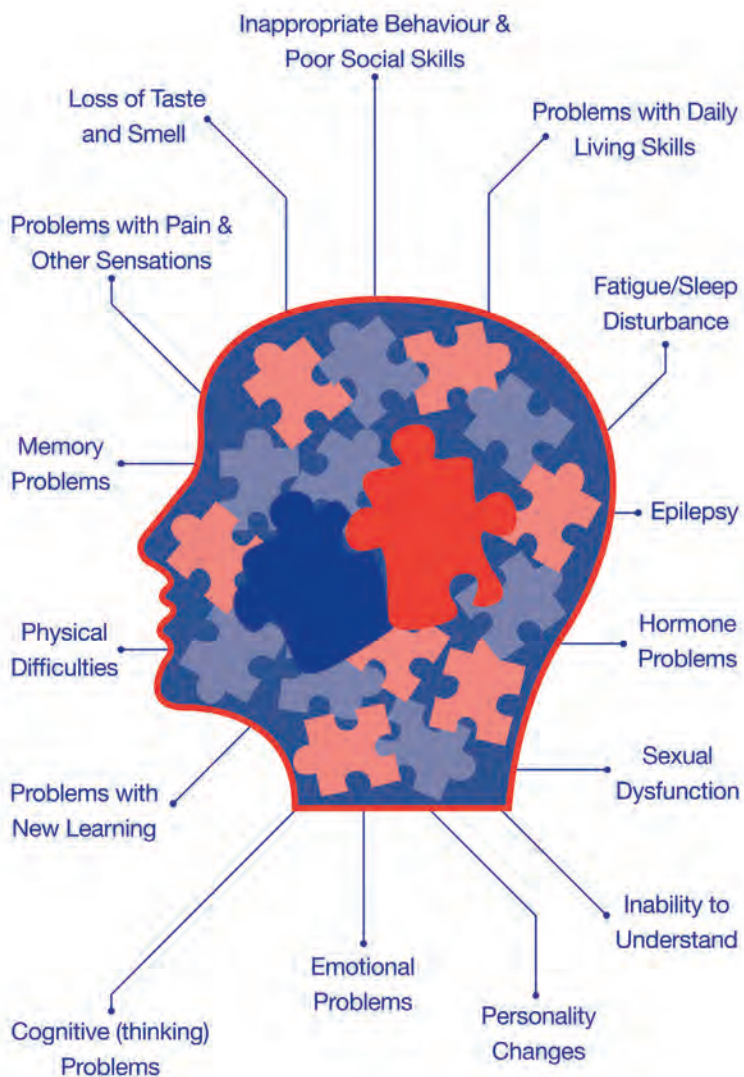
If you are unhappy with the hospital service or any other NHS service, you can make a complaint to the hospital or that service. Initially, it may be best to speak with the service/doctor firstly, before you make a complaint. Each hospital or service has a policy regarding the complaints procedure. Local 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 complained in time, for example, because of grief or trauma.

FURTHER SUPPORT AND INFORMATION

- ➔ **The Encephalitis Society** can provide support and direct you to those best placed to address your concerns.
Contact our Support Service:
support@encephalitis.info | +44(0)1653 699599
- ➔ **The Patients Association** provides information to patients and their families about the health care system.
www.patients-association.com | +44(0)20 8423 8999
- ➔ **Local Healthwatch** provides advice and support regarding complaints about the NHS and social care. Each local Health Watch works in partnership with other local organisations. An online search facility for your local Health Watch or your local complaints advocacy service is available on their website. **www.healthwatch.co.uk**

POST-ENCEPHALITIS CONSEQUENCES



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SECTION 3

THE IMPACT OF ENCEPHALITIS










3

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

KEY FACTS

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



Contents

- ▶ How the brain works 33
- ▶ Cognitive difficulties 36
- ▶ Emotional and behavioural difficulties..... 39
- ▶ Physical difficulties 43
- ▶ Social impact of encephalitis 46

HOW THE BRAIN WORKS

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

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

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

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



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

The immune response evolved to protect organisms against injury and infection by delivering white blood cells to sites of injury to kill potential pathogens and promote tissue repair. However, the powerful inflammatory response also has the capacity to cause damage to normal tissue. Unfortunately, the immune response to an infection of the brain can contribute more to the disease process than the infection itself.

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

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

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



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

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

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



COGNITIVE DIFFICULTIES

Cognition refers to the way we perceive, learn about and process the world around us. It can refer to mental processes such as those involved in information processing, memory, understanding, communication, problem solving, planning and organisation. These processes underpin our everyday activities from running a household to maintaining friendships, working, driving and studying. Following encephalitis, an individual may experience changes in these cognitive abilities to varying degrees and, in turn, have trouble in their everyday activities.

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

MEMORY

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

- Difficulties with learning new information such as remembering the names of people and places; following directions and finding locations; following the storyline of a book or movie; remembering recent conversations and remembering what they have to do at a future time, such as appointments or paying bills.



- ▶ Difficulties with recalling information from their past, before the brain injury.
- ▶ Difficulties trying to learn a new skill, a lesson at school or how to use technology (e.g., a new mobile phone).

ATTENTION AND CONCENTRATION

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

EXECUTIVE FUNCTION

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

Poor planning and problem solving

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



They may be inflexible in their thinking, becoming fixed on one particular thought and unable to consider alternatives.

Lack of initiative

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

PERCEPTUAL AND VISUOSPATIAL SKILLS

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

COMMUNICATION/LANGUAGE

Language problems are common after encephalitis. Many people experience word-finding difficulties and struggle to get their message across. As noted above, some people may also find difficult to take in and process conversations so that an individual experiences an overload of information. Others may find it difficult to understand what is being said to them. When talking we need to choose which words to use and put them together. Communicating with others also requires that we take turns in conversations, interpret and respond to social cues, show interest



in others, use humour appropriately and shift between topics of conversation. These aspects of communication may be affected following encephalitis to varying degrees. Changes may also occur to an individual's ability to monitor the correct volume and speed of speech, with difficulty using the correct tone and inflections.

EMOTIONAL AND BEHAVIOURAL PROBLEMS

SOCIAL BEHAVIOUR

Following encephalitis social behaviour may change due to cognitive difficulties (communication, impulsivity and memory) and emotional changes (anxiety, low mood and irritability). Individuals may have difficulty judging how to behave in social situations. Some individuals may appear to be self-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 family and friends, leading to a strain on relationships.

INSIGHT

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

CHALLENGING BEHAVIOUR

Changes to behaviour are common following encephalitis. For some individuals cognitive and emotional changes produce behaviours that are challenging to manage. For example, a person may be aggressive, sexually inappropriate or confused and vulnerable. Families and friends may struggle to understand and cope with these new behaviours, which may reflect a very different personality to how the person was before encephalitis.

FRUSTRATION AND ANGER

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

EMOTIONAL LABILITY

Following encephalitis, some people experience difficulty controlling their emotions and experience uncharacteristic extremes of emotion. They may become tearful more easily and without warning. Others laugh or smile inappropriately such as when being told a sad story or bad news.



For some people the brain injury can cause what seems to be an absence of emotion. A person may intellectually 'know' that something is distressing, but they are detached from the experience and do not 'feel' the distress caused. Such emotional lability can be very confusing for the individual and their family.

ANXIETY

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

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

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

DEPRESSION

Depression is a common response to the numerous life changes that may occur following encephalitis because of the functional limitations imposed by cognitive, behavioural and emotional difficulties. Mood changes may reflect a growing



realisation of the discrepancy between who they were before the 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.

IMPULSIVITY AND DISINHIBITION

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

PERSONALITY CHANGE

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



PHYSICAL PROBLEMS

FATIGUE AND SLEEP DIFFICULTIES

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

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

DIFFICULTIES WITH MOVEMENT, BALANCE AND COORDINATION

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

Difficulties with movement can also be related to 'apraxia', which involves problems with translating 'intention' into effective 'action' with a negative impact on everyday activities including dressing and cooking.



EPILEPSY AND SEIZURES

Seizures (fits) are the result of abnormal electrical activity in the brain. Seizures may occur during the acute illness and/or develop weeks, months, or even in some cases, years afterwards.

Seizures may be classified into different types depending on:

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

SENSORY CHANGES

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

HEADACHE AND PAIN

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



SEXUAL FUNCTIONING

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

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

HORMONAL CHANGES

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

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

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

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

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



SECTION 4

RECOVERY AND REHABILITATION

4




Support line +44(0)1653 699599



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

KEY FACTS

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



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Contents

► Guidelines for recovery	49
► What is rehabilitation?	51
► Professionals involved in recovery and rehabilitation	52
► Getting the most out of the meetings with professionals	57
► Managing cognitive difficulties	60
► Managing emotional and behavioural difficulties	64
► Managing physical difficulties	68
► Vocational rehabilitation: a return to work	72
► Obtaining the appropriate care, support and placement	75

GUIDELINES FOR RECOVERY

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

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

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

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

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

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



WHAT IS REHABILITATION?

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

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

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

Family members are often heavily involved in rehabilitation and are integral to the success of interventions. In fact, it is also important to note that a certain amount of rehabilitation takes place at home, without the formal involvement of professionals. This kind of rehabilitation involves people with encephalitis and



their carers using 'self-management' strategies, examples of which are discussed later.

PROFESSIONALS INVOLVED IN RECOVERY AND REHABILITATION

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

NEUROPSYCHOLOGISTS for:

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



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OCCUPATIONAL THERAPISTS for:

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

SPEECH AND LANGUAGE THERAPISTS for:

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

NEUROPHYSIOTHERAPISTS for:

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



These professionals often work together in multidisciplinary teams to provide support following ABI both in the community and in outpatient settings (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 and/or there may be other services available that you can access for free. The best thing to do is to 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.

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

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

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



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

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

Information about **private practitioners** can be found on the following websites:

- ➔ Royal College of Occupational Therapists
www.rcot.co.uk
- ➔ Association of Speech and Language Therapists in Independent Practice
www.beta.helpwithtalking.com
- ➔ The Association of UK Dieticians (BDA)
www.bda.uk.com
- ➔ The Chartered Society of Physiotherapy
www.csp.org.uk
- ➔ The British Psychological Society
www.bps.org.uk
- ➔ College of Sexual and Relationship Therapists
www.cosrt.org.uk



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GETTING THE MOST OUT OF THE MEETINGS 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 and emotionally, especially if you are anxious or upset. Good preparation can help to ensure that the experience is a positive one. Following are some recommendations for assisting you with these interactions.

ARRANGING THE MEETING:

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

BEFORE THE MEETING:

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

AT THE MEETING:

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

IF THINGS GO WRONG:

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



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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.

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, 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 re-register to another practice. 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.



MANAGING COGNITIVE DIFFICULTIES

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

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

Problems with memory

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



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

There are two important things to know:

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

Practical steps in managing memory problems:

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



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

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

FURTHER SUPPORT AND INFORMATION

- ➔ **Managing memory problems after encephalitis** factsheet, available from our website www.encephalitis.info/factsheets or our Support Service support@encephalitis.info | +44(0)1653 699599.
- ➔ The book **Coping with memory problems** by Linda Clare and Barbara Wilson.
(available from www.pearsonclinical.co.uk)

Slow thinking speed or difficulties with concentrating and attention

- ▶ Allow more time to complete tasks, whilst acknowledging the frustration that may accompany slower processing.
- ▶ Keep distraction to a minimum, including a reduction in background noise where possible.



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- ▶ Take notes to capture key points in order to manage problems with taking in what has been said.
- ▶ Attempt one task at a time, during peak energy times.

Problems with communication

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

Problems with planning and organising

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

Difficulties with 'get up and go'

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

Impulsive or disinhibited behaviour

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

Reduced awareness or denial of problems

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

MANAGING EMOTIONAL AND BEHAVIOURAL DIFFICULTIES

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

Some of the aims of their intervention include:

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



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

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

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

FURTHER SUPPORT AND INFORMATION

- ➔ **Managing anger after encephalitis and Depression after encephalitis** factsheets.
- ➔ **Responding to challenging behaviour following an acquired brain injury** booklet, produced by Synapse Australia and reviewed by Encephalitis Society.

These are available from our website www.encephalitis.info/factsheets or Support Service: support@encephalitis.info | +44(0)1653 699599.



THE BENEFITS OF SHARING EXPERIENCES AND CONNECTING WITH PEOPLE

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

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

➔ Connections Scheme

www.encephalitis.info/connection-scheme

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

➔ Support Volunteers

www.encephalitis.info/team-encephalitis-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.

Reading the narratives of other people who have experienced encephalitis is also often useful. Other people's narratives can provide hope that there is life after encephalitis, by sharing tips about different ways of coping and finding meaning in the experience. Some people prefer not to read narratives.



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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/helpful-books) has reviews of a wide range of books in which people have written about their personal experience of encephalitis or ABI more generally.

Below are some examples of these books.

Books (people's stories) specifically relating to encephalitis:

- ▶ A Narrative Approach. Life after Encephalitis by *Dr Ava Easton*
- ▶ Brain On Fire by *Susannah Cahalan*
- ▶ Bed 12 by *Alison Murdoch*
- ▶ A Quarter of an Hours by *Leanne O'Sullivan's*
- ▶ One Million Lovely Letters by *Jodi Ann Bickley*
- ▶ Out of It by *Simon Hattenstone*
- ▶ Awakenings by *Oliver Sacks*
- ▶ The Thief in the Night by *Catherine O'Toole Scott*

Books (people's stories) specifically relating to ABI.

- ▶ Our Time of Day. My life with Corin Redgrave by *Kika Markham*
- ▶ Time Out of Mind by *Jane Lapotaire*
- ▶ On the Edge: My Story by *Richard Hammond*
- ▶ Touching Distance by *James Cracknell and Beverly 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 (www.headway.org.uk | 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.

MANAGING PHYSICAL DIFFICULTIES

A range of professionals may be involved in managing physical problems after encephalitis, depending on the specific nature of the problem and the specialist knowledge required in order to help. Within the context of multidisciplinary teams, physiotherapists and occupational therapists are often most commonly involved in evaluating problems with movement and balance and the impact of this on one's ability to complete everyday tasks. However, for many physical problems, and when not undergoing formal rehabilitation, 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.



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FATIGUE AND SLEEP DIFFICULTIES

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

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

FURTHER SUPPORT

- ➔ **Managing fatigue** factsheet available from our website www.encephalitis.info/factsheets or Support Service: support@encephalitis.info | +44(0)1653 699599.
- ➔ **Managing fatigue after brain injury** booklet by Jacqui Cooper and Donna Malley available from Headway. www.headway.org.uk | 0808 800 2244
- ➔ **Sleep Unlimited** provides specialist assessment and treatment for sleep-related problems. www.sleepunlimited.co.uk | 0191580 008



EPILEPSY

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

FURTHER SUPPORT

- ➔ **Seizures and encephalitis factsheet** available from our website (www.encephalitis.info/factsheets) or Support Service: support@encephalitis.info | +44(0)1653 699599.
- ➔ **Epilepsy Action** (www.epilepsy.org.uk | 0808 800 5050) and **The Epilepsy Society** (www.epilepsysociety.org.uk | 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 or ophthalmologists. In the case of chronic pain, referral to a pain management clinic may be considered.

FURTHER SUPPORT AND INFORMATION

- ➔ **Fifth Sense** (www.fifthsense.org.uk) provides support and information on anosmia, smell and taste-related disorders via website, email or a regional hub network.
- ➔ **The Pain Toolkit** (www.paintoolkit.org) is a toolkit of pain management skills to enable an individual who suffers from chronic pain to become an active self-manager .



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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.

FURTHER SUPPORT

- ➔ The Pituitary Foundation (www.pituitary.org.uk | 0117 370 1320) provides information and support on conditions related to a dysfunction of the pituitary gland.



VOCATIONAL REHABILITATION: RETURN TO WORK

Vocational rehabilitation supports people to retrain and engage in work or study following ABI. Return to work can be an important goal for people following ABI. In addition to the economic benefits, engagement in work or other meaningful activities, it can enhance emotional adjustment and build a stronger sense of self post injury. However it is very important that people do not attempt to return to work too soon. An unsuccessful return to work can affect negatively on confidence and possibly lead to additional problems such as anxiety and depression.

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

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

- ▶ Whether the individual is able to complete tasks.
- ▶ Whether there are risks involved in returning to work and what the nature of these is (e.g., physical harm may be a risk if someone operates machinery and is distractable).



- ▶ The kinds of strategies need to be considered to help someone complete their job role (e.g., lists for remembering tasks, keeping organised, strategies for helping them to calm if they become upset).
- ▶ Any aids the person may be of benefit from for performing their job (e.g., whiteboards, checklist, adaptive aids for managing physical problems).
- ▶ Whether the job role needs to be changed such that certain tasks need to be removed from the job description in order for someone to return to work.
- ▶ Whether it is possible for the person to return to their old job or whether they need to consider getting a different job.
- ▶ Whether or not a return to work (in any form) is feasible.

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

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

Therefore, professionals involved in vocational rehabilitation may also provide advice about training courses that will help people find employment in the future, and help them access these courses. This again, may require consideration of how an individual's strengths and weaknesses following encephalitis match the requirements of the course and future profession, and making

recommendations about aids and strategies to help support them in completing relevant courses. They may also help the individual to source and manage voluntary work, or identify recreational activities of interest.

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 (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 the local Job Centre by speaking to a Work Coach. They can discuss the current employment situation and work to plan the best way back into work. They can do an employment assessment to identify what work or training suits best.

FURTHER SUPPORT

- ➔ **Momentum Skills (momentumskills.org.uk)** provides training and employability services to people with ABI/disabilities. It is a regional service, so please check their website for criteria of inclusion.



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OBTAINING APPROPRIATE CARE, SUPPORT AND PLACEMENT

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

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

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

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's 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 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 provide by the Council.
- ▶ Direct Payments. These payments gives 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.
- ▶ 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.



SECTION 5

ADDITIONAL SOCIAL AND LEGAL ISSUES








5

Support line +44(0)1653 699599



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

KEY FACTS

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

Contents

▶ Capacity to make decisions	79
▶ Driving after encephalitis	81
▶ Money and benefits	82
▶ Holiday and travel insurance	84
▶ Pathways through a medico-legal investigation	86



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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, 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.



DRIVING AFTER ENCEPHALITIS

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

It is your responsibility to inform the Driver and Vehicle Licensing Agency (DVLA) about your illness. You should also inform your Insurance Company of your recent illness and any associated change in circumstances, and that you have informed the DVLA. It is illegal to drive on the highways without a valid licence and you also risk be fined/prosecution if you do not inform the DVLA of any illness or injury that could affect your driving.

The DVLA has specific guidelines regarding driving and epilepsy, which vary depending on several things such as when you have seizures, how controlled by medication they are and when you had your last seizure. You can find out more about these guidelines on the following link: ➔ **www.gov.uk/epilepsy-and-driving**

Doctors are encouraged to advise people that their condition may affect their ability to drive. Please talk with your GP/consultant about how encephalitis affects your ability to drive. The GP has also a responsibility to alert the DVLA if they feel that you are unable to drive safely, but you are unwilling to inform the DVLA.



FURTHER INFORMATION ON DRIVING AFTER ILLNESS

- ➔ **DVLA** for England, Scotland and Wales:
Address: Drivers Medical Enquiries: DVLA, Swansea,
SA99 1TU; Tel **0300 790 6806**.
- ➔ **DVA** for Northern Ireland: Address: County Hall, Castlerock
Road, Coleraine, CO, Londonderry, BT51 3HS;
Tel **0300 200 7861**.
- ➔ **The Encephalitis Society** has a factsheet '*Driving after encephalitis*' which is available from our website
www.encephalitis.info/factsheets or Support Service:
support@encephalitis.info | +44(0)1653 699599.

MONEY AND BENEFITS

In the days following encephalitis, money can be a concern. Encephalitis and associated consequences may affect employment and a family's finances. If the person, who has had encephalitis, was employed before they were ill, their employer should pay them in line with any company sickness package or at least ensure they receive Statutory Sick Pay. 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 and communication. It is important to get professional advice and make applications as soon as possible so that money to which you are entitled is not lost.



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FURTHER SUPPORT AND INFORMATION

- ➔ **Citizen's Advice Bureau (CAB)** provides information about benefits on their website at www.citizensadvice.org.uk/benefits. Local CAB offices 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.
- ➔ **The Government** provides information about benefits on their website. www.gov.uk/browse/benefits
- ➔ **The NHS** provides detailed information on Direct Payments on their website. 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 of how to fill in the forms. www.headway.org.uk | 0808 800 2244
- ➔ **Headway Emergency Fund** helps families and individuals cope with the practical implications of a sudden catastrophic brain injury. www.headway.org.uk/emergency-fund.aspx
- ➔ **Debt Advice Foundation** offers free, confidential support and advice to anyone concerned about loans, credit and debt. www.debtadvicefoundation.org | 0800 043 4050
- ➔ **Turn2us** helps people in financial need to access welfare benefits, charitable grants and other financial help. Their website features an Online Benefits Calculator that can assist you to check what you are entitled to. www.turn2us.org.uk
- ➔ **Shelter** provides advice, support and legal services to people who are struggling with bad housing and homelessness. www.england.shelter.org.uk | 0808 800 4444



HOLIDAYS AND TRAVEL INSURANCE

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

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



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

► **Medication**

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

► **Destination**

Make sure you check with your doctor whether you need any vaccinations before going away (and any additional medications, which may be required following encephalitis). Be aware of where the medical facilities are at your destination, so that you can access them quickly if necessary.

► **Flight**

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

► **Insurance Policy**

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

► **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 fly back into UK or lost property.

FURTHER INFORMATION AND SUPPORT:

- ➔ **The Government's website** provides information about how to stay safe and healthy abroad:
www.travelaware.campaign.gov.uk
- ➔ **Headway** produces a booklet called **Holiday & Travel after Brain Injury**, which provides details of companies that cover travellers with a disability.
www.headway.org.uk | 0808 800 2244
- ➔ **Epilepsy Action** works with **Insurancewith** to offer a quality travel insurance policy for people with epilepsy, which includes cover for epilepsy-related incidents.
www.epilepsy.org.uk | 0808 800 5050
- ➔ **Tourism for All UK** provides information to people with disabilities and older people in relation to accessible accommodation
www.tourismforall.org.uk | 0845 124 9971

PATHWAYS THROUGH A 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 delay in recognising encephalitis as a possible diagnosis leading to delay in giving effective drugs, but other failures in this condition's management can unfortunately also occur.



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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 result of the encephalitis is worse than it would have been 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 solicitors' job to make sure the investigation and any claim are dealt with cost-effectively, you are kept fully informed and you are protected from financial risk.

FURTHER INFORMATION AND SUPPORT:

- ➔ **Encephalitis Society Support Team:**
support@encephalitis.info | +44(0)1653 699599
- ➔ **Encephalitis Society Neuro-Legal Handbook** available from our website **www.encephalitis.info/legal-advice** or Support Service on **+44(0)1653 699599**.
- ➔ **Law Society:** **www.lawsociety.org.uk**



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SECTION 6

MANAGING THE IMPACT OF ENCEPHALITIS ON THE FAMILY



6

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

KEY FACTS



Encephalitis can affect family relationships.



Families often go through a process of coming to terms with the illness and the consequences and then finding ways of coping.



Family members deal with emotions in different ways; strong feelings are understandable.



Disability following encephalitis can be 'hidden' and those around you may not be aware of how your everyday life has changed.



Being a carer has a big impact on everyday life, friendship, work or education.



Children in the family can be affected in many ways depending on their age and family support.



Carers need their own needs to be acknowledged and addressed.

Contents

► Impact on the family	91
► Support for carers	93
► Children and young people in the family	97



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IMPACT ON THE FAMILY

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

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

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

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



► **Why are they ill?**

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

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

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

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

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

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

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



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

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

SUPPORT FOR CARERS

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

SOCIAL SUPPORT

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

There are different types of social support including emotional, practical and informational. Emotional support refers to the actions people take to make you feel cared for, such as listening to you and giving you an opportunity to express your feelings. Practical support involves being provided with help with specific tasks, to make your life easier, such as cooking meals for you and your family or collecting your children from school. Informational support means being provided with facts that might help you manage your situation, such as 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 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 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 look after yourself. Replacement/respice care involves someone else, other than you, providing care on a temporary basis. The local authority may arrange for the respice care if this is in the plan as a result of an assessment. If it isn't in the plan, you may need to arrange it yourself. Local carers' groups may be able to recommend suitable places.

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



FURTHER SUPPORT AND INFORMATION

- ➔ **Relate** is a UK charity specialised in providing relationship counselling.
www.relate.org.uk; | 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.
www.mind.org.uk | 0300 123 3393
- ➔ **The British Association for Counselling and Psychotherapy** provides a list of local member counsellors.
www.bacp.co.uk | 01455 88 3300
- ➔ **The Encephalitis Society's Connection Scheme and events** connect people with similar experiences of encephalitis, helping to relieve feelings of isolation brought up by this condition.
www.encephalitis.info/connection-scheme
www.encephalitis.info/events-and-activities
- ➔ **Carers Service** may run local support groups which you can attend: Carers Trust:
www.carers.org | 0844 800 4361.
Carers UK produces Carers and their Rights guide to outline carers' essential rights and signpost what financial and practical help is available:
www.carersuk.org | 0808 808 7777
- ➔ **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



CHILDREN AND YOUNG PEOPLE IN THE FAMILY

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

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

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

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

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

Feelings experienced by children may include:

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



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

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

FURTHER SUPPORT

- ➔ **The Encephalitis Society's Support Service** can provide information and support on support@encephalitis.info | +44(0)1653 699599.
- ➔ **BrainLine** offers information and resources on helping children cope with a brain injury in the family. www.brainline.org/caregivers/family-concerns
- ➔ **Books by Jo Johnson**, a consultant neuropsychologist with an interest in brain injury explaining to children and young people their parents' brain injury: *'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.

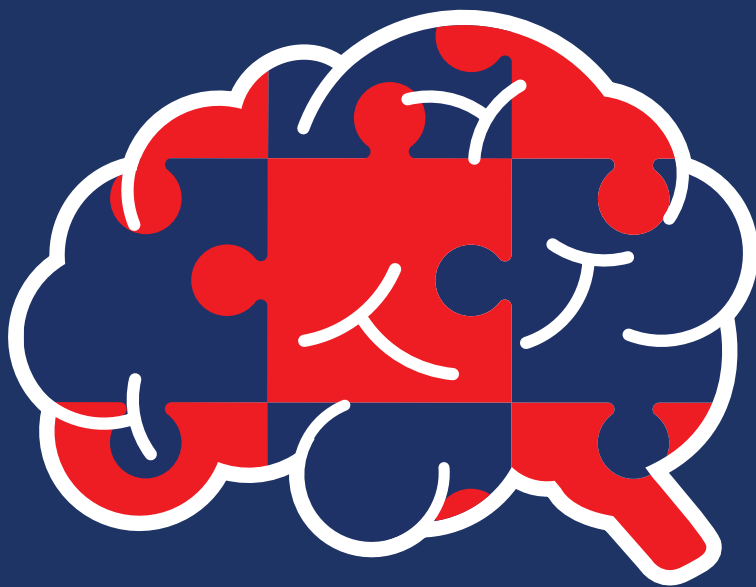
FURTHER SUPPORT

- ➔ The **NHS** website provides information about young carers' rights and help available. www.nhs.uk/CarersDirect/young/Pages/Youngcarershome.aspx
- ➔ **Action for Children** is a UK charity that provides support to young carers.
www.actionforchildren.org.uk | 01923 361 500
- ➔ **Barnardos** runs services across the UK which work to support young carers and their families in a variety of ways.
www.barnardos.org.uk | 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 Children Society** can help you find a young carers service near you. www.childrenssociety.org.uk/youngcarer/young-carers-services



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ENCEPHALITIS SOCIETY



Support line +44(0)1653 699599



WHO WE ARE

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

OUR VISION

is a world aware of encephalitis, its consequences and the support available.

OUR MISSION

is to increase global awareness of encephalitis, saving lives and building better futures.

OUR AIM

To improve the quality of life of all people affected directly and indirectly by encephalitis, by:

- ▶ Providing support and information.
- ▶ Raising awareness.
- ▶ Promoting and collaborating on research.

OUR KEY MESSAGES TO YOU

You are not alone, we are encephalitis experts and can provide the support, advice, information and training you need. Encephalitis is serious and indiscriminate - we must all act now to raise awareness of this devastating condition.



Find us online at www.encephalitis.info

HOW WE CAN HELP YOU

- ➔ **Support Service**
support@encephalitis.info | +44(0)1653 699599
- ➔ **Website** – Containing factsheets, books, booklets and leaflets which cover various issues regarding encephalitis.
www.encephalitis.info
- ➔ **Connect Newsletter** features the Society's activities, news, events etc. You can download a copy from our website.
- ➔ **Team Encephalitis Support Volunteers** who are trained to provide support to people with encephalitis and their families.
- ➔ **Residential weekends, meetings and events** for all the family, details of which can be found on our website.
- ➔ **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.
- ➔ **Provision of support and information** about encephalitis and its effects to interested parties (e.g. health, social care and education professionals; schools; GPs; workplaces etc).

HOW YOU CAN HELP US

- ➔ Become a member of the Society. Membership is free and helps us to raise our influence among the general public and medical profession. Call us on **+44(0)1653 692583** or become a member online at www.encephalitis.info
- ➔ Be part of our Team Encephalitis Volunteers.
Email us on mail@encephalitis.info or call us on **+44(0)1653 692583** to find out more about it.
- ➔ Take part in World Encephalitis Day – **22nd February** each year.
- ➔ Connect with us on social media – Facebook, Twitter & YouTube.
- ➔ Make a donation – Call us on **+44(0)1653 692583**, or email our fundraising team on fundraising@encephalitis.info

Support line **+44(0)1653 699599**





ENCEPHALITIS
SOCIETY

Saving lives through research

ENCEPHALITIS RESEARCH



Research into encephalitis is important and we are committed to increasing the amount of research we fund and take part in so that people affected by encephalitis can benefit from scientific advancements sooner. We are focussing on research that looks at early diagnosis, the best ways of treating people and recovery and rehabilitation as we know that these areas will give us the best chance of saving lives and reducing the likelihood of brain injury.

A small monthly gift towards our research activities and other vital work can make a huge difference to the lives of people affected by encephalitis and their families.

HOW YOUR MONEY MAKES A DIFFERENCE

£10 helps fund *Advances in Encephalitis Research Summary* – our go-to guide for professionals working in encephalitis.

£35 contributes towards one hour of the life-changing work of our PhD research fellow.

£75 funds a place for early-career researchers or junior doctors at our Encephalitis Conference for international experts.



www.encephalitis.info/donate

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ENCEPHALITIS SOCIETY

The brain inflammation charity

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