



ENCEPHALITIS SOCIETY

The brain inflammation charity



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Diagnosing and managing acquired brain injury (ABI),
including encephalitis, in adults and children

A guide for General Practitioners (GPs)

Foreword

This guide for GPs on early recognition of the features associated with acquired brain injury (ABI) is extremely useful and comprehensive. It is well presented in an easy-to-follow format that also highlights the importance of early management of potentially fatal conditions like encephalitis, both infectious and auto-immune in origin.

It covers the long-term effect of these disorders on the patients, their families and carers with clear guidance on how we can support them. With the ever increasing workload in general practice, such guidance is useful in aiding us to appreciate the complexity of these conditions, in navigating the system and signposting patients to the right services at the right time.

It's good to see that the roles of the different members of the rehabilitation team are included with emphasis on the importance of a holistic approach to management and the importance of having access to such services in the local communities. It's also helpful to read about the crucial role played by the voluntary

sector as well as the role of self-help advice for empowering patients.

The information about returning to driving and to work is very useful as are the links and the contact details of the related third party organisations.

As a GP, I am grateful to the members of the Encephalitis Society and for all those who helped in putting this guide together. I believe that it will assist me in my day-to-day care of the relevant patients and hopefully will also guide the Clinical Commissioning Groups (CCGs) in acquiring the appropriate services for our patients.

I encourage all GPs who look after patients with ABI to read this document and to pass it on to the appropriate lead in their CCG.

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I. The aim of this guide

Studies on the incidence and prevalence of acquired brain injury (ABI) are limited. However, those available show an increase in the incidence of ABI worldwide with millions of people diagnosed with an ABI each year. In the UK, every 90 seconds someone is admitted to hospital with an ABI and there are 1 million people living with the long-term effects of a brain injury in the UK (Headway, 2015). In the USA, more than 3.5 million people (children and adults) sustain an ABI each year (BIAA, 2018).

General practitioners (GPs) are often the first port of call for many people with a brain injury and are an important ally in their journey to recovery. In developing this guide we hope we can support GPs by providing evidence-based and up-to-date information to help with recognising and managing the acute symptoms and effects of an ABI. We also cover the unique challenges inherent in diagnosing encephalitis (inflammation of the brain) and managing associated consequences.

The information included here is aimed primarily at GPs but may be of interest to other healthcare professionals, particularly those in primary care such as practice nurses and professions allied to medicine.

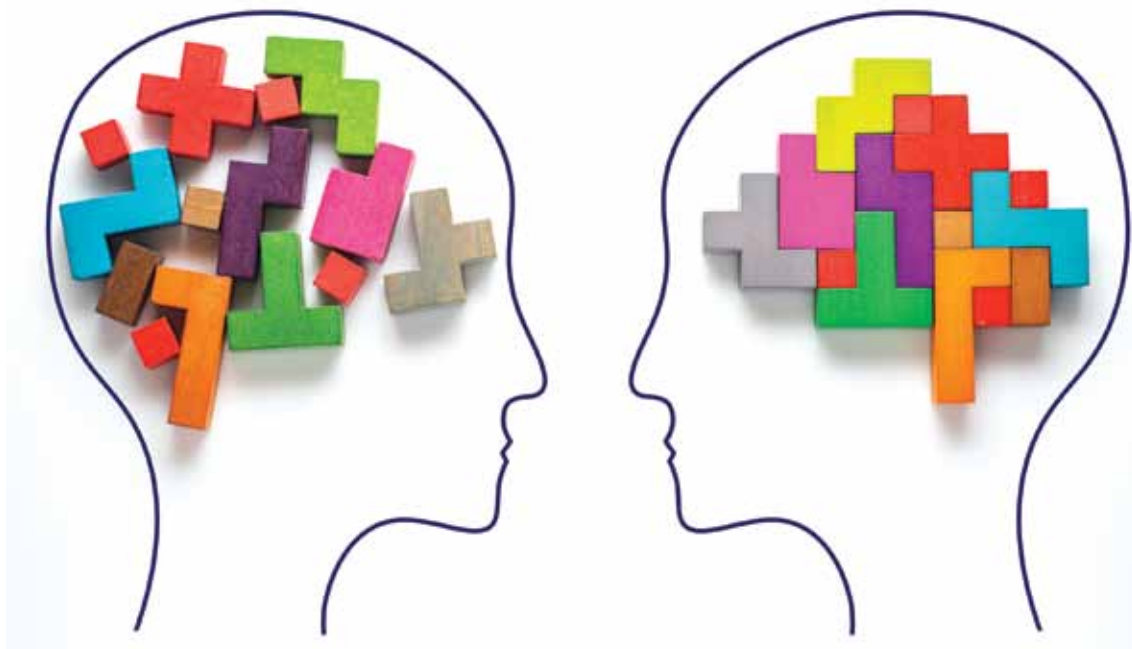
This guide has been developed after consultation with a range of patients, their families and the doctors and therapists who form our Scientific Advisory Panel (the details of which can be viewed toward the end of this booklet).

Whilst this guidance will focus on current UK practice, the issues which it highlights are relevant to many national contexts.

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Key messages

- ★ Early recognition of signs and symptoms of the acute brain injury is important as this potentially limits the extent of injury to the brain and enhances the chances of survival.
- ★ A full history of the illness from the patient and/or the family can assist the diagnosis and management of the causes and effects of an ABI.
- ★ Irrespective of the cause, these patients may be left with an ABI of various degrees.
- ★ Even in the case of mild brain injury, there can be an adverse impact on the person's everyday functioning with a need for education and management.
- ★ ABI is not a singular diagnosis and presentations can be complex.
- ★ The effects of an ABI may become obvious after the patient is discharged home when they attempt more challenging tasks.
- ★ The effects of an ABI are seen not only immediately after the brain injury, but also in the long-term, and, in the case of children, later in life when they are using news skills.
- ★ Early referral to appropriate services for managing an ABI enhances recovery.
- ★ ABI impacts not only on the patient but also on the family members, friends, carers, and their wider communities.



II. Managing the acute signs of brain injury

ABI refers to all types of brain injury that occur after birth and are non-progressive. The causes of ABI are various including traumatic (e.g., accidents, falls or assault), stroke, tumour, cerebral abscess, toxic (e.g., drugs, alcohol or other chemicals), anoxic (e.g., heart attack, carbon monoxide poisoning), metabolic disorder (e.g., liver and kidney disease), autoimmune (e.g., encephalitis) and infectious (e.g., encephalitis, meningitis).

Irrespective of the cause, in many cases, the effects (both mortality and morbidity) of a brain injury can be limited by early diagnosis. The most common place for an initial diagnosis and treatment is the hospital emergency department. Nevertheless, some people may see a GP first when they have a brain injury, before they get to the hospital, and therefore it is important that GPs are able to recognise early symptoms and signs of a brain injury.

Recommendations:

- ★ Recognise early symptoms and signs of acute neurological conditions, especially non-specific symptoms and signs.
- ★ Get a full history of the illness from the patient and/or the family.
- ★ Warn family about features which signify a deterioration, and may require them to rapidly attend an Accident and Emergency Department.
- ★ Be aware that the evolution of neurological conditions can be sudden and unexpected

III. Challenges in recognising and managing the effects of acquired brain injury

GPs are often in the difficult position of being the primary source of support and referral to specialist services for people with ABI. Therefore, it is important for GPs to be aware of the problems that commonly occur after ABI and the difficulties inherent in diagnosing them; obtain a thorough history of the onset and time course of these; and know how they can best help people with ABI.

1. Challenges in recognising the effects of ABI

There are many difficulties inherent in diagnosing the effects of an ABI. This is due to a number of reasons:

- ★ When the injury is to the brain, the person often looks physically well and there may be no outward signs that something has happened. They may also present very well during brief consultations. Their disability is therefore 'hidden'.
- ★ Although cognitive and behavioural consequences are difficult to identify in a brief consultation, these changes pose significant challenges when people attempt to return to work and their pre-injury life (Langton Hewer and Tennant, 2003).
- ★ The symptoms associated with ABI can be confused with other symptoms and causes (e.g., mental health problems such as anxiety or depression, substance misuse, metabolic disorders, pain or malingering).
- ★ The brain injury may not have been diagnosed at all. This might happen, for example, if the brain injury is mild (e.g., concussion), the person did not seek medical attention (e.g., forgetting that one has fallen the previous night when intoxicated), or because other injuries were the focus of attention when they presented at hospital (e.g., orthopaedic injuries following a car accident).
- ★ Significant brain injury can be sustained without there being evidence of this on brain imaging (Levin et al., 1987). Some brain imaging may not be sensitive enough to detect microscopic changes in the brain (Hofman et al., 2001).
- ★ People may lack awareness of their problems and deny difficulties, and therefore be unable to provide a reliable account of their difficulties. There may be conflict between their own and carers' reports of problems making it difficult to know what and who to believe.
- ★ At the time of discharge from hospital patients may appear to have made a good recovery. It is not unusual for people to be unaware of the full extent of their problems post-brain injury until they return to more demanding life roles such as work and school. Due to the time lag in difficulties becoming evident, their problems may be misattributed to factors such as 'stress' rather than the complicated factors associated with brain injury.
- ★ When brain injury is experienced in childhood, the full range of associated difficulties may not become apparent until much later in life, including late childhood, adolescence or early adulthood. Thus, when an adult presents to their GP reporting problems, a brain injury from many years ago may not be reported or seem to be relevant.

2. Common difficulties following ABI

With improvements in the diagnosis and management of brain injuries, many more people survive. This improvement in survival rates also means that many more people are left with cognitive, emotional, behavioural and physical problems that impact on their ability to complete everyday tasks and may limit their participation in society.

Below are some of the common consequences of ABI. These difficulties are presented separately, but of course their combined effect and causality must be considered (e.g., the cognitive deficit or the fatigue after a brain injury may result in emotional and behavioural problems).

2.1 Cognitive problems

Processing (thinking) speed, attention and concentration

After brain injury, people often report that it takes them longer to 'think things through'. They may also report difficulties with attention and concentration. Examples might include: being easily distracted; finding it difficult to do two things at once; having trouble taking information in or keeping track of conversations.

Memory

Memory problems are common following ABI. People most often report 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. Although less common, some will also report difficulties with recalling information from their past, before the brain injury.

Executive function (planning, problem solving and organisation)

After a brain injury, the person affected may have difficulty with planning, problem solving, organisation 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.

Language

Following brain injury, people may display difficulty with understanding speech (comprehension problems) or with expressing themselves. Problems with 'finding the right word' are commonly reported following ABI. It may be evident from your interaction that the person has problems with speech, in that it lacks fluency, or else is fluent but seems empty or tangential. Difficulties with receptive and expressive language following brain injury are termed 'aphasia'. Alternatively, patients may display difficulties with the pragmatics of conversation. For example, they may find it difficult to stick to the topic or 'monopolise' the conversation and have difficulty picking up non-verbal cues to take turns.

Visuospatial skills

Problems with visuospatial skills may be evident. Examples include: difficulty telling left from right; problems with awareness of self in space (such as when climbing stairs); or difficulty following directions. People may also have problems with identifying objects (agnosia) or faces (prosopagnosia).



2.2 Emotional and behavioural problems

Depression, grief and anxiety

After ABI people are more likely to develop major depression than the general population (Synapse, 2016). In some cases, a grief-type reaction is seen. Patients with ABI often find the process of adjustment to their new life situation challenging, which in turn can lead to depressive symptoms (Bombardier et al., 2010). Diagnosing depression after brain injury is difficult as what appear to be symptoms of depression can be confused with adynamia (a drive-related disorder), emotional blunting and/or difficulty regulating emotions.

Anxiety is also common following brain injury, and it is not unusual for symptoms of anxiety and depression to co-exist. Depression and anxiety following brain injury are associated with issues such as:

- ★ Loss of jobs, relationships, careers and future plans.
- ★ Making unfavourable comparisons between the pre and post-injury self.
- ★ Feeling concerned and even 'hopeless' about the future.
- ★ Re-living the traumatic experience (with intrusive thoughts, images and dreams).
- ★ As a result of cognitive problems, such as difficulty remembering or feeling overwhelmed.

Perhaps counterintuitively, an emotional reaction to the brain injury may sometimes be the first step on the road to recovery. This is because it suggests that the patient is more likely to have an understanding of their strengths and weaknesses and may therefore be more likely to benefit from rehabilitation.

Poor self-awareness

Self-awareness refers to the ability to recognise personal strengths and limitations, the impact of one's behaviour on other people and the ability to appreciate other people's feelings and intentions. It also refers to understanding 'who I am now' compared to 'who I was' before the brain injury.

Self-awareness can be adversely affected following brain injury. Patients may report that there is 'nothing wrong' with them whilst carers simultaneously report grave concerns for their safety due to engagement in impulsive and dangerous behaviours (Gronwall et al., 1998). Poor self-awareness may be mistaken for being 'self-centred' or 'lacking in empathy', when poor self-awareness may in fact be a direct result of injury to the brain.

Aggression

Aggression is a common consequence of ABI. This can take the form of both verbal and physical aggression. Difficulties with aggression can continue for many years after the initial brain injury (Baguley et al., 2006) and for some are a permanent feature of their behaviour in the longer term. Aggression may be a direct result of brain injury or secondary to challenges associated with the adjustment process.

Impulsivity and disinhibition

Impulsive and disinhibited behaviour can manifest in a number of ways. The person may appear to lack 'tact' after a brain injury

and be more direct or use offensive language. They may engage in risky sex practices that were not characteristic of them prior to the brain injury. Alternatively, there may be problematic use of alcohol or drugs. Impulsive, disinhibited and aggressive behaviour post-ABI has a negative impact on families and relationships.

Personality change

There is threefold increase in the diagnosis of personality disorder following brain injury (Hibbard et al., 2000). Carers may report that their loved one'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 effect of the brain injury although emotional adjustment can also play a part.

Poor emotional regulation

Following ABI people can experience difficulty with regulating their emotions. They can appear to switch rapidly between being happy and sad, be moved to tears easily, or display difficulty with knowing how and when to express their feelings. Such emotional lability can be very confusing for the individual and their family.

Post-traumatic stress disorder

Some people experience Post-Traumatic Stress Disorder (PTSD) after a traumatic brain injury. Symptoms may include: nightmares and flashbacks of the event, irritability, racing heart, shortness of breath, sweating, difficulty concentrating, poor sleep, negative thoughts or low mood, reduced interest in activities, and avoidance of reminders of the trauma. It is not unusual for people to experience some of these symptoms within a few weeks of a traumatic event and if the symptoms persist, then PTSD may need to be considered. The symptoms of PTSD can overlap with those arising from brain injury, so it is important to have an accurate diagnosis from a psychologist or neuropsychiatrist specialising in brain injury and PTSD.

2.3 Physical problems

Fatigue and sleep difficulties

Fatigue is a common symptom after ABI even in the case of mild brain injury. Many patients describe fatigue as being one of most disabling symptoms (McNicholl and Poppleton, 2011). Fatigue is closely linked to sleep disturbance and other consequences of ABI such as cognitive, emotional and behavioural difficulties. It can make return to work/education and participation in social activities extremely difficult and has an exceedingly negative impact on overall quality of life.

Fatigue related to brain injury may be a direct result of injury to the brain or be attributable to increased 'neurological effort' required to compensate for lost skills and abilities. It is different than the normal fatigue (Malley et al., 2014) in the way that:

- ★ It does not go away with rest.
- ★ It is intense.
- ★ Makes a challenge for people to think, communicate and tolerate sensory stimuli.
- ★ It is perceived as a 'shut-off of the brain'.

Even activities which are considered to be relaxing such as reading a book or watching television can be tiring for a person who experiences neurological fatigue following ABI (Gronwall et al., 1998).

Sleep problems may be a result of the brain injury itself or a result of fatigue, pain, stress or social consequences of the brain injury (e.g., difficulties returning to work and school, 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. For parents of children with an ABI, sleeplessness often causes big problems, especially when the child is overactive during the day.

Headaches and pain

Headaches are particularly common following ABI. The mechanisms of pain after ABI are not well understood. Headache, for example, may happen because of stress and tension, when the person tries to do too much, or may be a sign of anxiety (Gronwall et al., 1998). The cognitive and behavioural functioning of an individual are influenced by pain even in the case of mild brain injury. Pain is also associated with depression (Gosselin et al., 2012). It is important to consider pain characteristics such as onset, duration, location, triggers, as well as any psychological factors in determining how best to treat pain.

Seizures

Although most people will not have a seizure following ABI, seizures can happen as a consequence of neurological damage. Most seizures occur in the first days and weeks after a brain injury, but some may also occur months or years later.

Difficulties with movement, balance and coordination

Problems with movement, balance and coordination can occur following brain injury due to paralysis and weakness in limbs, dizziness and/or vestibular problems. 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.

Problems with speech and swallowing

Difficulties with speech production may be caused by damage to the muscles involved in speech (dysarthria), or planning the motor movements to say what one wants (dyspraxia) or a combination of the two. As a consequence speech may be qualitatively unusual, including sounding 'slurred' or 'slow'. It is also possible for the muscles involved in swallowing to be adversely affected following brain injury (dysphagia). For some this is associated with an increased risk of choking.

Incontinence

Incontinence can happen following ABI for a variety of reasons, with a significant impact on social functioning.

Sensory problems

Sensory problems following ABI are many and varied and include difficulties with perception of visual information (colour, shape, size, depth, distance) and auditory information (sound), as well as smell, taste, and touch (relating to pain, pressure and temperature).

Hormonal imbalance

Mood swings, depression, impulsivity and fatigue can sometimes be a symptom of hormonal imbalances as a direct result of brain injury to the endocrine system. Other symptoms include: sexual

difficulties, headaches, visual disturbance, weight gain, muscle weaknesses, reduced body hair, changes in skin texture, and difficulty regulating body temperature (Headway, 2013).

2.4 Social impact

The impact of cognitive, emotional, behavioural and physical changes following brain injury on an individual can be many and varied. The outcome of brain injury is different for each person and can include:

- ★ Difficulty with self-care (e.g., showering, cleaning, shopping, cooking).
- ★ An inability to catch public transport.
- ★ Being unable to return to driving.
- ★ Sexual dysfunction.
- ★ 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.

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

2.5 Impact on carers and family relationships

Family caregivers play an important role in providing social, emotional and practical support. The well-being of a carer has a direct influence on the well-being of a person with ABI (Uomoto, 2008). However, such caring is often associated with high levels of distress, depression, anxiety, reduced quality of life and physical health issues (Vogler et al., 2014).

Emotional changes such as reduced empathy, increased egocentricity, blunted emotional responses, and emotional instability can have a negative impact on relationships. Family members may grieve for the loss of the person as they were before the brain injury, with increased rates of divorce reported (Holloway and Fyson, 2016).



IV. ABI in children

1. The dynamic nature of early brain development

Children's brains develop throughout infancy, childhood and adolescence. Some areas are fully developed and functional at an early age whilst other areas continue to develop well into adolescence and early adulthood. Damage to fully developed areas of the brain may be immediately apparent through loss or impairment of former skills. The effects of damage to parts of the brain yet to be developed fully may not be apparent for some time after injury. This explains the emergence of difficulties with behaviour or subtle cognitive skills later in the child's development, perhaps years later after a brain injury. There is a risk that the brain injury is forgotten and these difficulties are not attributed to the early brain injury.

2. The impact of ABI on a child returning to school

Returning to school after encephalitis is a very important step in the child's recovery from ABI, in terms of both their social and educational reintegration. However, it is important to ensure that the child does not return to school before they are ready and a gradual return to school with a possible initial period of home schooling is considered. Support and education for both family and the school need to be in place to facilitate a successful return to school.

ABI may have a significant impact on a child's learning and school life, with the child no longer performing and behaving as before the illness. The child may experience cognitive, physical, emotional and behavioural problems (please see page 5 **Common difficulties after ABI**).

Deciding how best to meet the needs of a child with ABI (and their families) is often complex and requires input from various professionals. A referral to an educational psychologist may be necessary. This can be usually accessed via education, therefore the GP may need to ask the family to speak with the school staff about a possible referral.

3. The impact of ABI on family and siblings

ABI can be a bewildering experience for the whole family. Following a sudden, serious and, often, life-threatening injury or illness, the life of a child and their family may undergo significant changes. A study of the experiences of families of patients in intensive care units found that families of patients with brain injury experienced more symptoms of depression and stress at three months than families of patients with non-brain injury (Warren et al., 2016).

Relationships and roles within family may change and parents become unsure about what the future brings. They may grieve for the child they once had which can be a very emotional experience. Living with a child with an ABI can be very stressful and isolating as others may not understand the 'hidden' aspects of an ABI which has changed a child's behaviour. It can prove difficult to find appropriate services and professionals and prolonged stress can lead to feelings of anxiety, fear, anger, frustration and depression, which can further complicate the family's interactions with others and family life.

Siblings are not be forgotten in coming to terms with ABI in children. They may have mixed feelings towards their sibling with an ABI including love, protectiveness, jealousy, resentment and irritation. They may miss out on aspects of their own childhood, as their needs might not be met because of strain on finances, time or their parents' attention.



V. What can GPs do to help?

A supportive GP is crucial to the long-term management of people who have an ABI. Brain injury will affect every individual differently and some patients will require more support than others. Prompt support and help can lead to better outcomes for patients and their families. There are a range of ways in which GPs can assist.

1. Refer for rehabilitation and other special investigations

1.1 The role of rehabilitation

Quality of life after brain injury has been associated with acceptance and development of coping strategies (Van Bost, 2017) which can be facilitated by referral to appropriate rehabilitation and support services.

Neurorehabilitation following ABI has a positive impact upon recovery and reintegration back into social life (Oddy and da Silva Ramos, 2013). The aim of rehabilitation is to support a person with ABI (re)acquire 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.

Unfortunately, it is not uncommon to find that many people with ABI are discharged from hospital without adequate assessment or consideration of their long-term rehabilitation needs. This is in part due to the inevitable pressures on acute hospital beds.

Depending on the nature of the person's problems and goals, rehabilitation may range from receiving help from outpatient or community-based services to inpatient specialist residential brain injury units. People will have different rehabilitation needs following ABI such that one person may only need support from a few key professionals whereas another person will benefit from the input of a full multidisciplinary rehabilitation team, including medical and social care professionals. Rehabilitation can continue to be of benefit many years after an ABI as goals and personal needs change.

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 can enhance emotional adjustment and build a stronger sense of self post injury.

1.2 Professionals involved in rehabilitation

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 programmes 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.

Educational psychologists (who may specialise in neuropsychology) for:

- ★ Assessment of changes to thinking, memory and behaviour within an understanding of the young person's neurodevelopmental framework.
- ★ Consultation, advice, support and training to educational staff, parents in addition to the young person with the ABI.

Occupational therapists for:

- ★ Assessing abilities and supporting an individual to maximise independence in relation to simple (e.g., personal care, dressing) and complex (e.g., managing finances) activities of everyday living.
- ★ Helping someone to re-engage with their usual leisure activities or develop 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, dexterity and/or sensory changes (i.e., numbness, pins and needles).
- ★ Advice regarding pain management.

Community paediatrician for:

- ★ Concerns regarding attention deficit hyperactivity disorder (ADHD) or autism spectrum disorder (ASD) features post-ABI.

Child and Adolescent Mental Health Service (CAMHS) for:

- ★ Concerns regarding severe behavioural problems, obsessive-compulsive disorder (OCD)/post-traumatic stress disorder (PTSD).

Psychiatrist/child and adolescent psychiatrist for:

- ★ Behavioural issues.
- ★ Difficulties with social relationships and emotional adjustment.

Rehabilitation medicine consultants for:

- ★ Assessment of needs for rehabilitation and management of the referral pathways through the Rehabilitation Prescription.
- ★ Specialist physical interventions (e.g., spasticity, pain, vestibular disorders).
- ★ Support for medico-legal aspects (e.g. mental capacity, personal injury claims, Power of Attorney).

It can be challenging for individuals to negotiate services to access rehabilitation services, particularly if they have cognitive changes following their ABI. NHS community-based teams are a good place to start enquiries regarding available rehabilitation services. GPs can refer directly to these teams where these exist (e.g. NHS Community Neurology Rehabilitation Teams, NHS Community Brain Injury Teams, NHS Stroke teams). Assessments by such teams can also be useful in determining whether patients 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 and/or patients may need to be under the care of a neurologist to access rehabilitation and support. If you are having trouble referring your patients to appropriate services it may be useful to contact their previous neurologist or rehabilitation consultant to see if they can refer your patient. They may also be a valuable source of information about alternative local services.

If you are having difficulty accessing health professionals in the NHS with specialised expertise in ABI it may be necessary to consider alternative generic services, although this is not ideal. For example, Improved Access to Psychological Therapies (IAPT) services may assist in the management of emotional and behavioural problems post-ABI. These services offer cognitive behavioural therapy which may be suitable for patients with less severe or complex difficulties. Referral to clinicians and therapists in private practice who specialise in ABI is another consideration, particularly if your patient has private medical insurance (see 'Professional Bodies/Registers' in the reference section).

Other specialist services and professionals to consider might include:

- ★ Neurologists – for concerns about symptom relapse, medication advice, management of seizures and if review or further neuroimaging is required.
- ★ 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.
- ★ Dieticians – for concerns about a person's weight (under or overweight), or other nutritional issues (e.g., restricted diet, aversion to certain food textures).

- ★ 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 & throat specialists/audiologists/ophthalmologists – for managing sensory problems.
- ★ Endocrinologist/neuroendocrinologist – for management of hormonal irregularities.
- ★ 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.

For more information on rehabilitation please visit:

- ★ **Encephalitis Society**
www.encephalitis.info/rehabilitation-after-encephalitis
- ★ **British Society of Rehabilitation Medicine**
www.bsrm.org.uk
- ★ **Headway**
www.headway.org.uk

1.3 Rehabilitation in children

Those children who have been very unwell and treated within regional neurology centres may well be followed-up and seen more routinely. However, children treated more locally in district general hospitals may not get the same follow-up. Even those seen in regional centres may get discharged back to local care if there are no ongoing physical/medical rehabilitation needs. In addition, as previously mentioned, the effects of childhood brain injury can last well into childhood and adult years.

If the child is not routinely followed-up by a paediatrician, GPs are likely to be the first port of call for parents when they notice changes in their child's development and functioning. This is where GPs are vital in listening to families, getting a full history of the child and their brain injury and ensuring that they refer into specialist services, such as paediatric neuropsychology services (usually only available within regional neuroscience centres), Child and Adolescent Mental Health Services (CAMHS), paediatric neurology services within hospitals, educational psychologists (who can be accessed via schools), speech and language therapists, physiotherapists, occupational therapists or family therapists (please see page 9, **Professionals involved in rehabilitation**).

Reassessment/review at key transitional points in the child's development and schooling (e.g., emerging of new skills, transition to secondary school or college) is strongly recommended to ensure that any difficulties are identified early and support structures are put in place to manage these difficulties at home, school and in the wider local community.

1.4 Older adults and rehabilitation

Although the needs and experiences of different age groups are likely to vary, older adults can make similar gains in rehabilitation to those observed for younger adults so there is good reason to refer older adults for rehabilitation (Chan et al., 2013; Uomoto, 2008).

ABI in older adults needs to be distinguished from cognitive changes arising as a result of dementia as the rehabilitation process and outcome for ABI and dementia differ.

1.5 Specialist rehabilitation for working aged adults with highly complex needs

A small group of individuals have very complex needs following ABI. They may require referral to Level 1 and 2 specialised rehabilitation services commissioned by NHS England. Information about these services and how to refer to them may be found on the NHS website:

www.england.nhs.uk/commissioning/

2. Promote self-management of symptoms

Self-management programmes that address some of the difficulties that can follow an ABI, such as chronic pain, anxiety, depression, and fatigue, may alleviate some symptoms, or enable people to cope with their symptoms better. However, it may be difficult for people with ABI to access these programmes, particularly if they have difficulties with cognitive abilities such as attention, memory, and executive function. Also, these programmes are unlikely to suit all people with ABI. However, it is important that patients know about these programmes and are supported and encouraged to self-manage their symptoms.

Charities like Encephalitis Society (www.encephalitis.info), Headway (www.headway.org.uk), Child Brain injury Trust (CBIT) (www.childbraininjurytrust.org.uk), and Children's Trust (www.thechildrenstrust.org.uk) produce a range of factsheets, books and booklets to help people understand and manage the impact of different effects of ABI.

There are also various self-help apps or digital services for managing some of the symptoms, including mental-health, physical well-being and pain. Some of these apps are approved by the NHS. You can find more details on NHS apps library <https://apps.beta.nhs.uk/> or www.nhshealthcall.co.uk/digital-health-products/nhs-health-call-chronic-pain-management-service/

3. Provide advice in relation to a return to driving

Driving requires complex cognitive skills and intact physical abilities. Restrictions of driving following ABI can have a significant negative impact upon an individual's work, social and family life and can add to the difficulties with adjusting to life post-ABI (Liang et al., 2017). However, GPs should advise people that their

ABI may affect their ability to drive. It can be difficult for a GP to determine if their patient is safe to drive following an ABI. There are a number of Mobility Centres that offer on and off-road driving assessments to determine if someone is safe to drive after ABI.

More information on assessing fitness to drive at:

www.gov.uk/government/collections/assessing-fitness-to-drive-guide-for-medical-professionals

It is the responsibility of the person with an ABI to inform the Driver and Vehicle Licensing Agency (DVLA) about their condition. If the patient refuses to accept a diagnosis or denies the effect of their ABI and continues to drive, GPs can arrange for a second opinion. If the patient continues to drive against advice, the DVLA medical officer should be contacted. GPs do not need to inform the patient about their intention to do this.

4. Assist with return to work

Following an ABI, an individual typically requires time off work. Their GP may be asked to provide a Fit Note or Statement of Fitness for Work. This will provide the employer with information about how the ABI affects the patient's ability to work and how much time they will remain off work. The Statement of Fitness to Work can also develop understanding of how the employer might help the patient return to work sooner.

Return to work after ABI is important to facilitate engagement with pre-injury roles in addition to financial incentives. To ensure a successful return to work, the following factors should be considered:

- ★ Cognitive strengths and weaknesses. Assessment by a clinical neuropsychologist, speech and language therapist and occupational therapist can identify any challenges and develop an individualised rehabilitation programme to support return to work.
- ★ Education needs for the employer including the need for adaptations and a gradual return to work.
- ★ Emotional support for the individual with ABI, including awareness of and adjustment to difficulties.

It is important that a return to work is not attempted too soon and generally a gradual return is advised. An unsuccessful return to work or multiple failed attempts may adversely affect confidence, and lead to anxiety and depression.

The following website contains information and guidance for GPs on health and return to work:

www.gov.uk/government/collections/fit-note

www.gov.uk/government/collections/fit-for-work-guidance

5. Provide medical evidence

GPs are often asked to provide medical information about their patients by the patients themselves, employers, legal and government agencies regarding housing support letters, fit for work notes, Department for Work and Pensions (DWP) assessment forms or clinical negligence or personal injury claims. Such medical evidence is crucial for people with ABI to obtain necessary support.

6. Support carers

ABI is a family affair and can have a negative impact on those around the person with ABI. With consideration of this impact on the family, it is important for GPs to recognise that:

- ★ ABI can impact on all family members.
- ★ Sensitivity in communication with parents of a child with ABI is needed; labelling them as overprotective may bring even more stress into their lives.
- ★ ABI places relationships with partners/spouses under significant stress and these relationships may deteriorate. Counselling on an individual basis for carers or relationship counselling may be beneficial (e.g., Relate).
- ★ Changes in personality and behavioural problems following ABI impact the most on the carer's wellbeing (Jackson et al., 2009).
- ★ Carers and family members may need support for their own mental and physical wellbeing. This can support carers and family members to re-engage with their own lives including a return to work.
- ★ Respite care is available for people with ABI. A social worker or a local voluntary organisation may help with information about how to access it.

Please see Appendix for other useful links and contacts for supporting patients and their families/carers following ABI.

7. Additional considerations related to a patient's ABI

Some other factors to consider in consultations with a patient with an ABI include:

- ★ Patients may forget conversations and details due to memory problems. It is useful to write information down and keep information brief and to the point.
- ★ A carer or family member can provide valuable information in the initial clinical consultation. In addition to providing valuable information, they may also be able to ensure greater compliance and follow through of recommendations.
- ★ As the patient's needs are complex, they are likely to benefit from seeing the same GP for greater consistency of service. It may help to provide a named GP within the practice where possible.
- ★ Consider all possible after-effects of a brain injury, but be aware that not all health issues should be attributed to the brain injury.
- ★ Become familiar with local services available for people with ABI to maximise support options.
- ★ Be aware of adult and child safeguarding issues and refer on to appropriate services for immediate and longer term risk management.
- ★ Ensure the patient is aware of your surgery's opening hours, and advise them who they should contact if a problem arises outside of your working hours. This information should be provided in written form given possible memory difficulties.



VI. Encephalitis – unique challenges in the diagnosis and management of associated consequences

1. Key facts

- ★ Encephalitis is inflammation of the brain.
- ★ There are up to 6,000 cases in the UK each year and potentially hundreds of thousands worldwide (Granerod et al., 2013).
- ★ Inflammation is caused either by an infection invading the brain (infectious encephalitis which can be caused by herpes simplex virus, varicella zoster, enteroviruses, mycoplasma or viruses from mosquito or tick bite transmission) or through the immune system attacking the brain (autoimmune encephalitis including acute disseminated encephalomyelitis [ADEM] and antibody-mediated autoimmune encephalitis). In some cases of encephalitis no cause is identified (Granerod et al., 2010). This can prove challenging for individuals as they have no explanation for their illness.
- ★ It is important to differentiate encephalitis from other disorders that may cause similar neurological symptoms but have very different treatments. Disorders that mimic those of encephalitis include bacterial meningitis, stroke, brain tumours, drug reactions and metabolic disturbances, although these are usually sufficiently different based on clinical assessments.
- ★ Acyclovir is the most frequently used anti-viral drug. It is effective against the herpes simplex virus and varicella zoster virus. Unfortunately, for many viral infections there are no specific treatments at present.
- ★ It is increasingly recognised that autoimmune encephalitis is more common than infectious encephalitis (Dubey et al., 2018). Autoimmune encephalitis is due to a hyperactive immune system which incorrectly sees the brain as foreign. Treatments include drugs such as: steroids, intravenous immunoglobulin (IVIG), and plasma exchange. In addition, some patients are treated with other drugs which further dampen down the immune system, such as cyclophosphamide and rituximab.
- ★ Infectious types of encephalitis tend to occur only once and it is very rare for infectious types of encephalitis to recur later in life. Rarely, in some patients, an early apparent recurrence may relate to inflammation, 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 N-Methyl-D- Aspartate Receptor (NMDAR)-antibody-associated encephalitis (Irani et al., 2010).
- ★ Recent research has identified that herpes simplex encephalitis may sometimes be followed by the development of a NMDAR antibody-associated encephalitis (Venkatesan and Benavides, 2015).

- ★ The acute stage of encephalitis may be followed by a phase of fairly rapid improvement and a slower recovery can continue over the years to come.
- ★ The degree of brain injury can vary from minor to severe according to the cause, the severity of the inflammation, the parts of the brain affected, and any delay in treatment.
- ★ In addition to significant cognitive and physical changes, the emotional impact of encephalitis varies between individuals. It can reflect a direct effect of the encephalitis or a secondary reaction to changes in work, relationships and ability. Emotional reaction and adjustment will depend on the individual's pre-injury personality, their social support network and their stage of recovery.

2. Challenges in the diagnosis of encephalitis

2.1 The non-specific symptomatology

Initial symptoms and their rate of development vary widely and can make the diagnosis of encephalitis difficult. Patients can present with the following symptoms depending on the type of encephalitis, but the two forms often have overlapping features.

- ★ **Infectious encephalitis**
Flu-like illness (fever); headache; alteration in the level of consciousness (from mild confusion and drowsiness to loss of consciousness and coma); seizures; increased sensitivity to light (photophobia); inability to speak or control movement; sensory changes; neck stiffness; and uncharacteristic behaviour.
- ★ **Autoimmune encephalitis**
Confusion; altered personality or behaviour; psychosis; mood disturbance; movement disorder; seizures; hallucinations; memory loss; sleep disturbances.

Recognition of these symptoms should lead to rapid admission to hospital and prompt treatment as this can have a significant impact on outcome!

2.2 The newer types of encephalitis

In the last decade it has been recognised that there are other forms of autoimmune encephalitis associated with finding of specific antibodies in blood and spinal fluid. These antibody-mediated forms of encephalitis include autoantibodies against the NMDA receptor, LGI1, CASPR2, DPPX and the GABA_B, AMPAR and GABA_A receptors.

Prompt recognition of these forms of encephalitis is vital because the treatment (early and adequate) is a major factor in improving outcomes (Irani et al., 2014) (Thompson et al., 2018).

NMDAR antibody encephalitis

- ★ This happens when the antibodies react with NMDA receptor (a protein in the brain that helps control the electrical activity of nerves).
- ★ It often manifests with psychiatric symptoms including delusional thinking, mood disturbances and aggression (Dalmau et al., 2008; Irani et al., 2010) sometimes following a flu-like illness. In a patient with no history of psychiatric illness this diagnosis may be considered. It is often followed by confusion, mood disturbances, seizures and a movement disorder.

LGI1–antibody associated limbic encephalitis

- ★ This happens when the antibodies target the LGI1 protein (Irani et al, 2010).
- ★ Initially, family members usually notice that their relative becomes forgetful and confused. Importantly, seizures frequently occur, in particular patients may develop brief jerks of the face and arm (termed faciobrachial seizures) – this is an important feature as it is highly suggestive of LGI1-antibodies. Patients can also develop mood disorders (like depression) or bizarre thoughts and behaviours.

3. The role of the GP in early diagnosis of encephalitis

A GP plays a critical role in recognising the early signs and symptoms of encephalitis to facilitate prompt referral to hospital. A patient who displays symptoms and signs of encephalitis should be admitted to hospital as an emergency and acyclovir/ immunotherapy should be considered immediately.

If admission is delayed the risk of serious and permanent neurological sequelae, including death, increases.

Guidelines for Diagnosis of Infectious Encephalitis have been developed by the Encephalitis Society and are available to download from the Society's website (www.encephalitis.info).

Recommendations:

- ★ Current or recent febrile illness with altered behaviour, personality or consciousness or development of psychiatric symptoms/psychosis, and cognitive decline with or without seizures should raise the possibility of encephalitis.
- ★ Discussion with the family regarding the person's history of the illness and behaviour can assist diagnosis. A high proportion of family members reported that they knew something was wrong as the patient was acting outside of their 'normal' behaviour or character at the onset of illness (Cooper et al., 2016).
- ★ A follow-up should be arranged, if the patient is not referred to hospital, with provision of written information of symptoms that suggest a deterioration and what to do in case of deterioration.

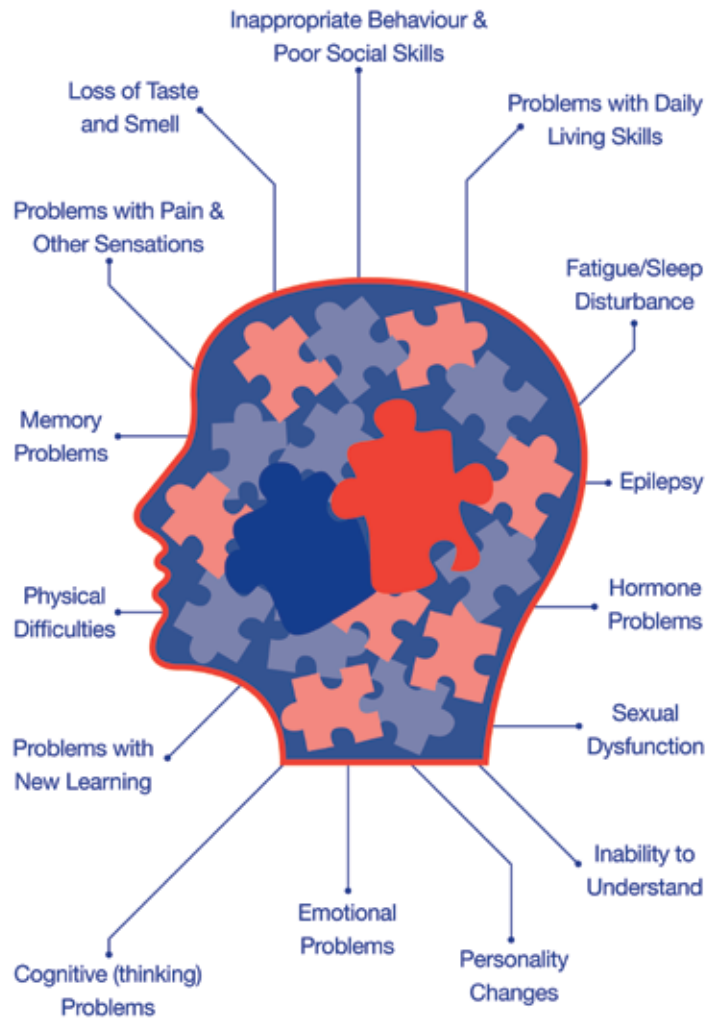


4. The role of the GP in managing the effects of encephalitis

People who have experienced encephalitis can present with problems in cognition, emotion, behaviour, and physical functioning. These difficulties can present shortly after their diagnosis and acute treatment and persist over time. In children, the neuropsychological deficits and extreme fatigue can be prolonged, even up to adolescence. Follow-up of patients after encephalitis and early neuropsychological assessment and interventions are essential (Granerod et al., 2017; de Bruijn et al., 2018).

Following encephalitis, it can be difficult for people to access services including ABI rehabilitation because of various reasons:

- ★ There appears to be less understanding of encephalitis and its effect among the general public and even professionals than is the case for other, more commonly occurring ABIs (Easton et al., 2006).
- ★ People with encephalitis overall appear to experience physical difficulties less frequently than is the case for other types of ABI and thus have shorter hospital stays which allows for their 'hidden' cognitive, behavioural and emotional changes to be missed in an acute setting.
- ★ In some geographical regions, people with encephalitis may be excluded from accessing services by referral criteria that cater to other, more common neurological conditions such as traumatic brain injury or stroke.



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How can GPs help manage the effects of encephalitis?

When supporting people with encephalitis it is important for GPs to be aware that:

- ★ Long-term changes in cognitive, emotional, behavioural, and physical functioning can endure following encephalitis.
- ★ For some people these changes have a devastating impact on their social functioning and quality of life, including their academic achievements, ability to return to work and driving. Encephalitis will also affect families including partners, parents and children.
- ★ Due to the nature of their difficulties, people with encephalitis may be more likely than those with other ABIs to be discharged from hospital without their long-term needs being recognised.
- ★ The problems that people experience post-encephalitis may become more apparent, not immediately after returning home from hospital, but when they attempt more challenging roles, such as returning to work and school.

- ★ Encephalitis in childhood can impact an individual's ability to return to school and engage with their peer group. Some cognitive and behavioural changes may not become apparent until later in childhood and adolescence with a need for long-term support systems.
- ★ The after-effects in children can be subtle and inconsistent which reflects their individual pattern of strengths and weaknesses and the acquired nature of cognitive and emotional changes. The child may also have difficulty emotionally adjusting to life following encephalitis.
- ★ Timely access to rehabilitation is important for improving long-term outcomes.

People with encephalitis benefit from some sorts of support and rehabilitation outlined in the general guidance for people with ABI.

VII. Encephalitis Society: how we can help

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

- ★ Supporting adults, children, families and carers of those affected by encephalitis as well as professionals involved in their care.
Support Line: +44(0)1653 699599;
support@encephalitis.info
Skype: [encephalitis.contact international](https://www.encephalitis.info/contact-international)
Meeting and events for children and adults:
www.encephalitis.info/events-and-activities
Connection Scheme which facilitates connections between people with similar experiences.
www.encephalitis.info/connection-scheme
- ★ Producing evidence-based, quality information about encephalitis accredited by the NHS England Information Standard in different formats: books, booklets, factsheets available on our website www.encephalitis.info or from our Support Line (support@encephalitis.info; +44(0)1653 699599).
- ★ Producing evidence-based information for health professionals such as:
 - Diagnosing and managing the effects of ABI in adults and children, including encephalitis
www.encephalitis.info/generalpractitioners
 - Management of viral encephalitis in adults and children
www.encephalitis.info/management-of-viral-encephalitis-guidelines
 - Advances in encephalitis. Research Summary
www.encephalitis.info/latest-research-on-encephalitis

- ★ Raising awareness about encephalitis, its consequences and the need for improved services.
World Encephalitis Day (22 February each year)
www.encephalitis.info/world-encephalitis-day
- ★ Facilitating training and learning opportunities on encephalitis.
Encephalitis Conference — the only international professional conference on encephalitis with renowned speakers and latest research findings (CPD points awarded).
www.encephalitis.info/encephalitis-conference
Providing training and awards
www.encephalitis.info/training-and-awards
- ★ Conducting research and working in partnership with other researchers. In addition, we are encouraging patient engagement in research which is often an altruistic, informative and satisfying activity for many patients and carers.
www.encephalitis.info/our-research

Further information about these services and events can be found on the Encephalitis Society's website www.encephalitis.info, by telephone: +44(0)1653 692583 or email: mail@encephalitis.info

Free membership of the Encephalitis Society

Become a professional member of the Encephalitis Society and help us in our mission to increase global awareness of encephalitis, save lives and build better futures.

By joining our world-renowned, award-winning organisation, you will be part of a professional community of several thousand professional members in over 100 countries.

Subscribe to our membership at www.encephalitis.info/professional-membership

APPENDIX

USEFUL LINKS AND CONTACTS

Other charities/voluntary organisations:

In addition to the Encephalitis Society there are various organisations who may be of help. Most of those charities have social media presence such as Facebook and Twitter accounts which may be very useful for your patients. Details about social media channels can be found on their websites.

- ★ **Brain and Spine Foundation:**
www.brainandspine.org.uk; Helpline: 0808 808 1000
Provides information and support on a full range of neurological conditions.
- ★ **Carers Trust:** www.carers.org
They provide access to breaks, information, advice and education. They help carers to maintain their own health and wellbeing, provide support to reduce feelings of isolation, and run play and support schemes for young carers.
- ★ **Carers UK:** www.carersuk.org
They provide expert advice, information, support and connect carers via online community or local carers groups.
- ★ **Cerebra:** www.cerebra.org.uk; Telephone: 0800 328 1159
They support family with children with brain conditions. They run a Sleep Service who can give advice and guidance on sleep difficulties.
- ★ **Challenging Behaviour Foundation:**
www.challengingbehaviour.org.uk;
Helpline: 0300 666 0126
Provides information about challenging behaviour and support to families and professionals.
- ★ **Child Brain Injury Trust (CBIT):**
[Http://childbraininjurytrust.org.uk](http://childbraininjurytrust.org.uk); Helpline: 0303 3032248
Supports families and professionals by providing Regional Child and Family Support, information and family and learning events.
- ★ **Disabled Living Foundation:**
www.dlf.org.uk; Helpline: 0300 999 0004
Provides impartial advice, information and training on independent living.
- ★ **Epilepsy Action:** www.epilepsy.org.uk; Helpline: 0808 800 5050
Provides information about coping with epilepsy and seizures, free help and advice through the telephone and has a network of groups of people giving the opportunity to share experiences and support each other.
- ★ **Fifth Sense:** www.fifthsense.org.uk;
Provides information on anosmia, smell and taste-related disorder and information about clinics which manage these disorders.

- ★ **Headway:** www.headway.org.uk; Helpline: 0808 800 2244
Provides support, services and information to brain injury survivors, their families and carers, as well as to professionals in the health and legal fields.
- ★ **Mind:** www.mind.org.uk; Helpline: 0300 123 3393
Provides advice and support to empower anyone experiencing a mental health problem.
- ★ **Relate:** www.relate.org.uk; Helpline: 0300 100 1234
Helps people of all ages, backgrounds and sexual orientations to strengthen their relationships.
- ★ **Sleep Unlimited:** www.sleepunlimited.co.uk;
Provide a range of specialist training, suitable for individuals with sleep problems, health and social care professionals and organisations.
- ★ **The Children's Trust:** www.thechildrenstrust.org.uk;
Telephone: 01737 365 000
They help children, young people and their families through rehabilitation, expert nursing and medical care, special education, information, research and policy development.
- ★ **UKABIF:** www.ukabif.org.uk
Provides a directory of rehabilitation services and has a network of regional groups around the country.

Professionals Bodies/ Registers

- ★ **Association of Speech and Language Therapists in Independent Practice (ASLTIP)**
<https://beta.helpwithtalking.com>
- ★ **College of Sexual Relationship Therapists (COSRT)**
www.cosrt.org.uk
- ★ **College of Occupational Therapists Specialist Section – Independent practice** www.rcotss-ip.org.uk
- ★ **Primary Care Neurology Society** www.p-cns.org.uk
- ★ **The British Psychological Society** www.bps.org.uk
- ★ **The British Association for Counselling and Psychotherapy**
www.bacp.co.uk
- ★ **The British Pain Society** www.britishpainsociety.org
- ★ **The British Society of Rehabilitation Medicine**
www.bsrm.org.uk
- ★ **The Chartered Society of Physiotherapy** www.csp.org.uk

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Encephalitis Society

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