At the bedside

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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, blood pressure, respiratory rates, blood tests, conscious level and input and output of any fluids.

The patient may also need:

- A urine catheter inserting in place of using the toilet. This also aids monitoring fluid intake/output.
- A tube into the nose (nasogastric tube) going down into the stomach in order to provide essential nutrients and fluids if they are unable to swallow or 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 (in place of a nasogastric tube)
- An intravenous line inserted into a vein enabling essential drugs to be administered as and when necessary.
- Anti-embolism stockings and/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. Scores are monitored over time and a deterioration is reported to doctors by nursing staff.

Intensive Care Unit (ICU)

Encephalitis can cause the brain to swell, which can affect areas of the brain that control life sustaining functions, such as breathing. In cases like this, patients are cared for in ICU, which is different to a normal medical ward in a few ways:

- There are more healthcare staff, usually one nurse to each patient, physiotherapists to help with patients breathing and movement, health care assistants, doctors and pharmacists. This is because the patients are more unwell and need more constant monitoring and care.
- There is lots of equipment by the bedside that monitors blood pressure, heart rate and rhythm, the levels of oxygen in the blood, and breathing. These can make lots of noise, but most of it isn't a cause for alarm. The nurse at the bedside will reassure you.
- At least two teams of doctors look after the patients; the neurologists who treat the encephalitis, and the ICU doctors who ensure the patients' blood pressure, heart rate and breathing are carefully controlled.

Patients in the ICU may be placed in a drug induced coma (sometimes known as sedative drugs). This coma is a temporary coma brought on by a controlled dose of drugs to put the brain into a coma and allow time to recover from the swelling caused by encephalitis. The doctors decide the length of the coma depending on the extent of injury and the way the patient reacts/responds when the sedative drugs are stopped temporarily to assess conscious levels.

Whilst in an induced coma, patients are unable to keep their airway open and breathe for themselves. So, the ICU doctors will need to place a tube from the mouth into the windpipe (trachea) to protect the airway-a process called intubation. This tube will be connected to a machine, called a ventilator (also referred to as a breathing machine), at the side of the bed that controls breathing and oxygen delivery. Constant monitoring of the blood pressure may be needed, so the ICU doctors or specialist nurses may insert a drip/cannula directly into an artery of the wrist or foot to monitor this. It also allows nurses to obtain blood samples and check oxygen levels in the bloodstream. The patient will be on a few different drugs including those to induce coma and treat the encephalitis, but they may need drugs to keep the blood pressure in a safe range and treat other infections. So, to give all these medications, direct access into a large vein (a central line) is used, either in the neck or the groin.

When the drugs for the induced coma are steadily reduced, the patient may wake up and begin to breathe on their own quickly, so the tube into the windpipe can be taken out. However, in some cases patients take longer to breathe on their own. Because the tube from the mouth to the windpipe prevents them from speaking or moving around, in these patients, the ICU doctors may consider a procedure to introduce a tube through the skin of the neck into the windpipe, called a tracheostomy. This allows them to begin to communicate and move more freely, whilst their breathing is still being supported.

In some ICU's a patient diary may be completed by the bedside nurse and other staff involved in your loved one's care. This can become very useful when they are recovering/recovered in helping fill any memory gaps they may have. If the ICU doesn't have this you can start and keep your own diary which some relatives find very useful too, to reflect on. Patients may be weak from having been in an induced come and make require physiotherapy and time to improve.

The acute confusional state

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

Psychiatric symptoms and their management

Some forms of encephalitis, particularly autoimmune encephalitis, can present with psychiatric symptoms. This is due to inflammation directly in the area of the brain that regulates mood and behaviour. These symptoms can include, but are not limited to the following:

- Behavioural problems – agitation, aggression, disorganisation, speech problems, unexplained laughter or crying, or a lack of inhibitions.
- Psychosis – seeing, hearing or believing things that aren't real, which may include thinking people are against them.
- Mood disturbances – depressed or very high (manic) and patients may potentially attempt self-harm or suicide.
- Sleep disturbances – sleeping during the day and waking up overnight, sleeping too much or not enough, or having bad dreams.
- Others – abnormal postures, obsessive or compulsive disorders, eating and drinking too much or not enough.

If a patient presents to hospital with these symptoms, they may be cared for by a psychiatrist at first.

<u>Management of psychiatric symptoms</u>

The cause of the psychiatric symptoms in encephalitis, are either due to general swelling, or an autoimmune process in the areas of the brain that regulate mood and behaviour. Therefore, as the cause of the encephalitis is treated, these symptoms should improve. However, when patients are having abnormal thoughts and behaviours, they may put themselves and others at risk. In these situations, when a patient is not able to make decisions for themselves because of an illness affecting their brain, medical professionals may need to keep the patient in hospital, even if they are saying they want to leave.

- In England and Wales, decisions like this must follow clear rules set out in the Mental Capacity Act or Mental Health Act. The Mental Capacity Act allows healthcare professionals to keep a patient in hospital to manage their physical health problems without their consent when they are unable to demonstrate they have capacity. To demonstrate capacity a patient must understand, retain, weigh up and communicate the information and their decision back to the healthcare professional. This is the Act commonly used in patients with encephalitis suffering from psychiatric problems. This is because the origin of the psychiatric symptoms stems from a physical condition and is not primarily a mental health issue. (1)
- Under section 5 of the Mental Health Act, in an emergency, any doctor or nurse can keep a patient in hospital for a short amount of time against their will; six hours for nurses and three days for doctors. Following an assessment by a psychiatrist, a patient may be kept in hospital against their will for much longer to have investigation or treatment, which is commonly referred to as being 'sectioned'. Depending on the individual situation, either section 2 or 3 of the Mental Health act would be used. Section 2 allows patients to remain admitted for 28 days for assessment and treatment, whilst section 3 remains in place for 6 months and can be renewed for longer periods if required.
- The Mental Health Act is usually used for patients at risk of harm to themselves or others due to their mental health conditions, regardless of if they demonstrate capacity. This Act may sometimes be used for patients with encephalitis due to the overlap of physical and mental health problems, or if encephalitis is not initially detected, albeit less commonly. (1)
- In Scotland the laws are slightly different but essentially mean the same.

<u>How to help with behavioural and mood symptoms</u>

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

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

Understanding encephalitis in the acute stage

Trying to communicate with the hospital doctors and nurses can sometimes seem difficult. Lack of information or too much specialised information can also be very daunting. You may not understand medical terminology.

So as to maximise the effectiveness of communication:

- Get to know the key staff involved in your relative/friend's care.
- Doctors are often very busy but most should be able to agree to set aside a time to update you and answer your questions even if they can't do so there and then
- Write down what you want to ask and take any opportunity to ask questions.
- Contact Encephalitis International's Support Service by phone +44(0)1653 699599 or email support@encephalitis.info.

Looking after yourself

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

Acknowledge your emotions and be aware that other family members may react differently. Some hospitals provide Family Therapy, which may help you deal with the stress and emotions at this difficult time. Ask a member of staff if this is available in your hospital. Involve your extended network of family and friends in providing you with practical support. Take them up on their offer of help. If they have not offered, ask them to prepare some food, do some washing, shopping or look after your children. The likelihood is that they want to help but don't know what to do for the best.

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Thank you!

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Encephalitis International is the operating name of the Encephalitis Support Group.

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