Involving patient groups to provide support and information in the care of rare conditions

Encephalitis can have devastating effects on patients and families. During recovery, it is essential to direct patients to organisations that can offer specialist support.

INTRODUCTION
Encephalitis is inflammation of the brain, most often caused by a virus, or an abnormal immune response.
Herpes simplex virus (HSV) is the most often diagnosed viral cause of encephalitis in western industrialised nations, with an estimated annual incidence of 1 in 250,000-500,000 (Whitley, 2006).

Herpes encephalitis can have devastating effects on patients and their families. It is a serious and life threatening condition with a high mortality rate and significant long term disability in survivors (Hjalmarsson et al, 2007).

However, because the condition is relatively rare, many patients have not heard of it, and many nurses and doctors know little about it, meaning the care they provide can be suboptimal.

Here we describe a case in which referral to the appropriate patient support group made a real difference.

BACKGROUND
Joseph (not his real name) was a healthy 21 year old. He worked as a mechanic Monday to Friday and liked to meet his friends and his girlfriend at the weekends. Friday night was much like any other, a couple of pints in the local pub and a Saturday morning lie in to look forward to.

However, one weekend, the lie in lasted the whole day and Joseph found it difficult to shake off what he thought was the effects of the night before. By Sunday, he was feeling even more lethargic and was complaining of a headache and flu like symptoms.

On Monday, he didn’t go to work and his parents were becoming increasingly concerned as his headache had become severe and his personality had changed.

After a home visit by his GP, Joseph was taken to accident and emergency by his parents. At this point, he was slightly confused and behaving out of character. He was admitted and promptly started on intravenous (IV) aciclovir for the treatment of herpes encephalitis.

TREATMENT
Joseph had a CT scan and a lumbar puncture to test his cerebrospinal fluid for the presence of HSV.

Treatment with IV aciclovir was continued for three weeks. During this time, he was often confused and required some sedation to nurse him safely and to keep his IV line in place due to his agitation. His family found his bizarre behaviour upsetting.

The medical and nursing staff did their best to help but many of them were unfamiliar with the disease and its effects, which made communication with the family difficult.

This situation improved once the family were put in touch with the Encephalitis Society which was able to explain some of the symptoms such as fever and confusion.

The society is a charitable organisation with information on many aspects of this brain infection and is run by people whose families have been affected and professionals with a specialist interest in encephalitis (www.encephalitis.info).

RECOVERY
Joseph’s recovery was slow following the completion of treatment with aciclovir.

The acute phase of the disease may be followed by a period of fairly rapid improvement that slows down but continues over the coming months and sometimes years (Easton et al, 2006).

The support that Joseph and his family got from the Encephalitis Society and the nursing staff was important in helping them deal with his sometimes aggressive and uncooperative behaviour. His family learnt that this was out of Joseph’s control and not directed at them personally.

CONCLUSION
After almost two months, Joseph went home from hospital but still required time to convalesce before a staged return to work.

He tired easily, had difficulty with his short term memory, and sometimes had problems with even the simplest tasks. Remembering people’s names and times of day were particularly problematic. This improved over the following months but required patience and support from his friends and employer, and further input from the Encephalitis Society.

In many cases, the family says that the person they took home with them is not the one they brought to hospital, with changes in personality, irritability and poor short term memory (Solomon et al, 2007).

While encephalitis is a rare disease, it is crucial to remember that it can happen at any age and at any time. Some people recover from it without any problems but, for the majority, there will be symptoms associated with an acquired brain injury. For others, the outcome may be fatal.

If we are to provide gold standard nursing care for patients, it is important to understand how the treatment and recovery period can affect the patient and their families. Involving outside organisations is one way of helping them gain support and understanding.

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Encephalitis Society Guidelines for Recovery: tinyurl.com/Encephalitis-Society

REFERENCES

