



## THE AFTER EFFECTS AND SOCIAL CONSEQUENCES OF ENCEPHALITIS

### PROJECT SUMMARY OF FINDINGS

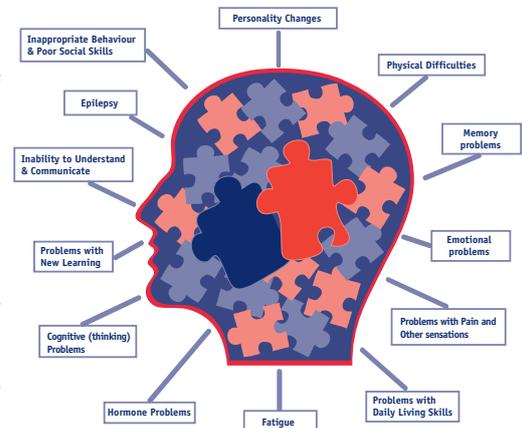
In 2008, the University of York and the Encephalitis Society completed a research study into the after effects and social consequences of encephalitis. This summary presents the findings from the study, which comprised a postal survey with Encephalitis Society members and interviews with individuals who had had encephalitis, their family members, and health and social care professionals.

The Encephalitis Society is an organisation of international reputation which has become a seminal resource for support, information and research into encephalitis for individuals who have had the illness, their families, and health and social care professionals. The Encephalitis Society has regular nationwide support meetings for its members. In addition, the Society has run a number of successful seminars for health and social care professionals in recent years, attracting key figures from neuropsychology and cognitive rehabilitation, such as Professor Barbara Wilson who is also the Society's President.

#### INTRODUCTION TO THE COMPLETED PROJECT

Encephalitis is a neurological illness in which the brain becomes inflamed. It has a number of different causes, including viruses. However, in more than 50% of cases of viral encephalitis, the specific virus that caused the illness is never known. Encephalitis may be difficult to diagnose, although there have been recent guidelines with suggestions to aid this diagnosis. There are no current, accurate figures as to the incidence of encephalitis in the U.K., but based on U.S. statistics, a U.K. figure has been estimated of 4000 new cases per year.

After encephalitis, individuals can recover with no or minimal after effects; others may be left with some form of long-term acquired brain injury. Post-encephalitic after effects include fatigue, memory problems, changes in behaviour, difficulty planning and making decisions, and epilepsy. However, other difficulties resulting from the illness are possible, so that each individual's experience of encephalitis and its after effects is never exactly the same.



#### ENCEPHALITIS AND CHRONIC PAIN

Research evidence also suggests that people may have chronic pain as the result of acquired brain injury - for example, chronic headache. They may also experience central pain which refers to different forms of altered sensitivity. For example, the person might feel pain in response to a trigger which would not normally cause pain, such as a light touch. We wanted to see if people who had had encephalitis experienced post-encephalitic chronic and central pain. We were also aware that, because acquired brain injury can result, there remains a need for individuals and their families to access a variety of services for many years after the illness. Their needs, however, are not always recognised by health and social care practitioners.

#### WHY WE DID THE PROJECT

Firstly, we wanted to look at a number of post-encephalitic after effects including chronic and central pain and ask people about their quality of life. We were also keen to speak to people who had experience of encephalitis, so we could see how individuals and their families managed the after effects of encephalitis in their everyday lives. Lastly, it was important to evaluate how services support individuals and families during and after the illness.

#### WHAT WE DID

We sent out a postal survey to all adult members of the Encephalitis Society (1281 people) of whom 59% returned a completed questionnaire. In addition we interviewed 23 individuals who had had encephalitis. With their consent, we interviewed one member of their family, with 18 family members agreeing to take part. Finally, we conducted telephone interviews with 15 health and social care professionals. These professionals included neurologists, neuropsychologists, occupational therapists and social workers. This project summary presents key findings from the postal survey and the three sets of interviews.

#### WHY THE PROJECT FINDINGS ARE IMPORTANT

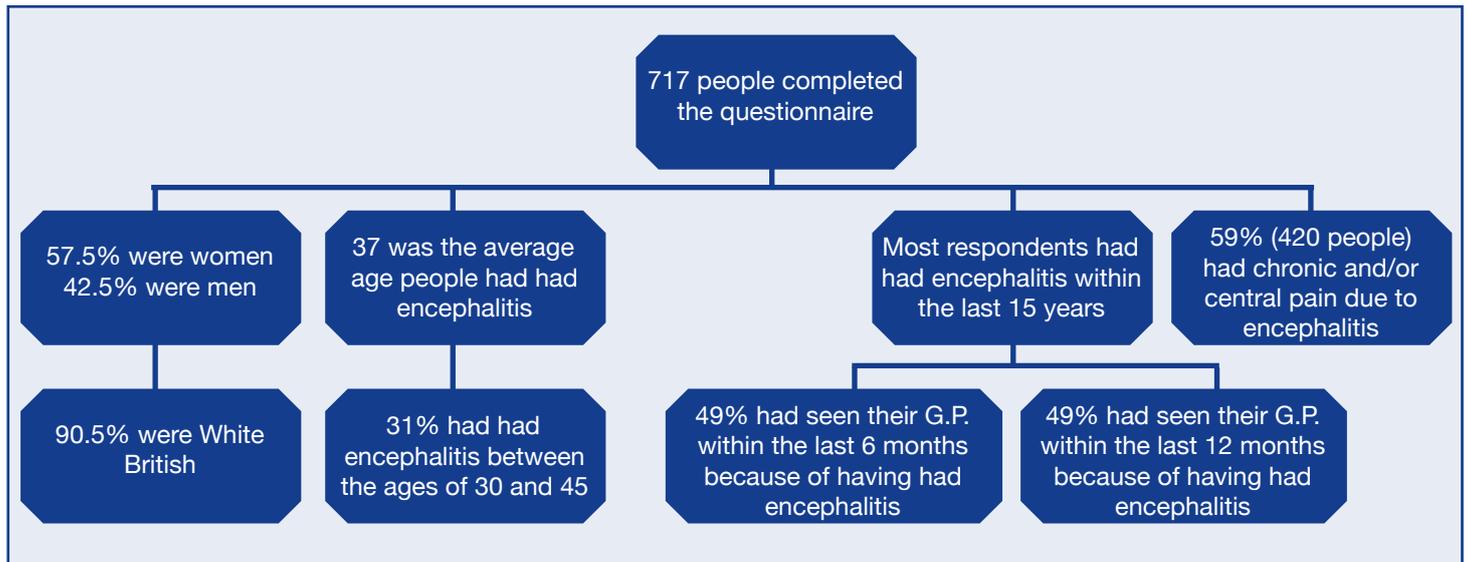
A project summary for specialist health and social care professionals has been produced, which aims to help practitioners better understand the difficulties faced by individuals and their families after encephalitis. A 'good practice' guide has been devised to inform professional practice. The project findings have also formed the basis for an on-line E-learning module which is being run by the Encephalitis Society.



# Findings from the postal survey

## ABOUT THE RESPONDENTS

The 'After The Illness' postal survey was completed by 717 people, of whom 53% did not know or were unsure as to what had caused their encephalitis.



## SOME POST-ENCEPHALITIC AFTER EFFECTS

- 28% reported having epilepsy because of encephalitis
- 70% (or more) reported fatigue, concentration and memory problems
- 60 to 69% reported depressed feelings, personality change & having less self confidence after the illness

## WORK SITUATION

- 39% reported that they were unable to work because of illness or disability.
- 44% of people felt they could no longer do paid work after encephalitis.
- 73.5% felt that their earning ability had been affected by encephalitis.

## QUALITY OF LIFE

Our findings suggest that many people experience long-term consequences following encephalitis. We included the SF-36 in the postal survey, which is a questionnaire asking about quality of life. The normal score in the healthy UK population is 50. For the SF-36 Physical Component Score, which looks at physical functioning to do with quality of life, respondents scored an average of 35. For the SF-36 Mental Component Score, which looks at emotional well-being, respondents scored an average of 40. Therefore, post-encephalitic respondents' scores were much lower than 50, indicating that their quality of life was poorer than for the rest of the UK population. These results were also worse than some studies into other forms of acquired brain injury.

## CHRONIC AND CENTRAL PAIN

- 420 people (59%) had chronic and/or central pain due to encephalitis. Only 9% of these 420 had been to a pain management clinic.
- People most often reported pains in the head, legs and hands.
- 236 people had head pain up to 8 years after encephalitis. (33% of everyone who filled in the survey.)
- When we interviewed service providers, they said that chronic headache due to acquired brain injury was common and could be difficult to treat.
- Chronic pain was linked to a poorer quality of life.
- People reported central pain (altered sensitivity) after encephalitis. (For example, 52% of the 420 reported feeling pain in response to a trigger which should not normally cause it.)

## SUMMARY OF KEY FINDINGS

- Post-encephalitic problems may persist for several years after the illness.
- People can have chronic pain due to encephalitis, particularly chronic headache.
- Central pain (altered sensitivity) can result from encephalitis.

# Talking to people who have had encephalitis

We interviewed twenty three people who had had encephalitis; fourteen women and nine men. Interviewees talked about a range of different after effects they were experiencing because of the illness. These included fatigue, restricted mobility, memory problems, difficulty making decisions and sensory overload. Sensory overload means that individuals cannot 'filter' sensory input (such as the noise and people in busy supermarkets), but instead become overwhelmed by it. When their fatigue was severe, individuals also talked about getting 'burn-out'. Although everyone talked about different after effects of encephalitis, pain and fatigue were often discussed.

## DESCRIBING BRAIN INJURY, DESCRIBING CHRONIC PAIN

To understand that an illness can cause acquired brain injury is difficult. The problems people can experience in the aftermath of encephalitis cannot be thought of as a chronic illness. Therefore, individuals may have difficulty finding a language to describe ongoing, post-encephalitic after effects. Problems resulting from encephalitis may persist long after the illness itself.

We wanted to speak to people who might have chronic (and central) pain because of encephalitis. Head pain was often talked about as a constant 'background' pain which at times could 'break through' or worsen. Examples of descriptions of central pain are included in the box below. Chronic and especially central pain can be difficult for people to describe, meaning pain can be difficult to discuss with healthcare professionals: pain may be overlooked or missed completely.

...if I've not done a lot, I can just have the muzziness without the headache. But as soon as I've done anything, it's there in the background.

**Mary, aged 53, four years since the illness**

## DISCUSSING HEAD PAIN

...my life's ruled by it basically, so everybody else is living by what I do, so their lives are ruled by my headaches as well. So if I'm crabby one morning, they'll know to leave me alone...It's consuming. It totally consumes you ..everything...My pain is just constant and it's not as painful as when I first was diagnosed with the encephalitis. It borders on a 10 but it never goes over a 10. A 10 is pretty intolerable as far as I'm concerned, it's really bad. On an average day, it will be about a 7 to 8.

**John, aged 36, four years since the illness**

## INTERVIEWEES' DESCRIPTIONS OF CENTRAL PAIN

- increased/decreased sensitivity to heat/cold
- sensitivity to shower water pressure
- "maggots in my head"
- "like I've got a log tied to my leg"
- "nerve pain like walking on cotton wool"
- sensitivity to having hair brushed
- "burning head pain"



- "a very heavy pins and needles"
- "just like dry rot"
- "leg aches like toothache"
- "like bedsores"
- "having your skin ripped off, being beaten with a baseball bat & then being put in a vat of vinegar"

## GETTING INFORMATION: MANAGING PROBLEMS

For some people, getting a diagnosis of encephalitis was difficult. Sometimes, a delayed or psychiatric misdiagnosis had been given. Individuals could not make sense of a psychiatric misdiagnosis as it did not fit with the experience of their illness. (Neuropsychiatric problems can result from but not cause encephalitis). There was a lot of variability in post-encephalitic after effects in terms of what and how severe these were. It also varied from day to day as to how well people could cope with such difficulties. On some days, people could manage the after effects of encephalitis but on other days it was more difficult. Individuals and their families were often good at developing their own coping strategies but wanted guidance and support from health professionals as to the kinds of strategies they should be implementing. Individuals and families suggested managing problems alone because of variable support from services, lack of assessment, and a 'gap' between acute and follow-up care.

## RECONCILING LOSS

Many individuals (and their family members) discussed the impact of post-encephalitic after effects on their lives in terms of reconciling loss. Several interviewees had lost previous skills and activities, changed their jobs or given up work completely. Loss of self-confidence was apparent and this was sometimes related to a loss of work identity. Individuals' social relationships and roles within the family were also altered.

## FINANCIAL CONSEQUENCES

There was often a reduction in family income due to individuals' losing or changing their jobs. Interviewees who had applied for Disability Living Allowance suggested that welfare benefits agencies did not understand the complexities and implications of acquired brain injury, particularly cognitive impairments.

## SUMMARY OF KEY FINDINGS

- Difficulty describing chronic and central pain
- Reconciling loss and altered relationships
- Managing the after effects of encephalitis in isolation from statutory services
- Misunderstanding of acquired brain injury by welfare benefits agencies

## Talking to family members

Well, I've often used the analogy that [on] (date of husband's illness) at just after 3 o' clock in the afternoon probably has had the same impact on me and the family unit as somebody that undergoes a bomb blast, an earthquake, a tsunami. It hits without warning and the devastation and the consequences, the fallout that comes from it can be never ending. And because nobody warns you, it's just basically survival tactics you're using initially on a day to day basis and to make sense of it. But somewhere along the line you have got to pick the pieces up and rebuild and it won't be the same as it was before.

**Philip's wife: 5 ½ years after the illness**

We spoke to eighteen family members of individuals who had had encephalitis and who had nominated them to take part. Most interviewees were the husbands or wives of those with a post-encephalitic acquired brain injury, some of whom saw themselves as carers for their relatives. Others did not see themselves in that role.

### THE FAMILY AND FAMILY RELATIONSHIPS

Family member interviews suggested a number of ways in which encephalitis and its consequences had affected the family and family relationships. For example, interviewees described having to take on more domestic tasks within the family and responsibility for the family finances. More generally, family members felt they had assumed overall responsibility for another person.



Family members talked about observing their relatives' loss of self-confidence because of encephalitis, or them now being very different people. Several reported that coming to terms with their relatives' altered personalities was particularly difficult. Reconciling loss was evident from both the interviews with family members and from those who had had the illness. Some family members even suggested having to reconcile 'grief' for the person they had lost whilst at the same time learning to live with the person who had survived the illness.

### FAMILY MEMBERS AS CARERS

Family members were often reluctant to see themselves as 'carers' and to think about their own situation and needs. In fact, they performed a number of different care and support roles such as personal care and prompting their relatives in completing everyday tasks. A few interviewees did describe themselves as carers; for example, being 'carer and patient' rather than husband and wife. However, for the most part, care-giving was seen as a normal aspect of family relationships. In this way, family members did not view their own needs as separate from those of their relatives.

### GETTING SUPPORT FROM HEALTH AND SOCIAL CARE PROFESSIONALS

Family member accounts often suggested that getting health and social care support for their relatives was an ongoing, difficult process. As a result, family members discussed taking on responsibility themselves for their relatives' rehabilitation after encephalitis but wanting expert information and guidance from health professionals on rehabilitation strategies. Both family member and individual interviewee accounts suggested little or no input from social care agencies, except with regard to the family's struggle in securing welfare benefits.

In general, information and service support for individuals and their carers was reported as variable. Family members did not report health and social care professionals as focusing on their separate needs as carers; for example, needing to work through their sense of loss due to a partner's encephalitis. Importantly, because care-giving within the family was viewed as normal, family members might be used as 'resources' or 'fellow workers' by health and social care agencies rather than being offered help themselves.

If you know what the worst can be, you hope for something in the middle. But at least you're prepared for whatever happens. Whereas now, we're just sort of fumbling along in the dark...it just seemed as if you're ill, you're in hospital, you're discharged. Cheerio!

**Jenny's husband, 14 years since the illness**

### SUMMARY OF KEY FINDINGS

- Reconciling loss due to encephalitis whilst rebuilding family life and relationships
- Care-giving as a normal aspect of family relationships
- Variation in service support for individuals and their families
- Family members' needs not addressed separately from those of their brain-injured relatives
- Family members providing care and rehabilitation rather than health and social care professionals

## Talking to service providers

I think it's absolutely haphazard and pot luck whether they get through to the right people or not. And that's partly if they've got the relatives asking the right questions or making a fuss. It's partly the medical people that they've seen first, if they're knowledgeable about rehab. But I'm sure many, many, many of them never get to see a neuropsychologist or get support that they need or that they could have. I don't think it's a good situation in general.

**Clinical Psychologist**

The idea that everybody with a serious brain injury or for that matter any serious long-term condition should have a main person in the community that they can contact as the first point of call for a problem is a joke really. Unfortunately.

**Clinical Consultant in Rehabilitation Medicine,  
discussing the NSF for Long-Term (Neurological) Conditions**

We carried out telephone interviews with fifteen service practitioners from the fields of acquired brain injury and pain management. These practitioners included neurologists, psychologists, occupational therapists, nurses, social workers and experts in chronic and central pain. (No one from primary care agreed to be interviewed).

### ENCEPHALITIS: DIAGNOSIS AND AFTER EFFECTS

Service provider interviewees suggested that diagnosing encephalitis in the first place can be difficult, especially when cases of the illness are 'mild'. Therefore, a delayed or psychiatric misdiagnosis is possible which can mean a delay in treatment and the risk of worse consequences. Several of the individual interviewees who had had encephalitis had initially been given a psychiatric misdiagnosis which of course did not 'fit' with their experience of the illness and its after effects.

Service practitioners talked about a number of different after effects of the illness but described cognitive impairment, personality and behaviour change as the main problems they had come across within their services. Interviewees' accounts of 'cognitive fatigue' were very much like individual interviewees' descriptions of 'sensory overload'.

### CHRONIC AND CENTRAL PAIN

Service providers supported the idea that chronic headache can be a common consequence of acquired brain injury and that such head pain can be difficult to treat. Interviewees also agreed that central (neuropathic) pain may be an after effect of encephalitis. Both chronic and central pain were seen as difficult for people to describe. Central pain in particular may be difficult for individuals to make sense of and articulate.

It's not all uncommon with neuropathic pain for people to find it very difficult to describe their symptoms...very, very, very commonly with neuropathic pain, the description of the pain is weird. Some patients feel embarrassed to say what it feels like. And that may be a very good reason why. It's a bit like a distortion in your hi-fi system...They're often made to feel it's their fault. Some of them feel guilty because they can't explain it, because there's no easy answer, because there's nothing to see. And sometimes they perhaps just give up in despair because nobody really understands what they're talking about.

**Consultant in Chronic Pain Management and Anaesthesia**

### EVALUATING SERVICE DELIVERY

Service practitioners saw managing issues of loss after acquired brain injury as central to their practice for individuals and family carers. Interviewees' accounts suggested some focus on family members as clients in their own right. However a lack of resources meant that service delivery for carers in particular was restricted. In a similar way, it was not possible to put all the requirements of the NSF for Long-Term Neurological Conditions into practice.

Practitioners themselves saw service delivery in general as variable with just 'pockets' of good services. They also suggested that physical problems after encephalitis might be emphasised in service delivery rather than emotional and other difficulties after the illness. Certainly they identified those with cognitive impairments ("the walking wounded") as clients whose problems may be missed. Cognitive rehabilitation was reported as a service which interviewees felt may not be included in what people thought of as 'rehabilitation'. Therefore interviewees emphasised the role of cognitive rehabilitation and neuropsychology after acquired brain injury.

#### SUMMARY OF KEY FINDINGS

- Variability in service provision and a 'gap' between care during the illness and follow-up support
- Lack of resources for putting the NSF for Long-Term Neurological Conditions into practice
- Poorer care for those with cognitive impairments ("the walking wounded")
- Needing to include cognitive rehabilitation and neuropsychology in thinking about 'rehabilitation'

## Key Summary

- It may be difficult for individuals to make sense of the fact that an illness can cause acquired brain injury.
- Describing the after effects of encephalitis in the longer term is complex, especially as problems may persist long after the illness itself.
- Chronic and central pain can be difficult to describe to others, so that pain may be missed by healthcare professionals.
- Chronic headache is common after acquired brain injury and can also occur due to encephalitis.
- Those who have chronic and/or central pain after the illness would benefit from access to pain management services.
- People's quality of life after encephalitis was worse than for the healthy UK population and may be worse than after other forms of acquired brain injury. (Some people reported few problems and a near 'normal' quality of life.)
- Individuals and families need to reconcile a sense of loss after encephalitis, particularly concerning the individual's altered personality.
- Service support after acquired brain injury is variable, so that families may experience a 'gap' between care during the illness and follow up support afterwards.
- Family members are depended on to provide care and rehabilitation for their relatives.
- Families may get little input or support from social care agencies.
- Welfare benefits agencies may not understand the complexities and implications of cognitive impairment in acquired brain injury, e.g. in claims for Disability Living Allowance.
- Those with cognitive impairments (the 'walking wounded') may get poor service provision after the illness, since their needs may be missed.
- Cognitive rehabilitation and neuropsychology may be underrepresented as key aspects of service provision in acquired brain injury.
- Family members saw care-giving as a normal aspect of family relationships. They did not see themselves as 'carers'.
- Family members' needs were not addressed separately from those of their brain-injured relatives.
- The Encephalitis Society needs to engage with individuals and families from diverse ethnic communities.

### CONTACTS FOR SUPPORT AND ADVICE

#### ENCEPHALITIS

The Encephalitis Society  
7b Saville Street, Malton  
North Yorkshire, YO17 7LL, UK  
Website: [www.encephalitis.info](http://www.encephalitis.info)  
Tel: 01653 699599

#### CHRONIC PAIN

Action on Pain  
20 Necton Road, Little Dunham  
Norfolk, PE32 2DN, UK  
Website: [www.action-on-pain.co.uk](http://www.action-on-pain.co.uk)  
Tel: 0845 6031593

#### CENTRAL (NEUROPATHIC) PAIN

The Neuropathy Trust  
P O Box 26, Nantwich  
Cheshire, CW5 5FP, UK  
Website: [www.neurocentre.com](http://www.neurocentre.com)  
Tel: 01270 611828

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