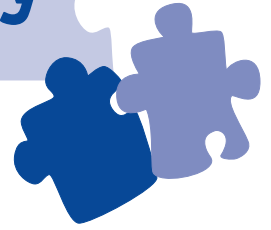


The Encephalitis Society

action for support, awareness, and research



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Encephalitis Patient Experiences of Neurological Services in the UK

By Ava Easton



1. Background

A survey by the Neurological Alliance¹ estimated that 10 million people in the UK have a neurological disorder and that, every year, 600,000 new cases are diagnosed. However, according to a report by the Association of British Neurologists (ABN)², the provision of neurology services for these people is far from adequate. In 2003, there were 352 fulltime consultant neurologists, the equivalent of one per 177,000 people. Though this represents an improvement on the 1997 figure of one per 200,000, it still falls way behind other European countries³. The ABN estimated that 1400 neurologists are needed to provide a round-the-clock service for all admissions, or half that number for an office-hours service only.

A second ABN report⁴ suggested a core list of appropriate standards of care for patients with acute neurological disease. These include:

- Easy and timely access to outpatient neurological services, regardless of geography
- Care from consultant neurologists with teams of appropriately trained staff – for all acutely ill inpatients with neurological problems
- Significantly reduced waiting times for non-urgent neurological investigations
- A multi-disciplinary approach, crossing the boundaries of primary, secondary, tertiary and social care
- Interdisciplinary working with elderly care physicians, nurse specialists and professions allied to medicine
- Services close to home but also allowing easy access to specialist expertise and equipment
- Tertiary centres
- Increases in staffing to achieve these goals

2. Introduction

Encephalitis is inflammation of the brain tissue. It can occur at any age in any part of the world and is caused either by infection, usually viral, or by autoimmune diseases. Many patients are left with an acquired brain injury, the nature and degree of which can vary.

The Encephalitis Support Group is a national organisation which was established in 1994, in North Yorkshire, England, with the aim of improving the quality of life of all people affected directly and indirectly by encephalitis. The organisation changed its name in 2003 to the Encephalitis Society, in order to better reflect its widening range of services. Though still UK based, the Society now has many international links.

The Society regularly conducts surveys of its members to gain a better picture of patient and family experiences of the condition. This paper summarises the findings of one such survey, carried out between September 2003 and May 2004.

3. Aims and Methodology

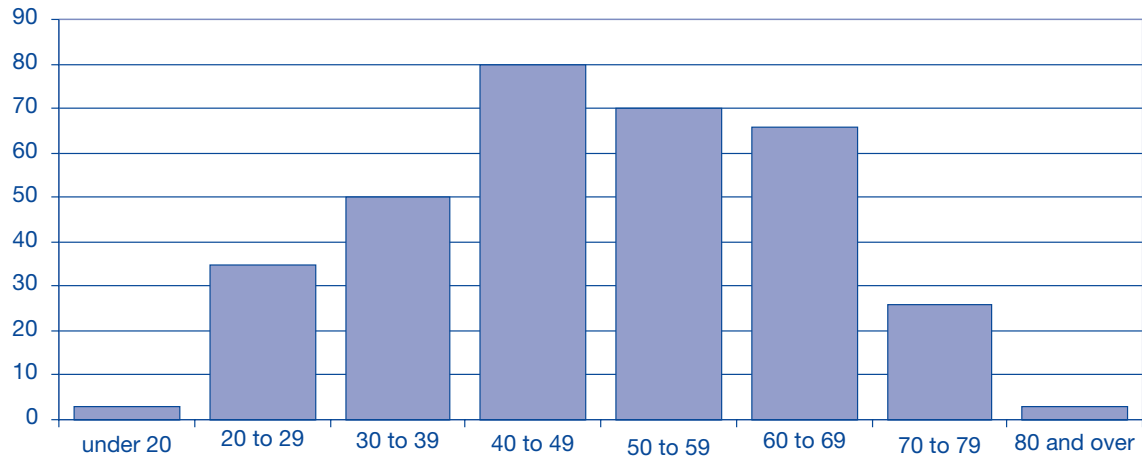
The purpose of the survey was to compare the experiences of the Society's members in the light of the standards of care recommended by the ABN. Questionnaires were distributed to 1188 members and recent contacts of the Encephalitis Society. 339 completed questionnaires were returned, equating to a response rate of 28.5%.

Please note that, unless stated, all percentages quoted below relate to the respondents to a specific question i.e. they are not percentages of the whole sample.

4. Findings

4.1 The respondents

Gender: 56% of the respondents were female, and the remaining 44% male. The graph below shows the age distribution of the respondents.



Year of illness: over three quarters (77%) of the respondents had developed encephalitis since 1995, and over half of these since 2000. However, a small number of the respondents had had the condition since the 1960s and '70s.

1960s	1970s	1980s	1990-1994	1995-1999	2000-2004
4	6	27	42	122	139
1.2%	1.8%	8.0%	12.5%	36.3%	40.2%

Comment: It is acknowledged that those respondents who have had the condition since the 1960's or '70's may have had very different experiences of hospital care, and that their comments may therefore be less relevant than those of the respondents who developed encephalitis quite recently. It is also unlikely that their memories will be as accurate.

4.2 Care in hospital

Just over a half (54%) of those responding said that, when they were first diagnosed, their hospital treatment had been under the care of a neurologist (37% said it had not been, 9% did not know).

Fewer than a half (45%) of those responding said they had been seen by a neurologist within 24 hours (22% had been seen on the second or third day; 19% had been seen between 4 days and one week, and 14% had been seen later than one week afterwards). Only 58% (194) of the respondents answered this question.

121 respondents (36% of all the respondents to the survey) said they were under the care of a doctor other than a neurologist. The largest group (47% of these) said their care had been overseen by a 'general' doctor; it is not clear what this might mean, though it does indicate that no specialist was involved. Smaller groups were overseen by other types of doctors as shown below, though again it is sometimes unclear exactly what these descriptions exactly imply.

'General'	Cardiologist	GP	House Doctor	Infectious Disease Specialist	Geriatrician	Other (13 categories)
57	11	9	7	6	6	25
47%	9%	7%	6%	5%	5%	21%

Only a minority of those responding (39%) said they had been cared for on a neurology ward (56% said they had not been, 5% did not know).

23% of those responding said they had been transferred to a neurology ward immediately or within 24 hours of admission, 6% had been transferred on the second or third day, and 11% between four days and one week. A further 10% said they had been transferred over a week after admission. However, one half (50%) had never been transferred to a neurology ward.

Comment: Many of the respondents had to wait to see a neurologist, or never received specialist care at all. Only a minority were cared for on a neurology ward.

4.3 Diagnosis

Almost two-thirds (65%) of the respondents said they had been given a definite diagnosis (30% said they had not been, 5% did not know). Of these, the large majority (91%) had been given an encephalitis-related diagnosis, although 9% had been given other diagnoses, such as brain tumour, dementia, epilepsy, multiple sclerosis, and stroke. This list seems to include a mix of symptoms, predisposing factors and, presumably, misdiagnoses.

Comment: The range of terms used was huge and is likely to have caused confusion not only to the patients but also to other practitioners involved in their care.

Encephalitis	Specific sort of encephalitis (e.g. Hashimoto's)	Viral encephalitis	Encephalitis with accompanying diagnosis (e.g. meningitis)	Encephalomyelitis incl. ADEM – Acute Disseminated Encephalomyelitis	Herpes simplex	23 other diagnoses
60	22	72	15	16	84	27
20%	7%	24%	5%	5%	28%	9%

Three quarters (76%) of those responding said they had been given a diagnosis before leaving hospital (18% said they had not been, 6% did not know).

Comment: Almost one in five patients left hospital without a diagnosis.

4.4 Information and advice

Fewer than one third (31%) of those responding said they had been given information or advice about encephalitis (two thirds - 65% - said they had not been, 4% did not know).

Only one quarter (25%) of those responding said they had been given information or advice about the consequences of encephalitis (71% said they had not been, 4% did not know).

Only 10% of those responding said they had been given information or advice about the Encephalitis Support Group (now the Encephalitis Society). 86% said they had not been, and 4%

did not know. However, it is acknowledged that, as the Group has only been running since 1994, 24% of the respondents could not have been told about it at the time they developed encephalitis as it was not in existence.

Only 7% of those responding said they had been given information or advice about any other support organisations (87% said they had not been, 6% did not know).

Comment: many patients did not receive the information and advice they need.

4.5 Discharge from hospital

Fewer than one quarter (23%) of those responding said they had a discharge-planning meeting before they were discharged (over two thirds - 68% - said they had not, 9% did not know)

Time spent in hospital before discharge ranged from one day to 2½ years, although only 4% were in hospital for over 6 months, and only 1% for over a year. The average (mean) hospital stay was 54 days, though the median stay was 24 days, and the most common duration in hospital was two to four weeks.

Less than one week	One week to a fortnight	A fortnight to a month	One month to two months	Two months to three months	Three months to six months	Six months to one year	More than one year
29	65	89	66	27	28	10	4
9%	20%	28%	21%	8%	9%	3%	1%

Almost all (96%) of those responding said they were still experiencing complications when they were discharged. Over a half of those responding said they were experiencing memory loss. Around a quarter were experiencing extreme fatigue and/or headaches. Weakness and lack of muscle strength, speech difficulties, balance problems and confusion were also all relatively common.

Memory loss	Extreme fatigue	Headaches	Weakness, lack of muscle strength	Speech difficulties	Balance problems	Confusion	Walking problems	Visual problems	Concentration
162	83	76	48	45	44	40	36	30	28
50%	25%	23%	15%	14%	13%	12%	11%	9%	9%

64% of those responding said they had received a follow-up outpatient appointment after discharge from hospital with a neurologist/ neuropsychiatrist/ neuropsychologist (one third - 33% - said they had not, 3% did not know). Of the 164 who specified which kind of specialist they had had an appointment with, 74% said it was a neurologist, 21% said it was a neuropsychologist, and 5% said it was a neuropsychiatrist.

Comment: although the majority of those leaving hospital did have access to specialist treatment/ advice afterwards, one in three who had complications when they left hospital were unable to access such support.

64% of those responding said that the hospital had communicated their diagnosis to their GP by the time of their first GP appointment after discharge (20% said it had not, 16% did not know).

4.6 Longer term effects of the condition

Almost all (95%) of those responding reported various aspects of their lives that had been most affected by encephalitis. In almost two-thirds (64%) of cases, ability to work had been affected. Nearly half reported effects on their driving, and over 40% reported effects on their relationships and on living independently. Those aspects most frequently reported are shown in the table below:

Ability to work	Driving	Relationships	Living independently	Needing carers	Education	Memory problems
208	152	136	134	94	55	34
64%	47%	42%	41%	29%	17%	10%

5. Conclusions and Recommendations

The survey provides strong evidence that the ABN minimum standards are not being attained in many, or even the majority of, cases. While it is recognised that the survey is based on self-reporting, and that by their nature, many members and contacts will have cognitive impairments, the survey does represent the ‘patient’s viewpoint’ and as such has a valuable contribution to make.

In summary, the survey found that:

- Many of the respondents did not have access to the care of a neurologist – or even to any kind of specialist
- Of those who did, fewer than a half saw the neurologist within 24 hours, and over one third had to wait more than three days
- At least half of the respondents were not cared for on a neurology ward. Of those who were, fewer than one quarter were transferred within 24 hours of admission
- The respondents were given a wide range of diagnoses (some of these were in fact symptoms, predisposing factors or misdiagnoses) which could have been very confusing for them
- Fewer than one third of respondents had received information and advice about the condition and its consequences, and even smaller numbers had been told about other sources of support
- Fewer than one quarter had a discharge-planning meeting, and one third did not receive a follow-up appointment with a neurology specialist - even though almost all were experiencing complications when they left hospital
- Almost all the respondents were still experiencing long-term effects on their lives because of encephalitis at the time of the survey.

These findings are particularly pertinent given the recent publication of the National Service Framework (NSF) for Long-term Conditions⁵. Quality Requirement 2 of the NSF states that '*people suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment...*', while Quality Requirement 3 is that '*people needing hospital admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.*'

The main recommendation is that The Society continues to support the recommended minimum standards as set out by the Association of British Neurologists, and the implementation of the Quality Requirements as set out in the new NSF.

Acknowledgments

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Correspondence should be sent to:

Ava Easton,

The Encephalitis Society, 7b Saville Street, Malton, North Yorkshire, England YO17 7LL.

Tel: 01653 692583 or email: ava@encephalitis.info

(Endnotes)

¹ http://www.neural.org.uk/docs/neuro_numbers/NEURONUM.PDF

² *Acute Neurological Emergencies in Adults* (2002) ABN

³ *The Lancet Neurology* 2002; **1** : 4

⁴ *UK Neurology – the next ten years. Putting the patient first* (2003) ABN

⁵ *The National Service Framework for Long-term Conditions* (March 2005) London: Department of Health



Encephalitis Society

The Encephalitis Resource Centre, 7B Saville Street, Malton, YO17 7LL UK
Administration. +44 (0) 1653 692 583 Fax: +44 (0) 1653 604 369
Email: mail@encephalitis.info Website: www.encephalitis.info

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