

Epilepsy care: a need for change

THERE is a current surge of interest in epilepsy. This is due in part to the arrival of new and effective anti-epileptic drugs,¹ some with fewer side effects, and improved prospects for surgical treatment enhanced by advances in imaging technology.² However, for patients with epilepsy to benefit from these developments, adequate services are necessary both in general practice and in specialist centres. General practice can only provide a high standard of epilepsy care within a structure offering good specialist services, and unfortunately, these are not generally available.^{3,4}

Surveys and audits of epilepsy care in general practice have identified deficiencies in care, including poor seizure control, inadequate follow up, ineffective use of drugs and lack of advice and information for patients.⁵⁻¹⁰ Misdiagnosis is a serious problem, involving 20% of patients referred to special centres with a diagnosis of epilepsy; partial seizures are missed, and syncope is frequently misdiagnosed as epilepsy.¹¹ Nevertheless, the potential to improve care in terms of seizure control and reduced drug side effects has been shown in hospital studies^{12,13} and in general practice.^{14,15} The former show that 76-88% of new patients can be controlled on one drug, and that patients with chronic epilepsy benefit from optimum drug therapy involving reduction of polypharmacy.

There has been no shortage of recommendations for services in a succession of government reports over the past 40 years.¹⁶⁻¹⁸ The most comprehensive, published in 1986, reviewed and added to earlier recommendations.³ It listed among criticisms of hospital services: long delays in obtaining appointments, inadequate or irregular follow up and supervision, and lack of continuity of care, attention to social requirements and counselling. Among its recommendations was a requirement for district clinics based on district hospitals, including the need for a member of staff, perhaps a health visitor, to foster links with other health service facilities and other organizations. General practitioners were to be responsible for the initial recognition and referral of patients with suspected epilepsy. District hospitals were to manage diagnosis and investigation, returning patients to general practitioners for follow up. Patients whose seizures were difficult to control or required particular expertise were to be referred to tertiary centres. The response to this recommendation has been disappointing, possibly because of a low priority given to epilepsy by health service planners and the medical profession, but almost certainly because of the scarcity of specialist neurologists in the United Kingdom, especially with an interest in epilepsy.¹⁹ There are only 21 clinics in the UK specifically for epilepsy and seven special centres. The latter are used where problems of diagnosis and treatment cannot be resolved in outpatient services and short term admission is required for monitoring and evaluation. In comparison the Netherlands has 10 times the number of neurologists for an equivalent population.¹⁹

The latest contribution to the debate on services is an 'epilepsy needs document', produced by a group of clinicians involved in epilepsy services.⁴ This document, which has the approval of the Joint Epilepsy Council representing all major patient organizations and care providers, describes services for epilepsy in the UK as 'poor in quality, fragmentary and poorly organized'. It sets out to define and quantify the scope, content, and standards of medical, paramedical, and nursing services required in primary care and from specialist centres, with the intention of influencing purchasers and providers. This report is encouraging, not just because of what it says, but because it is a product of

increasing interest in epilepsy among specialists and general practitioners.

Epilepsy carries unique burdens and consequences for patients and families. Apart from the experience of seizures there is the effect of felt or actual stigma, for some learning disability, and certainly for many, considerable problems with social life and employment. There is no shortage of evidence about what patients want or lack in the struggle to cope. Jones, in her illuminating trainee audit in 1980, observed that 'patients were not being counselled sufficiently on the problems of epilepsy, and over half the patients considered themselves to be unacceptable to the rest of society'.⁵ A British Epilepsy Association survey found that respondents 'would like an increase in provision of services and in the information conveyed', and expressed concern about 'the extent of management and of experimentation left to the patient and care giver'.²⁰ Dawkins and colleagues, in a general practice study, found that patients knew little more than the general population about epilepsy.²¹ Of patients attending a Belfast hospital clinic, 90% wanted more information about the disease, three quarters felt they had not been given enough information about drug side effects, and over 60% wanted someone to talk to other than the consultant, with a preference for a specialist nurse.²² A report of a pilot study, combined with an audit of primary care involving 40 practices, is equally revealing.²³ Although two thirds of respondents saw their general practitioner as primarily responsible for their care, only 60% felt it was easy to talk to the general practitioner about their epilepsy, and around a third of adult patients and a quarter of parents considered that they had not been given enough information. The role of personal continuity of care in allowing discussion of personally important aspects of epilepsy is explored in a paper in this issue of the *Journal*.²⁴ Ensuring that patients see the same general practitioner emerges as being less important than improving doctors' communication skills; doctors should pay specific attention to the psychosocial aspects of epilepsy as well as to seizure control.

The catalogue of apparent deficiencies in care revealed by audit should not obscure the positive consequences of audit. It is not unreasonable to speculate that practices involved in audit go on to improve services. Audits in a Doncaster practice^{14,15} acted as a spur to the development of a district service²⁵ incorporating a specialist clinic, guidelines for shared care, and a community based specialist liaison nursing service. Hall and Ross, after reporting on audit⁹ in their practice, went on to develop audit material for general use in collaboration with the British Epilepsy Association.

Also on the positive side is the contribution of British general practice to epilepsy research, particularly into its epidemiology and natural history. This has been aided by the structure of primary care, which allows full case identification and follow up even when patients move. The pioneering work of Crombie and colleagues²⁶ and Pond and colleagues,²⁷ has been succeeded more recently by the national general practice study of epilepsy,²⁸ which is a large prospective study of newly diagnosed epilepsy, which started in 1984 and involves 275 general practitioners and 1195 patients. This study has already added to our understanding of prognosis,²⁹ the frequency of seizure types,³⁰ the relevance of syndromic classification,³¹ and the social and psychological effects of a recent diagnosis of epilepsy.³² Awaiting publication are reports on the mortality associated with having epilepsy, and the cost of epilepsy which includes costs to

patients and socioeconomic costs including health services.

The evidence that there is a problem in epilepsy care is overwhelming, as is the evidence that it is possible to do something about it. However, although a diagnosis of epilepsy can be straightforward, often it is not, and special skills and experience are required for diagnosis, to manage difficult problems, and to help people cope with the condition. General practitioners, even those with a special interest in epilepsy, cannot compensate for inadequacies in specialist services. Although most practitioners feel that chronic epilepsy care is their responsibility, a minority regard it as a job for specialists, and of Doncaster practitioners replying to a survey two thirds acknowledged difficulties in diagnosis, counselling and in the use of drugs.²⁵ Since an individual practitioner will only have 10–15 patients with chronic epilepsy (two or three of these patients with difficult epilepsy) and see only one or two possible new cases each year this is perhaps not surprising.

Progress is required on two fronts. First, the case for improved services must be pursued, particularly for clinics at district level with appropriate tertiary services available. Given the clear need for information and counselling, specialist nurses, who have been shown to be effective in this regard,²⁵ should feature in such a service. Fundholding general practitioners are in a position to influence the development of services, as are practitioners advising purchasing health authorities. Next, the contribution of general practice requires definition, and a development of the epilepsy needs document⁴ for primary care, involving the Royal College of General Practitioners is in preparation. This document will be concerned with educational needs and the interface with secondary care but will not attempt to provide core information. Current sources of core knowledge include the RCGP epilepsy protocol,³³ and various guidelines produced in Cumbria,³⁴ Ireland³⁵ and Doncaster.²⁵ These guidelines set out to inform clinical management and decision making within a locally agreed framework of shared care.

A universally comprehensive service for epilepsy may be a long way off, but we must make a start, while pressing for adequate specialist services. Manipulating antiepileptic medication can be difficult but can be managed by a general practitioner with expertise. But most of us should be able learn to distinguish faints from fits, which depends mainly on obtaining a witnessed account, itself the basis for an accurate diagnosis. To find time to provide patients with information, or arrange for others, for example the British Epilepsy Association to do so, is perhaps our best gift to patients. Being helped to cope is as important as controlling seizures.

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