

# Structured management in primary care of patients with epilepsy

HOW should primary care teams manage patients with chronic epilepsy? Epilepsy care has been identified by the government as a key area for development: May 1995 saw 'national epilepsy week' supported by the government, and a number of new research and education initiatives in epilepsy care have been funded by the Department of Health. Placing the spotlight on patients with epilepsy is timely but it raises issues of profound importance for primary care's future management of epilepsy and other chronic illnesses.

Epilepsy is undertreated. There are highly effective drug treatments for epilepsy but many patients still receive inadequate or inappropriate therapy, partly owing to a lack of planned care and follow up.<sup>1</sup> The National Health Service is primarily designed to respond to patient demand; it has difficulty anticipating needs, especially in chronic illnesses such as epilepsy. Patients with epilepsy in primary care are treated if they attend their general practitioner or practice nurse but are commonly not followed up if they fail to attend.

It is only in the last decade that health promotion, disease prevention (with the exception of communicable diseases) and systematic and structured approaches to chronic disease management have been incorporated into the organization of health services. Nonetheless, the effort required to achieve structured management of, for example, asthma, diabetes and hypertension in primary care has been considerable. Proactive management of these diseases finally became established throughout NHS primary care in 1991 when it became a prerequisite for general practitioners to earn their target income. If the systematic management of epilepsy is now to be undertaken, will it be bolted on to existing systems for asthma, diabetes and hypertension management? Or should the way in which patients with epilepsy are managed in primary care be considered afresh, learning from the experience gained in treating more common chronic illnesses?

In this issue of the *Journal*, Thapar reviews the management of epilepsy in the NHS.<sup>2</sup> He notes that patients with epilepsy are seldom managed in a systematic or structured way. He highlights doctors' poor overall control of the condition, their inappropriate prescribing and their poor communication with patients with epilepsy; he also draws attention to patients' unsatisfactory understanding of their condition. Also in this issue, Ridsdale and colleagues show that both general practitioners and patients hope for a frequency of review and a depth of communication during consultations that are not being achieved.<sup>3</sup> They conclude that new resources and new skills are needed.

Providing structured care for patients with epilepsy would lead to a small increase in clinical workload in most practices. An average practice of 6000 patients with three general practitioners is likely to have between 30 and 50 patients with active epilepsy (those who have had seizures in the last two years or are taking antiepileptic drugs).<sup>4,5</sup> If each patient was seen three times a year for his or her epilepsy, including an annual review, between 30 and 50 consultations would be required per general practitioner each year. However, such an analysis conceals the other resources required to run a service of structured management. Such a service will require clinical and administrative leadership, and a framework within which systematic care can be provided.

To provide structured care for patients with epilepsy, a practice should expect to operate a disease register, a prescription register and a recall system. Team members should be able to

work to an agreed protocol. The protocol should either be locally devised or be based on authoritative guidelines interpreted for local application.<sup>6-8</sup> Audit is likely to be essential if the service is to be dynamic and responsive to new research findings and changing prescribing patterns.<sup>9,10</sup> This system of care demands leadership and cohesive teamwork. It will draw on the time and energy of key team members who are likely to be working at full stretch already.<sup>11</sup> Many general practitioners have reached the limit of their tolerance of workload. If epilepsy care is added to existing systems the overall cost may well be met at the expense of the core work of primary care.

Some highly motivated doctors have made outstanding gains in epilepsy care.<sup>4,12,13</sup> The service they offer stands out in contrast to the average primary care service for patients with epilepsy.<sup>2</sup> How can the average practice improve its care provision? Both Thapar<sup>2</sup> and Ridsdale and colleagues<sup>3</sup> propose the introduction of an epilepsy nurse specialist whose role may include working between practices in a peripatetic fashion, offering effective liaison between practices and the local hospital neurology unit, and providing educational and technical support to practice nurses and other team members. Access to neurology services is essential in the management of patients with epilepsy who often require access to special skills in diagnosis and management. Using a specialist liaison nurse to bridge the gap between primary and secondary care has already been described by Taylor and colleagues and opens up a variety of creative opportunities.<sup>14</sup> Practices would have to identify how much administrative and clinical time is needed both to set up and manage the framework for structured care and to allow team members to participate in service review and decision making.

Primary care may be vulnerable now to the incorporation of epilepsy in health promotion targets, following on its success in structuring care for asthma, diabetes and hypertension. Failure to define the additional resources needed for management of patients with epilepsy will delay the infrastructure developments that epilepsy care requires. When it is clear what resources are needed to establish structured care for patients with epilepsy it will be easier to negotiate for additional funds or staffing for the management of such care. How epilepsy is tackled is likely to determine, in turn, the way in which primary care approaches its responsibility for chronic illness management as a whole.

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## GP 2000: a general practitioner for the new millennium

TYPICAL of the comments heard in the wake of the imposition of the 1990 contract for general practitioners was 'I just feel devalued'.<sup>1</sup> Many general practitioners were left with no clear sense of direction and a feeling that the doctor-patient relationship was rapidly being eroded by ill-thought-out policies of health promotion and extravagant patient expectations stimulated by an illusory patient's charter. The reorganization of the National Health Service, with its overemphasis on managerial prowess, data collection and paperwork, seems to be creating successive layers of chaos. Higher stress levels, together with rapidly escalating amounts of night work, are linked with evidence that general practitioners are retiring younger (Medical Practices Committee chairman's report, 1993), and some principals appear to have moved to non-clinical occupations. A worrying decline in applications for vocational training for general practice (NHS statistical bulletin, *Doctors in general practice 1979-91*) indicates that the specialty is not attracting its share of the best graduates although staff numbers and curriculum time allotted to vocational training have increased. However, times of turmoil are also times of opportunity: during his presidency of the RCGP the Prince of Wales wrote of 'the perfect time to look at the fundamental issues which affect the role of the general practitioner'.<sup>2</sup>

This month sees the publication of the latest report of the RCGP, *The nature of general medical practice*.<sup>3</sup> These reports are usually written by official working parties of the RCGP and carry the implication of support by the RCGP if not necessarily being statements of policy. They have influenced government as well as the profession. The latest report is produced by a working party led by Professor Nigel Stott and incorporates comments and suggestions from people with an interest in primary care based on general practice. A formative input to it was the document *Patient care and the general practitioner*, produced by the RCGP Welsh council and the Welsh General Medical Services Committee.<sup>4</sup>

Why do we need the new document? As Stott points out, clinical standards have always been the legitimate business of the RCGP.<sup>5</sup> Defining the role of the general practitioner in terms that can be audited and refashioned is a basic means of standard setting. The classic job description in *The future general practitioner*,<sup>6</sup> published in 1972, has had a major influence on training and the evolution of general practice, but since then emphasis has moved from individual practice to the primary care team,<sup>7</sup> with a wider professional responsibility to the community.<sup>8</sup> The new report will generate interest outside the United Kingdom because many countries face similar problems.<sup>9</sup>

*The nature of general medical practice* looks at the role of the general practitioner and aims to clarify the essential content of practice. The general practitioner is the diagnostician in primary care, and needs to practise an art as well as apply science: scientific medicine is only one part of patient care. The consultation should take account not only of the disease (the medical model) but also of the illness (the social model) and the hopes, fears, feelings and expectations of the patient.<sup>10</sup> Each of us has experienced illness, and Brody maintains that, as patients, we take comfort from attaching meaning to the experience.<sup>11</sup> By taking a narrow scientific approach to diagnosis general practitioners may reject something important to the patients — their 'stories of sickness'.<sup>12</sup> Macnaughton reminds us that the context in which patients live is closely related to the ways they react to illness.<sup>13</sup> Being alert to this is good doctoring.

Over recent decades the working environment of the average general practitioner has moved from the traditional lock-up surgery to the health centre or group practice premises. The care of patients with chronic diseases such as asthma or hypertension is returning to primary care. Emphasis on care in the community is increasing and there is talk of an NHS led by primary care.<sup>14</sup> The solo practitioner has had to adapt to lead a therapeutic team, but not without feelings of unease regarding the nature of the new primary care and the general practitioner's role within it. How can general practitioners be both effective clinicians and efficient delegators of clinical practice? How do general practitioners reconcile new contractual responsibilities with professional ethics? Can advocacy for the individual patient be reconciled with commissioning concern for the whole population in primary care?

Working in a team absorbs more time than traditional curing and caring: every addition to the team means that more of an individual's time is spent in formal and informal interaction and less is available for patient care. A person may find team working, team building and developing the skills of fundholding, purchasing or computer-aided communications satisfying but may resent the time that has to be spent in these activities if there is less time for contact with patients. Practising clinicians need protected time for critical appraisal of the literature, for continuing education, audit and discussion so that they can update their skills regularly. The public relies on this. Innovative clinical management is important in improving patient care but it should be patient centred and evidence based rather than driven by the political rhetoric of consumerism.