

Deaths from epilepsy: what next?

A RECENT national sentinel audit of epilepsy related deaths¹ suggests that there are shortcomings in the care of people with epilepsy in the United Kingdom. This audit, driven and managed by a charity, gained the attention both of the media (it was front page news in *The Times* and was on the BBC national news) and Chief Medical Officers in the UK. An action plan for England is promised this summer. Action has been long in coming. Despite the generally benign nature of epilepsy, sudden death from epilepsy has been known for over 130 years.² It is a global problem and carries a mortality risk worldwide, with an increased standard mortality rate (SMR) of between 2.0 and 5.4.³⁻⁷

How does this compare with other chronic conditions, such as diabetes or asthma? Studies of people with type 1 diabetes from the UK, Sweden, and New Zealand show an increased SMR of between 1.5 and 3.5 depending on sex and age, with young adults particularly at risk.⁸⁻⁹ The highest mortality rate for diabetes was seen in a study from the UK, and the authors suggested that some of these deaths were avoidable.¹⁰

The epilepsy audit reported on 812 deaths in the year from September 1999 to August 2000 in the UK. This number of deaths is in line with official statistic from 1995 of 951 epilepsy deaths: a rate about 4.5 times higher than for asthma deaths in that year.¹¹ The audit also reported on care of people who died through epilepsy. While an audit of cases of epilepsy death may not reflect care of those 70% of people with epilepsy who have well-controlled seizures, the bleak findings suggest deficiencies in care across the NHS, which we ignore at our peril. An examination of 439 post mortem records and 286 case notes found a lack of standardisation of record keeping in both pre- and post mortem care, and inaccurate certification data in 41% of cases. Interestingly, this may be an international problem and has been noted in studies of causative mortality of diabetes in Europe and the United States¹²⁻¹⁴ and of elderly asthma deaths in Scandinavia.¹⁵

There was a lack of management plans or structured review in 89% of the primary care sample, with 41% having no record of epilepsy monitoring in the two years before death. There was poor choice of medication in 18% of cases and 14% had recorded problems with adherence to drug regimes. There was little recorded contact with families after death (7%), sparse information provision concerning the risks of death (1%), and a breakdown in some professional lines of communication, both between hospital departments and between primary and secondary care.

To suggest that care is deficient presupposes an agreed optimal standard; such standards have already been proposed for general and specialist care, with more in the pipeline.¹⁶⁻¹⁸ Ideally, guidance should explicitly list the source and strength of evidence¹⁹ and should consider strategies for implementation.²⁰ The Scottish Intercollegiate Guidelines Network (www.sign.ac.uk) is updating guidelines based on evidence for adults with epilepsy and will include advice on diagnosis, investigations, management and treat-

ments, women and epilepsy, shared care, and adolescent issues. Guidelines are expected for England and Wales in spring 2004 and will consider clinical and economic issues, for both adult and childhood epilepsy. The National Institute of Clinical Excellence is due to publish an appraisal of epilepsy drugs in the autumn of next year.

However, there are examples of how care can be improved by reviewing and developing services.²¹⁻²⁴

A correct seizure diagnosis is crucial for initial epilepsy management and an epilepsy specialist is best at delivering this, but misdiagnosis occurs in up to 25% of cases.²⁵ A recent service audit from a tertiary centre suggests that more neurologists and paediatric neurologists are needed²⁶ but their conclusions can be questioned. Some neurologists have epilepsy expertise but others may be more experienced in other conditions. There are some physicians, paediatricians, and psychiatrists with an interest in epilepsy, and sometimes (particularly in the elderly) general practitioners diagnose and manage epilepsy without specialist help. Indeed, primary care may have much to offer people with epilepsy.²⁷

Once the diagnosis has been confirmed and treatment has been decided, continuing care can be delivered in either primary or secondary care with seizure control being the deciding factor. Patients need information about the condition, but in only 1% of case notes was it recorded that the risk of death had been discussed.

For many conditions, it has long been accepted practice for risk of death to be discussed, particularly in relation to alcohol and driving, ischaemic heart disease, neoplastic disease, asthma, and diabetes — but not, it seems, for people with epilepsy. Is it because the risk is thought so small as to be unimportant? Are patients and professionals unaware of the risks of epilepsy-related death? Is it that a discussion of risk of death would only add to the considerable burden of epilepsy? Or indeed, is it felt that a discussion of risk in the absence of advice on how to reduce that risk may be harmful?

All may play a part, but a study of bereaved families to be published this year will tell us clearly that patients should be told. We can tell people who are seizure-free that they are not at risk, but those who are young, who are within two years of diagnosis, who have generalised tonic-clonic seizures, seizures when asleep or unwitnessed, and who do not adhere to treatment, are particularly at risk.

By discussing the importance of regular medication and seizure control, and disseminating the information presented by this audit as part of a two-way process of communication²⁸ offered to the individual in a clear and balanced way, we may be able to help people with epilepsy reduce the risk of death.

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The general practitioner with a special interest: new opportunities or the end of the generalist practitioner?

THE NHS Plan has at its aim the modernisation of the NHS and the way doctors and nurses work.¹ For nurses, the Plan talks of developing 'new skills and new roles for nurses', which will 'shatter the old demarcations that have held back staff and slowed down care'. For general practitioners (GPs), the Plan also highlights the need to create new careers, in particular to create intermediate practitioners, stating that 'there will be a bigger role for GPs in shaping local services, as more become specialist GPs'. Both these initiatives, perhaps led by a shortage of specialists and increasing hospital waiting times, nevertheless are seen as the natural way forward by their respective Royal Colleges.² Certainly, with respect to GPs, the creation of these practitioners has been supported by the Royal College of General Practitioners (RCGP), which sees it as a means of promoting portfolio careers and diversification of GPs while, and most importantly, maintaining their generalist expertise and role.

To emphasise this later point, the RCGP prefers to use the term 'GPs with a special interest' (GPWsi) rather than others that have crept into current terminology, such as the 'intermediate practitioner', 'specialist GP' (as in the NHS Plan), 'consultant GP' or 'specialised-generalist'.

While the term GPWsi is new, the concept is not. Many doctors have been working in this capacity for a number of years, largely unrecognised except within their local area. A survey commissioned by the Department of Health suggested that at least 4000 GPs currently have a special interest, be that in clinical, managerial, academic or teaching spheres.³ There are examples of GPs who are informally regarded as 'the expert' within their own practice or immediate locality, and of others who lead services that do not have natural parallels in secondary care, such as primary care drug misuse^{4,5} and the care of socially excluded individuals.⁶ What has changed in recent times, however, is the political

will to develop new roles for GPs, and for Primary Care Trusts (PCTs) to formalise their relationship with these doctors and commission them to provide services outside the confines of their practice. Advertisements are already appearing in the medical press for 'GP consultants', expected to lead local clinical areas.⁷

So what are the benefits of extending the roles and responsibilities of GPs? Perhaps the biggest advantage is that the GPWsi can provide an intermediate tier of expertise and advice to their primary care colleagues and alternative avenues for referral and access to specialist investigations. Working as a GPWsi should increase job satisfaction, improve retention, and delay burnout for GPs. Increasing the numbers and range of clinicians able to provide specialist opinions should reduce waiting times and improve access for patients. GPs working in specialist areas bring their unique and in-depth knowledge of primary care to the respective specialist clinical area and are able to work across physical, psychological and social paradigms, and the ability to provide effective multidisciplinary working and service delivery for patients suffering from chronic relapsing conditions.

There are of course risks involved in extending the roles of GPs, not least of which is the further dilution of numbers of generalists to do the work left behind by the GPWsi and limit the amount of time they are able to devote to mainstream general practice work. This is one of the most forceful arguments used by some members of the profession in their contention that we should resist moves to see GPs become more specialised. They argue that providing a locum is a poor substitute for a GP principal actually providing the care, as availability and standard of locum cover is subject to huge variability. However, Personal Medical Services pilots have given us alternatives, such as employing salaried GPs or nurse practitioners. By spending a set amount of time in the practice each week, they may represent a more viable option than locum staff.

There are other risks. Creating and consolidating the roles of a GP with special interest will require a clarification of the core skills, competencies, and service level agreements of that role. Diversity may well be needed to meet local requirements but locally defined contracts inevitably mean a lack of uniformity or consistency as to what is expected of the doctor in terms of contractual obligations, remuneration, support structures, and other key areas that are readily available in consultant contracts. This may leave the doctor open to exploitation and the service open to lack of clarity of roles and responsibilities.

A service that functions without clearly defined roles, responsibilities, terms of service, clinical governance, and other monitoring arrangements, will inevitably mean second rate secondary care/specialist services run by primary care practitioners. Such characteristics could not be further from those described in Health Improvement Programmes as models of best practice.⁸ To prevent this, PCTs will need to understand and use the new expertise wisely and ensure that they are not merely replacing consultant specialist opinion with a cheaper, less experienced one, risking de-skilling and undermining the expertise of the generalist doctor. For all concerned, the GPWsi should augment and add value

but not replace specialist services, something that, if forgotten, will lead to a diminution of the standards of care that patients can receive in any given area. However, on balance, introduced in a well-managed and organised system, the GPWsi will be a natural and coherent step forward in developing the 'portfolio careers of GPs' and will add value to patients and local health services.

The way forward now must be for the RCGP to take the lead in defining training and accreditation criteria, quality assurance, and continuing professional development criteria, and to clarify the terminology (for example, GPs with special clinical interests, GP specialists, GP practitioners) and give clarity to commissioners and service providers as to exactly what can be expected from a GP appointed into posts at every level. It is perhaps in the drug misuse field that this work is most developed, in trying to create a coherent framework for GPWsi. Through a grant obtained from the Department of Health, the RCGP has developed a Certificate in Drug Misuse. The certificate course covers the core competencies necessary to practice as a GP with special interest in drug misuse and this will provide some levels of uniformity with regard to the 'accreditation' of these practitioners. At the time of writing, around 500 GPs and prison doctors are taking part in this five-day training programme.⁹ Further funding will allow those on the waiting list, together with primary care nurses, pharmacists and others clinicians to take part in future training programmes. In time, a network of clinicians able to provide care to drug misusers and support local colleagues will result in reduced waiting times and improved services. Training programmes are also being developed in other specialty areas, such as ear, nose and throat.

In conclusion, GPs are playing their part at every level of service provision and we have gone a long way from the time when experts were even questioning whether the GP had a part to play at all in some clinical areas.¹⁰ New roles for GPs will help to finally put to rest decades of prejudice against general practice, where even before the start of the NHS, general practice was seen as the poor relation (both academically and financially) of the hospital specialist service. Finally, if we get the next stage right, then it opens whole new avenues for GPs; if we get it wrong, it could bring about the end of the generalist practitioner.

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