



# The Department of Health Action Plan ‘‘improving services for people with epilepsy’’: a significant advance or only a first step?

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## KEYWORDS

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**Summary** The government in England has supported the production of a number of reports on services for people with epilepsy over the last three or four decades but these have not come with any promise to provide resources or to achieve change. In recent years, the voluntary agencies have worked with government in undertaking some very worthwhile initiatives. The publication of the audit on epilepsy-related deaths and the commitment of the Chief Medical Officer have led to the production of an Action Plan entitled ‘‘Improving Services for People with Epilepsy’’. This Plan covers many of the key issues in the management of epilepsy and is seen as an important first step towards actual improvement of services. There is certainly a consensus that improvement is necessary with too many people receiving inadequate diagnosis and management leading, in some cases, to avoidable morbidity and mortality. A critical overview of the Action Plan and a suggested 10-point model Action Plan are presented. Whether the further necessary steps following the Department of Health Action Plan will be taken, remains to be seen. All those responsible for the management and wellbeing of people with epilepsy very much hope that the required measures will be taken to ensure significant long-term improvements in services.  
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## Preamble

A caring member of parliament with no particular medical knowledge was walking down the street, not far from the Houses of Parliament in Westminster, London, when he came across someone having a seizure. He did not know what to do. He called a policeman. The policeman did not appear to know what to do. The member of parliament felt that this situation could not be right. The result was that

he inspired other members of parliament to join with him to form an all-party group on epilepsy. The founder member of this group was John Battle MP. The group then continued its very valuable work under the leadership of Stephen Twigg MP and has recently been led by Baroness Gould of Potternewton. Several questions about epilepsy have been asked in the House of Commons in recent years and the all-party group has become a very positive influence on epilepsy policy.

A young woman was in a loving relationship with a man who had epilepsy. Her partner died unexpectedly. She was appalled by the ignorance

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surrounding the condition of sudden unexplained death in epilepsy (SUDEP). It became apparent that most doctors did not seem to know much about the condition or may not have heard of it at all. What action did she take? She became the founder of a highly active charity group: "Epilepsy Bereaved?"<sup>1</sup> This charity not only provides support to members of the family of any person with epilepsy who has died but has also implemented a number of valuable initiatives. As a result, research into SUDEP has increased markedly in the UK, an extensive audit report<sup>2</sup> has been produced, revealing information that some might consider to be shocking, and a group of people interested in the provision of epilepsy services has met with the Chief Medical Officer. The Chief Medical Officer's plan<sup>3</sup> also highlighted the problems of SUDEP and the need to improve epilepsy services. As a result of the undertaking by the Chief Medical Officer, government had to respond. The response is "Improving Services for People with Epilepsy: Department of Health Action Plan in Response to the National Clinical Audit of Epilepsy-Related Death".<sup>4</sup> The Chief Medical Officer has written to NHS Trust Chief Executives, Primary Care Trust Professional Executive Chairs and Strategic Health Authority Chief Executives drawing attention to the Plan.<sup>5</sup> However, will this "Action Plan" make any difference to services for people with epilepsy?

The aim of this paper is not only to discuss the question of whether the Action Plan is likely to make a difference. Other issues also need to be addressed. These include the following:

- Providing adequate training for professionals, not only those in health care but also those in other relevant caring professions and those in the teaching profession
- Educating the public
- Providing the patient with clear and full information on epilepsy, treatment and risks
- Improving the quality of diagnosis
- Providing adequate targeted investigation and treatment, including treatment of status epilepticus
- Supporting the psychological wellbeing of patients and families
- Making available expert attention for special groups, such as children, women of childbearing age, pregnant women, the elderly and people with learning disability or psychiatric disturbance
- Providing adequate epilepsy neurosurgery services for both adults and children
- Setting clear standards for epilepsy services, using limited resources to best advantage and establishing good resource planning

- Ensuring that there are good epilepsy services throughout the country instead of the current patchy provision

Clear government targets for epilepsy services are needed because, in our society, these become the priorities for resources.

Are there other reports that might provide a model for an Action Plan? How does the UK compare with other western countries? How should such initiatives be viewed in terms of the worldwide needs of people with epilepsy?

## An overview of the Action Plan

The document is broken into four sections. These will be discussed in turn, using the same headings and numbering as in the original report, except for the addition of the numbering I–IV before the main headings of the Action Plan to distinguish them from other headings in this paper.

### I. Introduction

- (1) The introduction states that epilepsy is the most common chronic disabling condition of the nervous system affecting around 380,000 people in England, of which almost 800 die yearly as a result of the epilepsy.
- (2) Reference is made to the National Clinical Audit of Epilepsy-Related Death (SUDEP) published in May 2002 ([www.sudep.org](http://www.sudep.org) and [www.nice.org.uk/pdf/epilepsyreport.pdf](http://www.nice.org.uk/pdf/epilepsyreport.pdf)).<sup>2</sup> It acknowledges the important role played by the voluntary organisation, Epilepsy Bereaved?,<sup>1</sup> in managing the audit.
- (3) Reference is made to the Chief Medical Officer's report. ([www.doh.gov.uk/cmo/annualreport2001/index.htm](http://www.doh.gov.uk/cmo/annualreport2001/index.htm)).<sup>3</sup> This is an excellent report with specific aims relating to epilepsy services, including the requirement that: "Within 3 months of completion of the National Sentinel Audit of Sudden Death in Epilepsy an Action Plan should be in place to cut the level of preventable deaths from this cause". The Action Plan was in response to this. The Plan states the hope that it will start a process of improving awareness and understanding of SUDEP and will lead to improved care and services for people with epilepsy.

(4 and 5) Cross references are made to other documents available on the web but some of these had not been prepared at the time the Action Plan was produced, notably the National Institute for Clinical Excellence<sup>6</sup> report on newer antiepileptic drugs and the National Service Framework for long-term conditions.<sup>7</sup>

## II. Pathology and post-mortem investigations

The following findings from the audit are quoted:

- There are no specific guidelines for the investigation of epilepsy-specific death.
- Death certification was of poor quality.
- Two-thirds of pathologists indicated that they had no mechanism to inform relatives about post-mortem results.
- Little evidence of contact with relatives after death, with only 10% of families contacted by specialists and 7% by a GP.

(6) The point about poor death certification was made some years ago in a letter to the *Lancet*.<sup>8</sup> However, it is worth emphasising because the situation continues. The other three points are clearly of considerable importance.

- (a) Attention is drawn to the Royal College of Pathologists' website ([www.rcpath.org](http://www.rcpath.org))<sup>9</sup> which is said to include a section on the neuropathology and epilepsy in *Guidelines on Good Autopsy Practice*. The author could not find this document on the website but, with the assistance of the Royal College, discovered that there was probably an error in the title; the publication is on the website as *Guidelines on Autopsy Practice*. There is a small section on epilepsy which makes worthwhile reading, apart from the fact that there is a rather vague reference to "status epilepticus", which is not defined. This is unfortunate since "status epilepticus" has often incorrectly been recorded as the certified cause of death in people with epilepsy when there has been no evidence of this. Many of these patients probably had SUDEP.

It is interesting to note that a search for the terms "epilepsy" or "epileptic" or "epilepsies" on the Royal College of Pathologists' website reveals four other documents. One of these states that the College is working with the National Institute of Clinical Excellence on the diagnosis and management of epilepsy in children

and adults. A further reference, ironically, is to the threats and challenges to neuropathology in the UK. However, the details of this document are available only to Fellows or Members of the College. The third reference was not relevant and the fourth reference was, it is pleasing to note, on the National Sentinel Clinical Audit of Epilepsy-Related Death.

- (b) The next reference in the Action Plan, to the "removal, retention and use of human organs and tissue" is regrettable.<sup>10</sup> Although this document indicates very necessary improvements in practice, the way in which the previous Secretary of State for Health and the media handled the question of organ retention, referring to it as "a scandal" instead of referring to it as practice that needed to be updated, has contributed to the current critical shortage of pathologists; this is particularly true of paediatric neuropathologists. The implication is that paediatric epilepsy neuropathology will be greatly hindered in the UK for many years to come. The reference to the Government document *Human Bodies, Human Choices, July 2002* ([www.doh.gov.uk/tissue/choices.pdf](http://www.doh.gov.uk/tissue/choices.pdf))<sup>11</sup> does contain the worthwhile statement that there should be "improved support and advice to families at the time of bereavement, including the development of the role of bereavement advisers within every NHS trust".
- (c) A particularly positive subsection, again mentioning support for the bereaved, is the reference to the fact that the Department of Health has been contributing to the coroners' review consultation document, which was expected to recommend the following.

- A more modern system for certifying and investigating deaths, including investigation of premature medical deaths, such as from epilepsy.
- Support for the bereaved which is at the heart of a reformed inquest process, with explicit service standards for the provision of information, advice on bereavement counselling, and the involvement of families in key aspects of any post-mortem examination decisions.

The outcome of these "expected recommendations" is awaited with great interest.

### III. Improving care, management and treatment of epilepsy

The findings of the National Clinical Audit of Epilepsy-Related Death on quality of care received by individuals in general practice and hospitals make quite shocking reading. The authors of the audit concluded that in hospitals 54% of adults had inadequate care, which led to the conclusion that 39% of adult deaths were considered potentially or probably avoidable. The main deficiencies identified were: inadequate access to specialist care (35%), inadequate drug management (20%), lack of appropriate investigations (13%), no evidence of a package of care (5%), inadequate recording of patients' histories (5%), adults with learning disabilities "lost" in transfer from child to adult services (6%) and one or more major clinical management errors (5%). 77% of children had inadequate care, which led to the conclusion that 59% of deaths in children were potentially or probably avoidable. The main deficiencies identified were: inadequate drug management (45%), inadequate access to specialist care (36%) and inadequate investigations (32%). In primary care management the main problems identified were: lack of timely access to skilled specialists, sparse evidence of structured management plans, triggers for referral sometimes being missed and professional communication failures. Although criteria for adequate care and management are open to debate, these results are, nevertheless, quite grim in that they suggest that 39% of adult deaths and 59% of childhood deaths were potentially or probably avoidable. The Department of Health might reasonably be expected to make a robust response to these figures.

(7) In the Action Plan there is a subheading, at this point: "Department of Health Response—How We Will Make Improvements". However, this section is full of "soft" terminology: "we will engage", "suggest", "refer them to", "we will discuss with", "liaising with", instead of using words such as "require", "implement", "set clear standards" or "expect specific targets to be met".

(a) The Action Plan states that the Department of Health will engage with NHS and Primary Care Trusts, and Strategic Health Authorities to suggest they review local epilepsy services. They will be referred to the Joint Epilepsy Council's *National Statement of Good Practice* ([www.jointepilepsycouncil.org.uk](http://www.jointepilepsycouncil.org.uk)).<sup>12</sup> Why does the Action Plan use the wording "we

will refer them" instead of stating "we shall expect them to follow"? This is one of several examples of very weak wording in the document. The Joint Epilepsy Council's *National Statement of Good Practice* is an extensive document with useful and specific recommendations. It might be argued that the Action Plan could have drawn more heavily on this document and on other reports that have been published within the UK in recent years, notably the high quality Scottish Intercollegiate Guidelines Network (SIGN) document "Diagnosis and Management of Epilepsy in Adults".<sup>13</sup> The Department of Health also undertakes to "link this with" the Modernisation Agency's National Primary and Care Trusts Development Plan (NaTPaCT) competency framework website ([www.natpact.nhs.uk](http://www.natpact.nhs.uk)).<sup>14</sup> At the time of writing of this paper the NaTPaCT website makes almost no reference to epilepsy apart from having a link to the epilepsy plan with the statement: "PCTs urged to carry out local epilepsy service reviews as part of drive to cut sudden deaths".

It should be noted, in this context, that the production of guidelines for the appointment of general practitioners with a special interest in the delivery of clinical epilepsy services<sup>15</sup> represents a very positive move forward.

(b) The Action Plan undertakes to discuss with the Modernisation Agency a range of initiatives aimed at improving neurology services, including epilepsy. £1.2 million is allocated for investment in a 2-year project to improve quality and access in neurology services, starting in April 2003. It is pleasing to note that resources are being committed but it is difficult to see how this sum of money could be spent in a way that will actually improve services. With approximately 380,000 people who have epilepsy in the country, this sum represents less than £4 per patient. Some specific indication of how the money will be spent might have been helpful.

The statement that there will be liaison with neurology professional organisations and the Royal College of General Practitioners to produce the specific framework to help develop more general practitioners and nurses with a special interest in neurology is very much welcomed but again, this statement is rather vague.

- (c) Reference is made in this section to the Children's National Service Framework.<sup>16</sup> Many dedicated professionals are, at the time of writing this paper, putting an enormous amount of effort into producing a good Children's NSF but at this stage it is not at all clear what will be included in the final documentation.
- (i) The Action Plan does state that the Disabled Child module of the Children's NSF will set generic standards aiming to improve multi-agency support for disabled children, including those with epilepsy. It will be interesting to see how this translates into practice. The Action Plan gives no indication of how this might occur.
- (ii) Reference is made to the Maternity module of the NSF, pointing out that nine epilepsy-related deaths were identified in the report on confidential enquiries into maternal deaths in the United Kingdom: *Why Mothers Die 1997–1999*.<sup>17</sup> It should be noted that the Action Plan gives an out-of-date website at this point. The correct website is [www.cemach.org.uk](http://www.cemach.org.uk). *Why Mothers Die* is a lengthy, detailed, high-quality report with over 30 references to epilepsy. The comments about epilepsy safety are very relevant. For example, it rightly draws attention to the unnecessary deaths of pregnant women with epilepsy by drowning in the bath and also considers SUDEP.
- (d) The website on the NSF for Long-term Conditions ([www.doh.gov.uk/nsf/longterm.htm](http://www.doh.gov.uk/nsf/longterm.htm))<sup>7</sup> has a number of links, including those to the working groups. One of the links quotes the Health Minister, Jacqui Smith, as stating, in June 2002, that the NSF for Long-Term Conditions would have "a particular focus on the needs of people with neurological conditions and brain and spinal injury". It also comments that the previous Secretary of State, Alan Milburn, had announced in February 2001 that it would cover services for people with epilepsy, multiple sclerosis, Parkinson's disease, motor neurone disease as well as brain and spinal injury. It will be interesting to see what the final contribution on epilepsy will be.
- (e) The Department of Health strategy *Pharmacy in the Future (2000)* is mentioned in the Action Plan. The website is [www.doh.gov.uk/pharmacyfuture/index.htm](http://www.doh.gov.uk/pharmacyfuture/index.htm).<sup>18</sup> However, "epilepsy", "antiepileptic" and "anticonvulsant" could not be found in this document, which refers to general principles.
- (i) The Action Plan states that clinicians involved in the epilepsy audit will be invited to participate in the future *Medicine Management Services (MMS) Programme* collaborative workshops for PCTs. It is not at all clear what the impact of this would be. Good guidelines for pharmaceutical management might provide a firm way forward in this regard. The website is [www.doh.gov.uk/pharmacyfuture/medicinesmanagement.htm](http://www.doh.gov.uk/pharmacyfuture/medicinesmanagement.htm).<sup>19</sup> It states that local pilot sites will need to define their own specific local and measurable targets within which they will be able to demonstrate five listed goals including improved patient satisfaction with medicine management services provided. These valuable goals are all very general and could apply to any disease or disorder.
- (ii) Reference is also made to *Task Force on Medicines Partnership*, a 2-year initiative aiming to help patients benefit from their medication by exploring how to improve partnership between patients and health care professionals. It is said that epilepsy will be prioritised in these projects and that the task force will pilot professional development for neurologists and others involved in epilepsy in relation to medicines. It will also undertake to look at individual patient experience. These initiatives appear to be very worthwhile, although it is difficult, at this stage, to estimate what the impact will be. Information on the Task Force on Medicines Partnership can be found at the website [www.medicines-partnership.org](http://www.medicines-partnership.org).<sup>20</sup> This discusses the transition in concept from compliance to concordance. The latter implies a partnership in which the patient understands the reasons for the prescription of the medication and works together with the prescriber rather than simply complying with instructions. Again, these are very laudable aims but they are general and do not apply specifically only to epilepsy.

- (f) The National Institute for Clinical Excellence (NICE)<sup>6</sup> is currently examining the role of the newer antiepileptic drugs in the treatment of epilepsy. The current author has read the initial drafts both for adults and children. Regrettably the emerging documentation is not encouraging and leaves the clinician with the impression that the purpose of the exercise is to limit costs rather than to provide best standards of antiepileptic drug treatment. It should be noted, however, that these comments have been made on the emerging documentation and not on the final report. It is to be hoped that by the time the final report is prepared, many of the reservations that experienced clinicians have had about the emerging documentation will have been resolved.
- (g) This section acknowledges that workforce recruitment, education and training issues are important. It comments that a group to look at workforce and training issues for the Long-Term Conditions NSF<sup>7</sup> has already been formed but there is no further information other than a statement that there is a plan to support the NSF over its 10-year implementation period.
- (h) The importance of neuroimaging is acknowledged and there is a statement that by the end of 2004 central programmes will have provided a total of approximately one hundred MRI scanners and two hundred CT scanners for the NHS. These neuroimaging facilities are much needed, although it should be noted that CT scanning is of very much less value than MRI scanning in the investigation of epilepsy. The Action Plan states the target date for having provided these scanners but it does not state the start date, which leaves the reader wondering what has been achieved over the last 2 or 3 years.
- (i) The Action Plan refers to *The Expert Patient: A New Approach to Disease Management for the Twenty-First Century*. The website is [www.doh.gov.uk/cmo/ep-report.pdf](http://www.doh.gov.uk/cmo/ep-report.pdf).<sup>21</sup> This is another example of general good practice being advocated by the Government. It refers to the amount of expertise patients have on particular diseases or disorders. The Action Plan states: "We will look at the feasibility of developing a disease-specific module for epilepsy in the next phase of this work". It should be noted that the wording is again hardly em-

phatic. The Action Plan does not undertake to provide a module for epilepsy but only to "look at the feasibility". Incidentally, it is inappropriate to suggest that epilepsy is a disease; it is a disorder that may result from a number of identifiable diseases but usually is the result of no identifiable disease. The report covers some important issues relating to epilepsy. For example, "up to 20% of epilepsy patients may be misdiagnosed and receive inappropriate and unnecessary treatment".

#### IV. Information provision

- (8) This section of the document is preceded by a paragraph from the audit.
- "The audit found deficiencies in communication between health care professionals, patients, their carers and families. There was little evidence that epilepsy management and hazards, such as the risk of death, had been discussed with patients, their families and carers by any health care professional in primary or secondary care."
- (a) At this point in the Action Plan, some specific recommendations are made. The Department of Health undertakes to provide information by working with epilepsy voluntary organisations to produce an information leaflet on epilepsy, particularly around managing risks of the condition. The voluntary epilepsy agencies, while welcoming such co-operation, expressed some surprise at the implication that literature was lacking in view of the fact that some of them produce extensive patient leaflets, which provide much information on the condition. However, working together with Government on providing information is certainly to be encouraged because it is very clear that neither professionals nor the general public have the information on epilepsy that they require. The Action Plan undertakes to provide resources for this work in the financial year 2003/2004.
- (b) One of the few definite actions taken in this "Action Plan" is to provide £288,600 to the National Society for Epilepsy to expand its epilepsy information network. The aim will be to provide improved information and support to epilepsy patients and their families. This is to be welcomed. However, it perhaps highlights one of the difficulties in organising epilepsy services within the UK, namely the fragmentation of the voluntary

organisation. An attempt has been made to overcome this fragmentation by the Joint Epilepsy Council. There is no doubt about the excellence of the work of the National Society for Epilepsy but the reader is left wondering why some resources to improve information were not given to the joint organisation.

- (c) The Department of Health undertakes to improve the provision of information by "suggesting that NHS Direct Online review and update the epilepsy information in its encyclopaedia regularly". No-one would argue against this. However, such updating should, in any case, form an essential part of NHS Direct, which is intended to be the first point for providing information to the public about any medical condition. Those outside the UK may not be aware of the role of NHS Direct. This provides telephone information to the general public on any medical situation. It is widely thought that the aim of NHS Direct was to try to reduce the number of unnecessary calls to general practitioners. NHS Direct Online is the web-based arm of this service. The website is [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk).<sup>22</sup> The section on epilepsy in the encyclopaedia provides some useful information but certainly could be improved.
- (d) This section refers to: "Taking advantage of a NHS Direct Online and Medicines Partnership Task Force project improving medicines information for patients". It is stated that this will result in the development of clear information on medicines for conditions including epilepsy. The current NHS Direct Online encyclopaedia could be improved in this regard and any initiative to undertake this would be worthwhile.
- (e) The Action Plan refers to copying letters to patients. Many physicians already do this. It is to be encouraged.
- (f) This section states that information will be improved by engaging with the Royal Colleges to raise awareness of the audit (on epilepsy-related death), particularly highlighting the issue of informing patients about epilepsy management and the risks associated with their condition. Again, this is a rather vague statement but it is, nevertheless, welcomed.

The Action Plan lists a number of epilepsy organisations with websites and telephone num-

bers. This information is very useful, although the list is by no means complete.

## What form should an Action Plan take?

In putting forward the following model Action Plan, the current author is not suggesting that it will be perfect nor that it will be the final word. On the contrary, the model is meant to provide a stimulus to the discussions on how to implement the necessary changes in epilepsy services that are so long overdue.

It is also acknowledged that current government policy is to devolve decision-making down to the local level. For conditions that involve hundreds of thousands of people, such as epilepsy, many in the field would maintain that a national plan is very much needed and that this should avoid the inefficiency of having to "re-invent the wheel" in separate local policies throughout the country.

In the opinion of the present author, an Action Plan should be clearly set out and easy to follow. It should be in a standardised format that allows rapid reference to the issue, the solution and the proposed outcome measures. In the light of issues raised earlier in this paper, the following format is suggested.

## Suggested format for 10-point model Action Plan

### Issue 1

Providing adequate training for professionals in health care, other relevant caring professionals and teachers.

### Current situation

Knowledge about epilepsy is poor among professionals generally.

### Solution

Each profession will devise a body of "core knowledge" required by members of the profession about epilepsy. This will be achieved by representatives from the profession meeting with the Joint Epilepsy Council and a suitable tertiary educational body. The "core knowledge" will be incorporated into the training courses for each professional discipline. Individuals will be examined/assessed on this knowledge to ensure that an adequate standard has been reached before they earn their qualification. For professionals who are already qualified, a

requirement of their continuing professional development will be that they have acquired the agreed standard of "core knowledge".

#### **Outcome measures, targets and timescale**

A pass rate of at least 90% in the epilepsy module of those gaining a professional qualification.

At least 20% of those who have already qualified will attend continuing professional development courses on the "core knowledge" per year.

### **Issue 2**

Educating the public.

#### **Current situation**

Ignorance about epilepsy leads to fear of the condition, increasing stigma. This greatly impairs the quality of life of people with epilepsy and their families.

#### **Solution**

All schools will include an epilepsy module in their health education curriculum. The details of the module will be agreed between the Department of Education, the Joint Epilepsy Council and representatives from the teaching profession/schools. Information on these teaching modules will also be available on the web. Children will be encouraged not only to discuss the information with teachers but also to share and discuss the information with their parents.

#### **Outcome measures, targets and timescale**

The educational package for schools will be implemented within 2 years. This implies that all children attending school will have had education on epilepsy within 3 years.

### **Issue 3**

Providing the patient with clear and full information on epilepsy, treatment and risks.

#### **Current situation**

Good information leaflets are available on seizure types, epilepsy types, treatment, pregnancy and risks, including the risk of drowning in the bath and the risk of SUDEP. However, this information is often not provided to newly-diagnosed patients and many of those who have well-established epilepsy have never had access to it.

#### **Solution**

Provide all patients with epilepsy with a suitable series of information leaflets, targeted to the pa-

tient. Although the voluntary organisations produce good leaflets, these should be merged, under the umbrella of the Joint Epilepsy Council, and should be scrutinised by the Department of Health before being made available to all general practitioners for this purpose. The leaflets will provide a list of the key sources of help and information, including contact details for the major voluntary epilepsy organisations and "Epilepsy Bereaved?" Some general practices may prefer to print this documentation off the web whereas others may prefer to have it in hard copy, provided by the Department of Health.

#### **Outcomes measures, targets and timescale**

The Joint Epilepsy Council will provide the necessary documentation agreed by the Department of Health within 18 months and will be given the necessary resources to achieve this. Within the following 12 months general practitioners will be required to provide all newly-diagnosed patients with the relevant information sheets. Within the ensuing 12 months all GPs will be required to write to each patient with epilepsy offering information as hard copy and indicating where the information leaflets can be viewed on the web. The information will indicate when it is likely that specialist referral will be required and how to obtain such referral through the general practitioner.

### **Issue 4**

Improving the quality of diagnosis.

#### **Current situation**

Various studies on the accuracy of diagnosis by the medical profession have indicated that the rate of misdiagnosis is of the order of 25%.

#### **Solution**

As part of the initiative above "providing adequate training for professionals" all medical schools and nurse training courses will be required to provide adequate "core knowledge" teaching to medical students and nurses about the diagnosis and management of epilepsy. All relevant Royal Colleges will be asked to incorporate assessment of "core knowledge" of epilepsy at post-graduate level in their assessments/examinations. Web-based continuing professional development modules on epilepsy, incorporating both training and self-assessment, will be developed for doctors/nurses in training and for those that are already qualified.



**Outcome measures, targets and timescale**

Core knowledge for medical students and nurses will be determined by the Department of Health in consultation with the appropriate agencies within 18 months. All medical schools and nurse teaching establishments will incorporate the agreed core knowledge about epilepsy into their curricula within the following 2 years.

It will be a requirement of continuing professional development of all practising doctors that they acquire a specified level of knowledge about epilepsy within 5 years, either by attending specified courses or by completing a web-based continuing professional development module on epilepsy.

**Issue 5**

Providing adequate targeted investigation and treatment, including treatment of status epilepticus.

**Current situation**

There is generally poor knowledge of what investigations and treatment are appropriate for specific types of epilepsy. Delays in treatment of status epilepticus may result in permanent brain damage or death.

**Solution**

Specific guidelines for investigation and treatment will be provided by the Joint Epilepsy Council, in consultation with the Royal Colleges and the National Institute for Clinical Excellence.

**Outcome measures, targets and timescale**

The guidelines will be produced within 2 years. The degree to which the guidelines are followed will be audited within a further 2 years of their publication. The audit results will be used to inform Government about necessary changes that may be required in the guidelines or their implementation.

**Issue 6**

Support for the psychological wellbeing of patients and families.

**Current situation**

Although there is increasing awareness of the wide-ranging effects of epilepsy on individuals and their families, there is still a tendency, among some professionals, to imagine that treating the seizures is the only issue.

**Solution**

The epilepsy voluntary organisations, including Epilepsy Action (British Epilepsy Association) and the National Society for Epilepsy will, through the umbrella organisation of the Joint Epilepsy Council, co-opting other parties as necessary, make specific recommendations to central Government for addressing these issues, drawing on both positive and negative experiences of their members. Appropriate resources for this project will be provided.

**Outcome measures, targets and timescale**

The report and recommendations will be produced within 18 months. Agreement with Government departments will be achieved within 1 year of publication of the report and the findings will be implemented within the following 2 years.

**Issue 7**

Making available expert attention for special groups such as children, women of childbearing age, pregnant women, the elderly and people with learning disability or psychiatric disturbance.

**Current situation**

Services for these special groups are particularly patchy at present. There is a lack of good models of service.

**Solution**

The Department of Health will be responsible for drawing together working groups for each of these special groups of patients.

**Outcome measures, targets and timescale**

The working groups will report within 12 months with specific recommendations for addressing the needs of each special group. Implementation of appropriate measures will be agreed with the Department of Health within 12 months of these reports. The situation will be audited within the following 2 years to assess whether the needs of each group have been met adequately.

**Issue 8**

Providing adequate epilepsy neurosurgery services for both adults and children.

**Current situation**

It is estimated that there are 380,000 people with epilepsy in the UK, of whom perhaps 30% have uncontrolled epilepsy. Of this 30% (114,000) it is estimated that around 4,500 might benefit from neurosurgery. The current capacity for epilepsy

neurosurgery would only cope with a tiny fraction of this number. Furthermore, there are very few centres that adequately staffed and set up to manage young people undergoing neurosurgery, although it has been suggested that the earlier surgery is performed the better the outcome.

### **Solution**

The current situation will be audited with attention both to the overall resources available and the geographical location of resources. The audit will include gathering of information on epilepsy surgery facilities for children and teenagers. Recommendations will be based on the outcome of this audit. This information will inform planners so that they are able to advise on the number of people who will need to train as epilepsy neurosurgeons and as other members of the multidisciplinary team, to make up the shortfall.

### **Outcome measures, targets and timescale**

Because it is anticipated that the audit will show that there is a major shortfall in epilepsy neurosurgery both for adults and children, it will probably take decades to make up the shortfall. Because the time required to train surgeons and other staff in this speciality is considerable, a realistic target would probably be to decrease the shortfall by 25% in 10 years and by 50% in 15 years. A tertiary centre capable of providing epilepsy neurosurgery should generally be available within a reasonable distance (e.g. 100 miles or 2 h travel) of all major population areas within the UK within the next 5 years.

### **Issue 9**

Setting clear standards for epilepsy services, using limited resources to best advantage and establishing good resource planning.

### **Current situation**

The best delivery of epilepsy services is almost certainly through multidisciplinary teams, making full use of epilepsy liaison nurses. The role of the epilepsy liaison nurse has increased in a major way over recent years but such services are by no means uniformly provided. This implies that expensive consultant time is used in an inefficient manner to fulfil needs that, in some cases, could be better fulfilled by specially trained nurses.

### **Solution**

Models of best practice of multidisciplinary delivery of epilepsy services will be re-examined, with particular attention to efficient use of resources. Use of resources will be audited against these mod-

els in three or four randomly-selected areas of the country and recommendations will be made on the basis of this audit.

### **Outcome measures, targets and timescales**

Each tertiary service will have at least one epilepsy liaison nurse within 5 years of the audit. Specific planning for addressing geographical and different ethnic/social class inequalities will be produced within 2 years and will be implemented in a step-wise fashion over the ensuing 10 years.

### **Issue 10**

Ensuring that there are good epilepsy services throughout the country instead of the current patchy provision.

### **Current situation**

There are inequalities of provision across geographical areas and across different ethnic/social class groups. There are few centres of excellence for epilepsy services in the UK. Specialist epilepsy services between these areas vary from good to non-existent. This implies that a patient with problematic epilepsy may need to wait for a long time and travel a long distance to obtain the service they need.

### **Solution**

The present service will be audited in 10 randomly-chosen areas of the country and the service provided will be assessed against known models of good service. The audit will be led by the Department of Health. The form of the audit will be devised by this department in close consultation with representatives from the Joint Epilepsy Council, two acknowledged centres of excellence and patient representatives. The results of the audit will be used for workforce planning to rectify the inequalities and shortfalls in service over the country.

### **Outcome measures, targets and timescales**

The audit will be devised in 1 year and completed in the following year. Within 18 months of the completion of the audit, a plan will be produced to address the workforce implications, geographical, social and ethnic inequalities, and any shortfall in other resources. The target will be to rectify at least 50% of the shortfall and inequalities within 10 years of the plan and at least 90% in 15 years.

## Comment on the model Action Plan

Although the current author takes full responsibility for the suggested 10-point model Action Plan, the information on which it is based is available in a series of good reports produced over the years. In this context, particular attention should again be drawn to the Scottish Intercollegiate Guidelines Network document *Diagnosis and Management of Epilepsy in Adults—A National Clinical Guideline (April 2003)*,<sup>13</sup> the Joint Epilepsy Council *National Statement of Good Practice for the Treatment and Care of People who have Epilepsy*<sup>12</sup> and a number of previous documents.<sup>23–27</sup>

There are, no doubt, considerable gaps in the suggested Action Plan provided by the current author. However, this should only serve to strengthen the case for involving agencies fully in the development of any Action Plan adopted by government. It is a great credit to the Department of Health that agencies such as Epilepsy Action (the British Epilepsy Association), the Joint Epilepsy Council and Epilepsy Bereaved? were consulted. However, from the response made by some of these agencies to the Plan, it could be argued that a more complete consultation process is still required.

## Conclusions

Both the Government and the Chief Medical Officer are to be congratulated for having put epilepsy services on the health agenda. It is also important to see this document in context. Worldwide, most people with epilepsy have no access to treatment whatever and the treatment gap (those with epilepsy who have no access to antiepileptic medication) is over 90% in some areas of the world.<sup>28</sup> At least everyone in the UK has access to antiepileptic drugs. How does this government initiative compare with those in other countries of the western world? Although some countries have well-organised epilepsy services, most do not. Some of the most “developed” countries in the world would be jealous of people in the UK who have a government that considers these issues worthy of attention and debate. Although approximately 380,000 people in the UK are said to have epilepsy it would be quite wrong to suggest that this is the number of people affected by the condition. Most people with epilepsy have families. The presence of a member of the family with epilepsy can have a profound effect on the rest of the family. In this sense, epilepsy probably affects well over a million people in the UK, although only a third of this num-

ber actually have the condition. There seems to be general consensus that the provision of epilepsy services has been inadequate. This has been highlighted by the audit on epilepsy-related deaths and has been acknowledged in the excellent report of the Chief Medical Officer.<sup>3</sup> The Department of Health has produced an Action Plan.<sup>4</sup> It should, more properly, perhaps have been called an interim plan. Those who have a particular interest in managing epilepsy have, on the whole, had a similar reaction to the document. It is an important first step, and for that everyone is grateful. However, reaching a destination generally requires more than a first step and unless this document is followed up by a number of specific undertakings with measurable outcomes, targets and timescales, it may fall into the category of being yet another interesting document that has little or no effect on the quality or availability of services for people with epilepsy. We very much hope that the Department of Health will not falter in taking the necessary further steps to achieve the ultimate goal of providing good and effective services for people with epilepsy.

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