

# Evidence-based standards of care for adults with epilepsy—a literature review

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Epilepsy is the most common serious chronic neurological condition. All patients with epilepsy regardless of location should receive the highest quality of services that can be provided. In order to do this current service provision has to be reviewed and benchmarked against ideal standards of service provision that cover a comprehensive range of services to meet all patient needs.

By critically reviewing the relevant literature, criteria were developed for an ideal epilepsy service.

The literature review generated evidence-based ideal standards for the following service areas:

- The role of primary care and the interface with secondary care in the management of epilepsy;
- The role of Accident and Emergency (A&E) departments in the care of epilepsy;
- Epilepsy clinics;
- Specialist epilepsy nurses for treating epilepsy;
- The role of the general practitioner (GP) specialist;
- Services for adult epileptics with learning disabilities;
- Services for complex epilepsy; and
- User views.

Although many of the recommendations are based on evidence of a lower grade, the direction of the existing evidence obtained from several sources, suggested similar standards for an epilepsy service. The effectiveness and value of epilepsy services, particularly in relation to the changes recommended above, must be further researched.

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*Key words:* epilepsy; literature review; service standards.

## INTRODUCTION

A recent report from the Chief Medical Officer<sup>1</sup> highlighted the plight of people with epilepsy. It showed that since 1953 there had been five Government reports concluding that services for people with epilepsy are fragmented and poorly co-ordinated, yet there has been no major change. The report suggests that

genuine commitment is now needed to put right the serious and long-standing weaknesses in the standard of care for what is the commonest serious chronic neurological disorder in the country. The forthcoming National Service Framework for long-term health conditions, expected in 2004, will also focus on the needs of people with long-term health conditions, such as epilepsy. However standards of local services

need to be improved now, if we are to ensure that people with epilepsy have their specific needs addressed. All patients with epilepsy, regardless of location should receive the highest quality of services that can be provided. In order to do this current service provision has to be reviewed and benchmarked against ideal standards of service provision that cover a comprehensive range of services to meet all patient needs.

## RESEARCH QUESTION

The aim of this literature review was to answer the following question:

Based on the available evidence, what is ideal service provision for epilepsy services?

The criteria for developing an ideal service, that provides a comprehensive range of services, were developed from the quality of the available evidence.

The outcome of the literature review is therefore a set of recommended standards for developing an ideal service.

## METHODS

A systematic search of electronic bibliography databases for English language published literature was carried out. Search terms were identified from discussion with public health colleagues and with a librarian. Where relevant, reference articles were also retrieved.

Databases searched were—MEDLINE PLUS, EMBASE, PSYCHINFO, HMIC, ENVIRONMENT PLUS, AMED, ASSIA for health, BNI plus, CINAHL, RPS EPIC, SIGLE. The search was supplemented with grey literature identified by public health colleagues and clinicians working in the field of epilepsy, internet sites of the Joint Epilepsy Council and Department of Health, standard neurology and medical textbooks for background information, and from an internet search (November 2002) using Google.

By inspecting titles and abstracts, papers addressing epilepsy service provision were identified and obtained.

Quality of papers was assessed individually, with robust methodology being the most important factor. Review articles with a comprehensive list of references were given more weight than small individual papers. Where meta-analysis or randomised controlled trials were available, these were given more weight than papers with less robust methodologies.

The evidence is graded to differentiate between information based on strong evidence and that based on weak evidence. The grading system used in this literature review has been adopted from the Typology of Supporting Evidence in the National Service Framework for Older People<sup>3</sup>.

## Evidence from research and other professional literature

- A1 Systematic reviews which include at least one Randomised Control Trial (RCT) (e.g. systematic reviews from Cochrane or Centre for Reviews and Dissemination);
- A2 Other systematic and high quality reviews which synthesise references;
- B1 Individual RCTs;
- B2 Individual non-randomised, experimental/intervention studies;
- B3 Individual well-designed non-experimental studies, controlled statistically if appropriate; includes studies using case control, longitudinal, cohort, matched pairs, or cross-sectional random sample methodologies, and well-designed qualitative studies; well-designed analytical studies including secondary analysis;
- C1 Descriptive and other research or evaluation not in B (e.g. convenience samples);
- C2 Case studies and examples of good practice; and
- D Summary review articles and discussions of relevant literature and conference proceedings not otherwise classified.

## Evidence from expert opinion

- P Professional opinion based on clinical evidence, or reports of committees;
- U User opinion from Older People's Reference Group or similar; and
- C Carer opinion from Carers' Focus Group or similar.

## FINDINGS

Due to the nature of the question posed most items retrieved by the literature search were review articles, consensus statements or descriptive observational studies. Overall, there were few papers with robust quantitative methodologies. Grey literature searches identified useful reports of expert committees and associations.

The literature can be divided into the following topic areas:

Topic area	Peer reviewed publications	'Grey' literature
The role of primary care and the interface with secondary care in the management of epilepsy	3	4
The role of Accident and Emergency (A&E) departments in the care of epilepsy	1	1
Epilepsy clinics	6	0
Specialist epilepsy nurses for treating epilepsy	2	0
The role of the general practitioner (GP) specialist	0	2
Services for adult epileptics with learning disabilities	3	1
Services for complex epilepsy	1	2
User views	5	0

The total number of papers included is not a sum of the above, as some papers covered more than one topic area.

The literature can be categorised into the following main topic areas.

#### The role of primary care and the interface with secondary care in the management of epilepsy

Following a first seizure, patients will usually present to their GP, who will then take a history and make the necessary referral to an epilepsy specialist. A comprehensive review of epilepsy needs in the UK<sup>2</sup> suggests that, as GPs will only see a small number of epilepsy cases per year, this is insufficient to develop skills in accurate diagnosis. It goes on to suggest that because of this potential problem of misdiagnosis, it is important that patients are seen quickly by an epilepsy specialist and that GPs should not normally initiate treatment unless the patient faces a long delay in seeing an epilepsy specialist. The Scottish Intercollegiate Guidelines Network states that there was unanimous agreement by those present at a national conference held to discuss the guidelines that all patients presenting with a seizure should be referred immediately to a specialist for diagnosis<sup>21</sup>.

Following diagnostic assessment and initial specialist management, it should be expected that 60–70% of patients will become seizure free and will be returned to primary care for continuing care. However, the remaining 30–40% who continue to experience seizures will require further specialist follow up<sup>2</sup>.

Primary care based continuing care, closely integrated with specialist epilepsy services is felt to be the ideal model of service provision<sup>13, 20, 21</sup>. A survey of West Glamorgan GPs found that the majority agreed that the care of people with epilepsy should be primary care based. This survey also found that less than a quarter of responding GPs felt that initial

management of people with epilepsy was straightforward, whereas more than three-quarters felt that the long-term management of epilepsy by the GP is usually straightforward<sup>14</sup>. This probably reflects the differences between the perceived difficulties in making a diagnosis and starting treatment in the initial stages and the long-term maintenance of treatment once a diagnosis has been made. GPs also felt that a lack of knowledge about epilepsy (34% of responders), unfamiliarity with new drugs (65% of responders) and a lack of time (41% of responders) were perceived barriers to the provision of effective care. Almost all the GPs felt that guidelines would be useful and that specialist epilepsy nurses in the community was the most popular option for improving the care of people in the community.

Another survey of GPs, this time in the Bristol area, resulted in the following recommendations<sup>15</sup>:

- The introduction of co-operation cards (containing the clinical history of the patient);
- More teaching sessions on epilepsy;
- Encourage GPs to audit their practice;
- Implementation of a recall system for patients;
- GPs need to be encouraged to re-refer patients for specialist advice such as preconceptual counselling and monitoring during pregnancy;
- Where GPs feel the patient requires urgent medication, the GP should be encouraged to seek specialist advice about the most appropriate anti-convulsant for that patient; and
- Introduction of a specialist nurse may help increase awareness of the difficult issues involved in the treatment of epilepsy.

In a survey of clinicians carried out by the Clinical Standards Advisory Group (CSAG), better communication between general practice and the hospital was one of the most common suggestions made<sup>22</sup>. The survey suggested the following ways to improve communication between general practice and the epilepsy centre:

- Epilepsy specialist nurse;
- Epilepsy co-operation cards;
- Shared care protocols for new referrals, chronic uncontrolled epilepsy, controlled epilepsy, controlled epilepsy, reproductive issues, psychiatric co-morbidity;
- Electronic patient records;
- Data/information sheets about aspects of epilepsy management for GPs;
- Chronic disease management clinics at general practice level;
- Seminars and training for GPs/practice nurses; and
- Telemedicine.

The 30–40% of patients who continue to require access to specialist epilepsy services, the tasks of ongoing care are to investigate intractable seizures, revisit the diagnosis, alter medication, assess for neurosurgery, advise on stopping treatment, manage epilepsy in pregnancy, manage additional problems, such as neurological or psychiatric illness or learning difficulties<sup>2</sup>.

### The role of Accident and Emergency (A&E) departments in the care of epilepsy

Epileptics also commonly present to the A&E departments. This retrospective audit carried out in 12 A&E departments in the South Thames region found significant inconsistency in interdepartmental management and documentation of this common problem. This audit proposes the introduction of a proforma for the management of this condition, which incorporates guidelines aiding junior and inexperienced doctors who are often the first responders in dealing with a patient who has had an epileptic seizure<sup>19</sup>.

A review of models of good practice by the British Epilepsy Association<sup>4</sup> also recommends that an epilepsy specialist should make the diagnosis of epilepsy. Both the aforementioned papers suggest that all patients should be seen within 4 weeks of first seizure<sup>2,4</sup>.

### Epilepsy clinics

In recent years many concerns have been expressed over the standard of epilepsy services including the lack of systematic follow-up; patients often not seen by an epilepsy specialist and patients taking inappropriate combinations of drugs. As a result of these perceived deficiencies about the quality of care offered to epilepsy patients, it has been proposed that specialist epilepsy out-patient clinics may have advantages over the management of patients in general neurology clinics or general medical clinics, which often do not have professionals with specialist training in epilepsy.

A survey of all consultant neurologists carried out in 1997<sup>10</sup> found that epilepsy clinics were significantly more likely than general neurology clinics to have on-site provision of relevant investigations and associated specialists, as well as shorter waiting times to see patients. It concluded that epilepsy clinics had definite advantages for patients over general neurology clinics in improving access to investigations and specialists but importantly suggested that further research was required in order to evaluate whether these advantages were translated into positive health outcomes.

A systematic review<sup>5</sup> was conducted to evaluate the existing evidence on whether specialist epilepsy clinics are more clinically effective and cost effective than general neurology outpatient clinics. This review identified only three studies; one randomised controlled trial<sup>6</sup>, one matched study<sup>7</sup>, and one audit<sup>8</sup>.

Several concerns were expressed about the internal and external validity of the one randomised controlled trial. A large number of the patients originally included in this study were subsequently excluded. It was found that these patients were significantly different from those included and no satisfactory explanation was provided for these exclusions. Also, the number of patients followed up in each group was also not stated. It was also possible that bias could have been introduced as the assessment of outcomes was not blinded. The results of the trial suggest that there were significant improvements in seizure frequency at 3 and 6 months but not at 12 months. However, at 12 months in the epilepsy clinic group, there were significant increases in the level of advice and in patient satisfaction when compared with the neurology clinic group.

In the matched study, again the authors expressed concerns as this was a small study and patients were matched according to seizure type and duration, but unfortunately not matched to severity of epilepsy.

The audit clearly showed the existence of selection bias as the mean seizure activity index was significantly higher at the epilepsy centre than the neurology clinic.

The systematic review concluded that currently there was no evidence to suggest that epilepsy clinics improve either seizure frequency or seizure severity when compared to neurology outpatient clinics and that more research is needed to determine the most clinically effective model of service provision for people with epilepsy.

Similarly, a Cochrane review<sup>9</sup> on epilepsy clinics versus general neurology or medical clinics concluded that as yet it is not known whether specialist epilepsy clinics improve outcomes for people with epilepsy. This review failed to identify even a single controlled trial of suitable quality.

### Specialist epilepsy nurses for treating epilepsy

Specialist epilepsy nurses are specially trained nurses that support people with epilepsy and manage any problems that may arise. A Cochrane review<sup>11</sup> considered the evidence from all randomised and quasi-randomised trials, which examined specialist epilepsy nurse interventions with standard care. This review included three trials, two based in general practice and one in a neurology centre. The population of each of the three studies was quite different, as one study excluded patients with learning disabilities, and one only recruited newly diagnosed patients and in view of these differences the review did not attempt to pool results in a meta-analysis. The results suggested that there was no convincing evidence that specialist epilepsy nurses improved outcomes for people with epilepsy, although there was some evidence that those patients who had had an epileptic seizure in the last 6 months were less at risk for depression. There was also some evidence that newly diagnosed patients with poor knowledge about epilepsy may improve their knowledge after nurse consultation. The authors of this review concluded that there was clearly a paucity of research on the effectiveness of specialist epilepsy nurses and that further research is needed.

Similar results were obtained from another systematic review<sup>5</sup>. This review also assessed the cost implications of epilepsy nurses and found that employing epilepsy nurses works out slightly cheaper in the long run because nurse consultations work out cheaper than doctor consultations.

### The role of the GP specialist

Recently increasing attention has been given to the development of an intermediate specialist, in the form of a GP who has received additional training in epilepsy management. This model of service provision involves setting up community satellite clinics to cover each

Primary Care Trust area. The community satellite is proposed as the place where most people would have their diagnosis confirmed by a specialist GP. The specialist GP would be the first point of contact for colleagues and would work in close liaison with district epilepsy services<sup>12,13</sup>.

### Services for adult epileptics with learning disabilities

Epilepsy is common in individuals with learning disabilities. Approximately one-third of patients who have a learning disability have a diagnosis of epilepsy<sup>2</sup>. Also, intractable epilepsy is more common in people with learning disabilities<sup>23</sup>.

CSAG survey of patients and learning disability doctors found that there was often little liaison between consultants for learning disabilities and specialists in epilepsy with a general lack of access for patients to mainstream epilepsy facilities<sup>22</sup>. The survey also found that epilepsy nurses with learning disability training and psychiatric nurses with a special interest in epilepsy were highly valued. People with learning disabilities also reported a lack of co-operation between health, social and education services.

The partnership for Developing Quality Care Pathways in the West Midlands region has developed a care pathway for learning disability patients with epilepsy<sup>24</sup>. Five stages are described in the care pathway. Stage 1 involves allocating a co-ordinator. As epilepsy care commonly involves more than one health care professional, sharing of information between professionals is very important. The use of a co-ordinator is a useful way of facilitating information sharing. Stage 2 involves an assessment of the patient's epilepsy. Stage 3 sets out training requirements for individuals, carers and health care staff. Stage 4 is about setting treatment objectives as only if treatment objectives are explicit can the success of their implementation be measured. Stage 5 involves a review to check on progress towards the objectives. The pathway allows the flexibility to tailor interventions to the needs of the individual whilst maintaining a co-ordinated system.

### Services for complex epilepsy

Approximately 40% of patients will continue to require access to specialist epilepsy services due to one or more of the following problems<sup>2</sup>:

- Unacceptably high rate of seizures despite treatment;
- Still having seizures 2 years after diagnosis;



- Diagnosis remains uncertain; and
- Additional problems such as additional neurological or psychiatric illness or learning difficulties.

At re-referral, if the diagnosis remains uncertain, further tests maybe required. Special EEG studies to record a seizure (using Ambulatory EEG monitoring) should be undertaken.

A high quality Magnetic Resonance Imaging (MRI) is considered mandatory in patients who continue to have seizures after 2 years<sup>2</sup>.

The range of options for this group of patients includes second-line drugs, experimental drugs, epilepsy surgery, inpatient facilities, special assessment centres for epilepsy, specialised neuropsychiatry<sup>2,22</sup>.

Epilepsy surgery should be considered fairly early in individuals with focal epilepsy not responding satisfactorily to anti-epileptic medication.

CSAGs suggestions for improving epilepsy surgery in the UK include a need to increase the awareness of the role of surgery in the treatment of difficult epilepsy among physicians and non-specialists<sup>22</sup>. Epidemiologically 30 people per million per year could be evaluated for epilepsy surgery with approximately one-third (10 per million) progressing to surgery<sup>2</sup>.

Review studies of requirements for epilepsy surgery suggest that pre-surgical evaluation require the following facilities<sup>2,13,22</sup>:

- A team that includes a neurosurgeon, neurophysiologist, neurologist, neuropsychiatrist and neuropsychologist;
- Neurosurgical unit with intensive care facilities;
- High quality MRI and other imaging techniques; and
- EEG Videotelemetry.

Recommendations from CSAG suggest that units must assess at least 50 patients annually in order to maintain the requisite experience. International professional guidelines suggest that no epilepsy surgical unit should be carrying out less than 25 epilepsy operations a year in order to maintain the necessary skills and experience. This also has implications for training, with professional opinion suggesting the establishment of a formal training programme in epilepsy surgery, both for physicians involved in pre-surgical assessment and for neurosurgeons performing the operations<sup>22</sup>.

Inpatient facilities for patients with epilepsy are necessary for acute admissions for seizure exacerbation, elective admission for medication changes where outpatient changes have been problematic, and short-term diagnostic assessment<sup>22</sup>.

The literature suggests that for patients who have problems in diagnosis and treatment that cannot be resolved with outpatient resources or short-term inpatient admission, admission to a special epilepsy assessment unit can be beneficial. These multidisciplinary units admit patients for a period of weeks or months in order to carry out a detailed assessment of medical, social and psychological issues. These units are useful in reassessing the diagnosis, observation, intensive monitoring of seizures, evaluating the relationship between epilepsy and behaviour, and assessing the degrees of social handicap, learning difficulties and educational problems<sup>2,22</sup>.

Areas of overlap exist between epilepsy and psychiatric illness<sup>2,22</sup>. The particular problems are: major affective disorders, e.g. psychosis and depression; identification and management of non-epileptic seizures (pseudoseizures); behavioural and cyclical disorders; and drug-related problems. The clear association between the neurological and psychiatric components mean that any specialised epilepsy services must include a neuropsychiatric component. Neuropsychiatrists also have an important role to play in providing behavioural psychotherapy for refractory epilepsy.

## User views

A survey of an unselected, community-based population of patients with epilepsy was conducted in one UK health region in order to determine patients' satisfaction with their care<sup>16</sup>.

The survey found that doctor's interpersonal skills was the most influential factor affecting patient satisfaction. Patients placed a great importance on having a doctor who was approachable, communicative and knowledgeable. These characteristics were found to be strong predictors for patient satisfaction, whereas clinical features of epilepsy were found to have little influence. A sizeable proportion of patients felt that they had not received enough information from either their GP or hospital doctor. Another noteworthy point was that patients who described their care as shared between GP and hospital were more likely to be satisfied with their overall care. This highlights the important fact that care maybe better delivered once there is improved communication and collaboration between GPs and hospital doctors, with the roles of those providing care being more clearly defined.

Similarly, a survey of patients attending a tertiary referral epilepsy outpatient clinic were found to know more about epilepsy in general than about their own condition, particularly around accurate indications of their drug regimes<sup>17</sup>. This study supports the need for clinicians to check patients' knowledge about their condition. Multidisciplinary services, especially

specialist nurse in epilepsy, were requested by a sizeable percentage of patients. Additional resources such as an on-site epilepsy clinic information centre with leaflets and videos could also be a valuable resource in improving patients' knowledge about epilepsy<sup>17</sup>. Data from a general practice-based audit of epilepsy care showed evidence of poor communication and infrequent clinical review. It was felt from this audit that services could be improved by increased communication between patients, primary and secondary care<sup>18</sup>.

Quantitative surveys of this kind have their limitations. Data about patient satisfaction obtained from structured questionnaires inevitably limits the study's explanatory power. Also, the non-response rate was 25%, and these non-responders maybe the very patients who are most dissatisfied with the care they currently receive. Despite these limitations, the survey has raised some important issues.

The Clinical Services Advisory Group postal survey of patients' views found that the wide spectrum of patient experiences suggests that ability to cope with epilepsy is related to the amount of social support. Health services must address the psychosocial aspects of care in addition to the medical aspects<sup>22</sup>. Most people in this survey found it easy to talk to their GP and of those attending hospital clinics, 73% reported seeing the same doctor on most occasions. However, face-to-face interviews with patients revealed concern over poor communication, lack of continuity in hospital clinics and poor access to information. Patients wanted information on help from social services, lifestyle advice, side effects of drugs, causes and likely course of their epilepsy. Possible solutions suggested included drop-in centres for patients and carers, as well as educational programmes to increase public acceptance of people with epilepsy. Satisfaction with care was higher in patients attending epilepsy clinics, especially those with continuing epilepsy. The study also showed that many patients would be content to be managed at primary care level, which is appropriate for individuals with controlled epilepsy. This shows the need for specialist services to support primary care effectively and improve communication between primary and secondary/tertiary care professionals.

A survey ascertaining patients views on primary care services for epilepsy found that general practice care for epilepsy is presently reactive and that a more structured approach with regular planned reviews could be beneficial for patients<sup>25</sup>. Although patients in this survey were generally content with general practice services, the 'shared care' approach was felt to be the desired option for patients. Like the studies above, this study found the provision of information about epilepsy as being rather poor. An unacceptable 40%

of people could not recall receiving information about driving. Also, nearly 80% could not recall first aid being discussed and only one-third of women received any information about contraception or pregnancy. It was also rare for GPs to change anti-epileptic medication, this was surprising as people in this study had frequent seizures. This situation maybe due to the fact that GPs have little confidence in the use of anti-epileptics or that they do not see themselves as the lead professional. GPs may benefit from educational initiatives.

A review of 10 years of research has explored the information and counselling needs of people with epilepsy<sup>26</sup>. The review aimed to answer three questions:

- What are the information and counselling needs of people with epilepsy?
- What are the preferred formats, timing and delivery of epilepsy information and counselling?
- What are the outcomes of information giving and counselling for people with epilepsy?

Fifteen papers identified specific information needs for epilepsy patients. Results from these papers suggest that patients want information on, epilepsy in general, diagnosis and treatment options, medication and side effects, seizures and seizure control, injury prevention, psychological issues (especially stress), social security, driving and insurance, employment, prognosis, life style and social issues. Counselling issues identified were anxiety, depression, emotional support and information.

Eleven studies identified the epilepsy specialist nurse as a means of meeting some of the information needs of people with epilepsy as well as helping the general communication process between patient and professional.

There was little evidence to suggest the best timing or format of information delivery, although an individualised approach was supported whether information was written or oral. The review also identified the need to assess existing levels of knowledge, attitudes and perceptions and target information appropriately. The precise outcome of epilepsy education is limited from either the patients' perspective or from measurable health outcome perspective. However, six studies showed that information was related to well being, quality of life, coping, control, self-efficacy, and self-esteem.

As with all the surveys reviewed in this literature review, sampling techniques have an inherent bias by focusing on people who are in contact with health services. Those that are excluded from such studies are likely to be those most in need. The needs of this group of patients require further research.

## SELECTION OF EVIDENCE-BASED CRITERIA FOR IDEAL SERVICE PROVISION

The literature is complex, with evidence from different subject areas being relevant to epilepsy services. The quality of evidence is often of a lower grade and much of the information has been gathered from either review articles or consensus statements. However, despite this, certain evidence-based criteria have been established (see below).

### Primary care and the interface with secondary care

GPs should promptly refer possible cases to an epilepsy specialist. GPs should not normally initiate treatment unless the patient faces a long delay in seeing an epilepsy specialist (Grade D).

All patients should be seen by a specialist within 4 weeks of first seizure (Grade D).

Following initial diagnosis and control, the management of epilepsy patients should be primary care based closely integrated with specialist epilepsy services (Grade D).

Primary care based management should include:

- Shared care protocols for new referrals, chronic uncontrolled epilepsy, controlled epilepsy, reproductive issues, psychiatric co-morbidity;
- Information sheets about epilepsy management for GPs and nurses;
- Specialist epilepsy nurses in the community in order to increase the awareness of difficult issues, communication and patient support in the community;
- Epilepsy co-operation cards containing the clinical history of the patient;
- Chronic disease management clinics at general practice level with implementation of a recall system for patients;
- Seminars and training for GPs/practice nurses; and
- GPs should audit their epilepsy practice (Grade B3).

### Accident and emergency management of epilepsy

A proforma for the emergency management of epilepsy, which incorporates guidelines aiding junior and inexperienced doctors, should be introduced (Grade C1).

### Epilepsy clinics

Epilepsy clinics have definite advantages for patients over general neurology clinics in improving access to investigations and specialists, with shorter waiting times. Epilepsy clinics significantly increase the level of advice and patient satisfaction when compared with neurology clinics (Grade B3).

However, there is currently no evidence to suggest that epilepsy clinics improve seizure frequency or severity and further research is needed (Grade A1).

### Specialist epilepsy nurses

Epilepsy nurses improve patient satisfaction and knowledge and are also less costly than doctor consultations. However currently there is no convincing evidence that specialist epilepsy nurses improve outcomes for people with epilepsy. Further research is needed (Grade A1).

### Role of the specialist GP

The community satellite epilepsy clinic is proposed as the place where most people would have their diagnosis confirmed by a specialist GP. The specialist GP would be the first point of contact for colleagues and would work in close liaison with specialist epilepsy services (Grade D).

### Epileptics with learning disabilities

Care for their epilepsy should be an integral part of the overall care for people with learning disabilities. There is a need for close co-operation between specialist epilepsy services and learning disability teams. There should be a named neurologist and named learning disability consultant responsible for providing and co-ordinating care and advice (Grade B3).

Each person with a learning disability and epilepsy should have a care pathway with an allocated co-ordinator. This should include epilepsy management and liaison arrangements (Grade P).

Epilepsy nurses with learning disability training and psychiatric nurses with a special interest in epilepsy should be part of the team caring for epileptics with learning disabilities (Grade B3).

### Services for complex epilepsy

Patients with the following problems will require review and follow-up specialist epilepsy services:



- Unacceptably high rate of seizures;
- Still having seizures 2 years after diagnosis;
- Diagnosis remains uncertain; and
- Additional problems such as neurological or psychiatric or learning difficulties (Grade D).

At re-referral, if the diagnosis remains uncertain, further tests maybe required. Special EEG studies to record a seizure (using Ambulatory EEG monitoring) should be undertaken (Grade D).

A high quality MRI is considered mandatory in patients who continue to have seizures after 2 years (Grade D).

Epilepsy surgery should be considered fairly early in individuals with focal epilepsy not responding satisfactorily to anti-epileptic medication.

There is a need to increase the awareness of the role of surgery in the treatment of difficult epilepsy among physicians and non-specialists (Grade D).

Pre-surgical evaluation of patients requires the following facilities:

- A team that includes a neurosurgeon, neurophysiologist, neurologist, neuropsychiatrist and neuropsychologist;
- Neurosurgical unit with intensive care facilities;
- High quality MRI and other imaging techniques; and
- EEG Videotelemetry (Grade D).

Epilepsy surgery units must assess at least 50 patients annually in order to maintain the requisite experience. They should be carrying out at least 25 epilepsy operations a year in order to maintain the necessary skills and experience. There needs establishment of a formal training programme in epilepsy surgery, both for physicians involved in pre-surgical assessment and for neurosurgeons performing the operations (Grade D).

Inpatient facilities for patients with epilepsy are necessary for acute admissions for seizure exacerbation, elective admission for medication changes where outpatient changes have been problematic, and short-term diagnostic assessment (Grade D).

Specialised epilepsy assessment units are necessary for patients who have problems in diagnosis and treatment that can not be resolved with outpatient resources or short-term inpatient admission. These multidisciplinary units must admit patients for a period of weeks and months in order to carry out a detailed assessment of medical, social and psychological issues. These units should assess diagnosis, intensively monitor seizures, evaluate the relationship between epilepsy and behaviour, and assess the

degrees of social handicap, learning difficulties and educational problems (Grade D).

The clear association between the neurological and psychiatric components of epilepsy mean that any specialised epilepsy service must include a neuropsychiatric component. There must be close liaison between neuropsychiatrist and epilepsy specialist (Grade D).

## Users views

Specific information needs for epilepsy patients include:

- Epilepsy in general;
- Diagnosis, aetiology and treatment options;
- Medication and side effects;
- Seizures and seizure control;
- Injury prevention;
- Psychological issues (especially stress);
- Social security;
- Driving and insurance;
- Employment;
- Prognosis;
- Life style issues; and
- Social issues (Grade D).

Counselling issues identified include:

- Anxiety;
- Depression; and
- Emotional support and information (Grade D).

The epilepsy specialist nurse should be used to meet some of these information and counselling needs (Grade D).

Provision of leaflets and videos through drop-in centres for patients and carers could also provide a valuable resource (Grade B3).

The format for information delivery (whether written or oral) should be individualised for the patient. There is a need to assess existing levels of knowledge, attitudes and perceptions (Grade D).

## CONCLUSIONS

The effectiveness and value of epilepsy services, particularly in relation to the changes recommended above, must be further researched. Although many of the recommendations are based on evidence of a lower

grade, the direction of the existing evidence obtained from several sources, suggested similar standards for an epilepsy service. It must be added, that although several recommendations have been derived from review articles, these papers had a comprehensive list of references.

More research with robust methodologies is needed in order to determine the most clinically effective model of service provision for people with epilepsy. It must be borne in mind that despite the lack of strong evidence on the effectiveness of epilepsy services, the present quality of care for patients with epilepsy is generally poor and improvements are necessary.

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