This publication has been produced as part of the Joint Epilepsy Council (JEC) Good Practice Initiative, a Section 64 funded project. The Section 64 General Scheme (Section 64 of the Health Services and Public Health Act 1968) represents the greatest single source of financial support that the Department of Health provides to the voluntary sector. The JEC Good Practice Initiative seeks to focus on the implementation and/or barriers to implementation of good practice guidelines for epilepsy care in England.

Authors: Frost S, Crawford P, Mera S, Chappell B.

First published: March 2002

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Registered Charity No: 1061820

Designed and typeset by Clockwork Communications WA3 3HP
Printed in the UK by Gemini Print (Wigan) Ltd. WN4 8DT

If you require further copies of the publication please contact:
Joint Epilepsy Council
c/o Mersey Region Epilepsy Association
Glaxo Neurological Centre
Norton St
Liverpool
L3 8LR

This document is also available in pdf format on the JEC website:
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The Joint Epilepsy Council of the UK and Ireland (JEC) is an umbrella body that exists to enable 21 organisations to work together for the benefit of people with epilepsy.

Referencing
This National Statement should be cited as follows:
## Grades of recommendation - Typology of Supporting Evidence

<table>
<thead>
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<tr>
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<tr>
<td><strong>A2</strong> Other systematic and high quality reviews which synthesise references</td>
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<tr>
<td><strong>B1</strong> Individual RCTs</td>
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<td><strong>B2</strong> Individual non-randomised, experimental/intervention studies</td>
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<tr>
<td><strong>B3</strong> 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</td>
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<tr>
<td><strong>C1</strong> Descriptive and other research or evaluation not in B <em>(e.g. convenience samples)</em></td>
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<tr>
<td><strong>C2</strong> Case studies and examples of good practice</td>
</tr>
<tr>
<td><strong>D</strong> Summary review articles and discussions of relevant literature and conference proceedings not otherwise classified</td>
</tr>
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</table>

### Evidence from expert opinion:
- **P** Professional opinion based on clinical evidence, or reports of committees
- **U** User opinion from Service Users Reference Group or similar
- **C** Carers opinion from Carers Focus Group or similar

*Adopted from*

*Typology of Supporting Evidence in National Service Framework for Older People, Department of Health, March 2001 (page 11).*
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Foreword

“Much more could be done to improve health care and quality of life for people with epilepsy including raising professional awareness, designing a proper framework for care, ensuring that standards of local services are higher and more consistent…”

(Annual Report of the Chief Medical Officer of the Department of Health, 2001)

This comment, made by Chief Medical Officer, Liam Donaldson, highlights the Department of Health’s recognition of the need for improved health services for epilepsy.

This National Statement of Good Practice provides a series of recommendations for attaining high quality National Health Service treatment and care for people with epilepsy in England.

The 1990s saw an increased interest in epilepsy care provision and numerous publications were produced. This National Statement of Good Practice attempts to consolidate all the information and evidence from this previous work in one concise document. All the recommendations made within this National Statement are based on data collected and views expressed in previous work with people with epilepsy, their families and professionals working in the field. By placing an emphasis on medical, social and psychological care, this National Statement reflects the fact that epilepsy has the potential to affect individuals and their families in many areas of their lives.

The National Service Framework for Long Term Health Conditions is due to be implemented in 2005, therefore this National Statement provides a timely opportunity to review the design and delivery of epilepsy services. This should help to ensure that the treatment and care received by people with epilepsy meets their individual needs.

I hope you find this National Statement a valuable and useful resource for improving epilepsy services and I warmly welcome its publication.

Baroness Gould of Potternewton
Chair, All Party Group on Epilepsy


3.1) Immediate Care

**Aims**

- To improve the clinical management of epilepsy with particular emphasis on the role of integrated care.
- To recognise the importance of, and to improve, social and psychological management.

**Standards**

### 3.1A Integrated epilepsy care

a) All people experiencing seizures should have rapid access to diagnostic services and appropriate treatment (Brown et al, 1998; CSAG, 1999). \textit{GRADE P}

b) Planned integrated care covering general practice and specialist epilepsy services is the preferred model of care (Epilepsy Working Group, 1995; CSAG, 1999). \textit{GRADE C2}

c) A Patient Held Record where all parties recognise their role should be developed for each person. This plan should address the clinical, social and psychological needs of the individual. Copies of this plan should be held by all concerned, including the person with epilepsy or their guardian. \textit{GRADE P and U}

### 3.1B Diagnosis

a) All service users presenting with a first seizure should be seen within 28 days of referral (Brown et al, 1993; Epilepsy Task Force 1998; Epilepsy Advisory Board, 2000) to a specialist with an interest in epilepsy. \textit{GRADE P & U}

b) Specialist services should be encouraged to organise first seizure clinics, where investigations and consultation/s can take place on the same day. \textit{GRADE P}

c) The misdiagnosis rate for epilepsy has been estimated to be around 20-30% (Scheepers et al, 1998; Wallace et al, 1997; \textit{GRADE P}); therefore all pertinent information should be collected and extreme care taken before making a diagnosis. The medical history and eyewitness accounts are still the most important pieces of information (SIGN, 1997; Taylor, 2000). \textit{GRADE B3}

d) A level three diagnosis (e.g. a syndromic diagnosis) should be made wherever possible. If not, level two should be attained (e.g. seizure type/s). A diagnosis of simply epilepsy is very rarely, if ever, justified (SIGN, 1997). \textit{GRADE P}

### 3.1C Investigations

All appropriate investigations need to be conveniently available within 28 days (Brown et al, 1998; Epilepsy Advisory Board, 2000). This will help the physician to make decisions quickly and safely, especially concerning the initial diagnosis. Investigatory delays that consequently delay clinical decisions are unacceptable. \textit{GRADE P & U}
3.1D Non-epileptic seizures
Non-epileptic seizures are more common than once thought (King et al, 1982). All staff of each service should be sensitive to the potential diagnosis of non-epileptic seizures and, where appropriate, be able to contribute towards their diagnosis. There are few staff in England that specialise in this area of care. Relevant referral needs to be considered, if and when local knowledge is insufficient. GRADE P

3.1E Communicating a diagnostic decision
An individual's feelings on receiving a diagnosis of epilepsy should be respected. Communicating the diagnostic decision appropriately is arguably as important as making the initial decision itself. Individuals need to be informed fully about their diagnosis and its potential implications, (Cooper and Huitson, 1986; Risdale et al, 1996; Wallace et al, 1997) therefore adequate time should always be allowed for reaction and questions. Privacy is essential. Where needed, access should be provided to other sources of support (Risdale et al, 1996; SIGN, 1997; Wallace et al, 1997; Brown et al, 1998; Epilepsy Task Force, 1998). GRADE P & U

3.1F Early follow-up

a) Support systems should be in place to provide help and information within 7 days of diagnosis. All service users should be able to access relevant follow up with a professional who has the required experience. GRADE P & U

b) This should provide both opportunity for the service user to ask questions about their concerns and for the professional to confirm the facts and issues raised by the diagnosis. GRADE P & U

3.1G Starting treatment

a) People should not be treated if there is uncertainty about the diagnosis (SIGN, 1997). Inappropriate treatment can worsen seizure disorders (Parker et al, 1998), GRADE C1

b) It should not be assumed that everyone diagnosed with epilepsy will want treatment. This matter should always be explored, as non-compliance with prescribed therapies is a major issue (Stanaway et al, 1985). How treatment works should always be explained. GRADE B3

c) Unlike other diagnoses, people with a certain diagnosis of unprovoked generalised tonic-clonic seizures should be offered treatment after the first seizure, if the seizures are associated with previous myoclonic and/or absence seizures (FIR. S.T. Group, 1993). GRADE A1

d) The decision to treat other seizure types may depend on the seizure frequency and severity (SIGN, 1997). GRADE P

e) Seizures arising from alcohol withdrawal and other metabolic or drug-related causes of or sleep deprivation should not routinely be treated with AEDs. Treatment may be considered if there are recurrences suggestive of epilepsy (SIGN, 1997). GRADE P

f) All people developing seizures as a consequence of head injury should be treated but drug withdrawal should be subsequently considered (SIGN, 1997). GRADE P
4 References


### 3.1 National Statement of Good Practice for the Treatment and Care of People who have Epilepsy • 2002 • Joint Epilepsy Council

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<tr>
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*SUDEP* = Sudden unexplained Death in Epilepsy

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<tr>
<td>Felt and enacted stigma</td>
<td>Complex partial seizures</td>
<td>Contact details and information about services provided by voluntary organisations is available from the Joint Epilepsy Council, c/o Mersey Region Epilepsy Association, Glaxo Neurological Centre, Norton Street Liverpool L3 8LR.</td>
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<td>Stress</td>
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<td>Depression</td>
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(Adopted from SIGN, 1997; Epilepsy Association of Scotland 'Epilepsy Checklist'; CSAG, 1999). **GRADE C1**

Information on all these topics is available from the voluntary sector. Specialist Epilepsy Nurses have an important role in this information provision (Taylor, 2000; Wallace et al, 1997; Scambler et al, 1996).
3.4B The Role of General Practice (within integrated care)

General practice has a vital role in the management of epilepsy, especially in the co-ordination of care with particular emphasis on social, psychological and emotional support.

General practice should provide:

a) A comprehensive standard protocol for referral that helps to secure an accurate diagnosis.

b) Access to the best available specialist epilepsy service within reasonable travelling distance.

c) Support pre and post the diagnosis of epilepsy.

d) Guidance about accessing information by using resources such as specialist nurses, local and national voluntary organisations.

e) Prescription and adjustment of AEDs should be recorded in the individuals Patient Held Record.

f) Regular review of individuals on a practice register dependent on severity and changing circumstances. This should be at least annually for all.

g) Re-referral to specialist services when appropriate, i.e. poor control of seizures, adverse events, withdrawal of AEDs, pre-conception etc.

(Taylor, 2000; CSAG, 1999).

GRADE C2

The prevalence of active epilepsy is 5-10 per 1,000 persons.
(Sander and Shorvon, 1996; CSAG, 1997; Brown et al, 1993)
II) Vagal nerve stimulation

Vagal nerve stimulation may be a useful treatment for some individuals. GRADE B1. It is a treatment option that should be considered at a similar time to neurosurgical options (Schachter and Saper, 1998). GRADE P

III) Complementary (Alternative) therapies

There is no data to support the use of complementary therapies instead of AEDs, but there is data to suggest (Betts, 1995) that used in combination with AEDs (complementary) they may benefit some people (Taylor, 2000). This is especially so in those with associated anxiety and depression (Boden et al, 1990). GRADE D

e) Social and psychological care

Professionals should avoid concentrating on clinical issues if the individual’s agenda is different. It is likely that social and psychological issues will be high on the individual’s agenda at differing times (CSAG, 1999; BEA, 2000). GRADE C1. Individuals should be referred to appropriate information and support services (Epilepsy Advisory Board, 2000; Wallace et al, 1997). GRADE B3

f) Information needs

Continuing information and education needs of individuals and their family may vary dependent on the clinical, social and psychological outcome of early care. Continuing care should recognise the importance of accurate information (SIGN, 1997; Cooper and Hutson, 1986; Jain et al, 1993; Risdale, 1996). GRADE P

Epilepsy is as common as insulin-dependent diabetes.
(Boyle et al 1998)
3.3) Remission

Aim

- To increase the number of people who successfully withdraw from therapy.

Standards

3.3A Making a decision

Withdrawal of medication is possible under certain circumstances as it has been shown that twenty years from diagnosis approximately 50% of people will be seizure free and off medication (Annegers and Hauser, 1979). Deciding when remission actually occurs is difficult but it is sensible to discuss withdrawal after two years seizure free (AED Withdrawal Study Group, 1991 - GRADE B1; Taylor, 2000). A decision to start withdrawal of therapy should consider all relevant factors and importantly involve the complete co-operation of the individual (SIGN, 1997; Taylor, 2000).

3.3B Discussing the potential risks and implications

A recurrence of one seizure may have massive implications (for employment, education, driving etc.) therefore each individual should be fully informed through extensive discussion and information provision (Taylor, 2000; SIGN, 1997). GRADE P

3.3C Withdrawing therapies

All AEDs should be withdrawn gradually (Taylor, 2000), especially the barbiturates and benzodiazepines (Berg et al, 1997). GRADE A2
3.4) Specialist Service Requirements and the Role of General practice

Aims

- To outline the multidisciplinary team that is required to provide quality epilepsy services.
- To describe how general practice should contribute to quality epilepsy care.

Standards

3.4A Specialist Epilepsy Services (within integrated care)

a) Dependent on the group of service users, the lead physician should be a consultant with a specialist interest and experience in epilepsy from a relevant speciality (Epilepsy Task Force, 1998; CSAG, 1999; Epilepsy Advisory Board, 2000). GRADE P & U

NB: 'A particular interest in epilepsy' requires substantial experience in the treatment and care of a wide range of people with epilepsy plus a commitment to ongoing professional education.

b) Integrated epilepsy care should also include the following:

I. Swift access to appropriate Neurophysiology and Neuroimaging services, e.g. MRI and video-telemetry.

II. Specialist Epilepsy Nursing.

III. Well developed links to other professional services, e.g. Appropriate in-patient facilities, Psychology, Psychiatry, Social Work, Occupational Therapy, Counselling, Neurosurgical services (traditional, vagal nerve stimulation and gamma knife) and Complementary Therapists.

IV. Access to information, support and other services from the voluntary sector (Brown, 1998; CSAG, 1999). GRADE P & U

c) Some people may require access to the following additional services:

I. Clinical psychology (especially for neurosurgical assessment).

II. Research services, i.e. new therapies in development (Brown et al, 1998). GRADE P
3.2) Continuing Care

Aim

- To improve the medium and long term quality of life for those with epilepsy, whether seizure free or not.

Standards

3.2A On-going Care

Planned integrated care spanning general practice and specialist epilepsy services should continue (Epilepsy Working Group, 1995; CSAG, 1999). GRADE C2

The Patient Held Record where all parties recognise their role should continue. GRADE P

3.2B Specific areas of care

a) Diagnosis

If seizures are continuing the diagnosis should be reviewed and other differential diagnoses ruled out (SIGN, 1997; Epilepsy Task Force, 1998; Scheepers et al, 1998). GRADE B3

b) Investigations

Where relevant, rapid access should be available to further pertinent investigations. These may be new investigations or repeats of previous in an attempt to find new information concerning causation, syndrome or any other relevant reason. GRADE P

c) AEDs

Where the first choice or choices of AEDs have been unsuccessful the specialist team should carefully consider other alternative monotherapy or reasoned polytherapy (Heller et al, 1995; Richens et al, 1994; Turnbull et al, 1985; Mattson et al, 1985; Mattson et al, 1992) GRADE A1

d) Non-pharmaceutical treatment

1) Neurosurgery

All services should provide access to neurosurgery as there is a significant group of people who do not respond satisfactorily to AEDs who will benefit from neurosurgery if selected correctly (Wieser, 1998). GRADE A2

Services should purchase neurosurgical services from specialist centres.

Certain cases of lesional epilepsy may be directly amenable to neurosurgical treatment after suitable work up. Neurosurgery should be considered in ALL client groups after two years of unsuccessful AED treatment (SIGN, 1997; Taylor, 2000; Wallace, 1997; CSAG, 1999). GRADE P
3.5) Education and Monitoring

Aims

- To improve the professional development of people who work in the epilepsy field.
- To improve epilepsy services through review and reflection.

Standards

3.5A Relevant professional education

Staff within the ‘Specialist Service’ should show a commitment to ongoing professional education in epilepsy. A recognised qualification in epilepsy and membership of an appropriate professional body is desirable. e.g. International League Against Epilepsy (ILAE) or Epilepsy Specialist Nurses Association (ESNA).

GRADE P & U

3.5B Monitoring epilepsy services

All epilepsy services should be audited once every five years. Audit protocols for local adaptation are contained within the document, "Adults with Poorly Controlled Epilepsy" by Wallace et al (1997) available from the Royal College of Physicians, London. GRADE P & U

I For an epilepsy service generally

"Audit Measures for the Organisation of an Epilepsy Service"

II For individuals with epilepsy

"Audit Protocol for the Case Notes of a Patient with Epilepsy"
3.1H Anti-epileptic drugs (AEDs)

AEDs are the first line treatment for epilepsy. There is now additional choice in the range of AEDs. Principally the choice of AED should be based on the most appropriate for the person’s seizure type/s and syndrome, their age and sex (Taylor, 2000). Associated consideration should be given to potential adverse effects. There is now a wide variance in the cost of AEDs (British National Formulary, 2001.) Where there is clear evidence that an individual will benefit from a more expensive AED this should not be denied due to budgetary constraints. Although there is no evidence to suggest that one AED is generally more efficacious that any other, there is evidence (Heller et al, 1995; Richens et al, 1994; Turnbull et al, 1985; Mattson et al, 1985; Mattson et al, 1992) that some are more efficacious for certain seizure types and syndromes. There is evidence that some have better adverse event profiles (Richens et al, 1994; Mattson et al, 1992; Brodie et al, 1995). GRADE A1

3.1I Potential social and psychological issues

**Common social issues**

Many people with epilepsy rate social implications as a major problem (Taylor, 2000; Collings, 1994). Where the law allows, suggestions should be made as to how people can safely partake or participate in the normal range of social activities. GRADE C1

**Common psychological issues**

Epilepsy has psychological implications for some people (CSAG, 1999; Jacoby et al, 1996). This should be at the forefront of the service provider’s agenda. A positive attitude communicated by the service provider can be very helpful. More common topics that require addressing are, ‘felt and enacted’ stigma, stress, mood changes (including depression), and family and other relationships. GRADE B3

3.1J Information and education needs of individuals and their family.

**What and when?**

a) The information needs of people with epilepsy and their family are diverse in terms of content and relevance to the individual, and the timing of provision. The following checklist is offered as an aide memoire to ensure that needs are fully explored, if and when relevant:
There is a risk of increased morbidity (Sillanpaa, 1992; Griffin, 1991) (i.e. short and long term consequences of seizures and/or treatment and the effects of social deprivation and increased mortality (Nashef et al, 1995) (twice that of the general population) (Cockerell et al, 1994b; CSAG 1999). The person with epilepsy is also more prone to accidents and concurrent illness (Epilepsy Task Force, 1999a) and educational under achievement (Austin et al, 1998).

Service provision for epilepsy is fragmented throughout England (Epilepsy Task Force, 1999b, CSAG 1999). There is also to date a lack of commitment to the commissioning of specific epilepsy services (Brown et al, 1999). Previous authors (e.g. Brown et al, 1998) have suggested that specific services for epilepsy should be available for all people.

3 Key Interventions

This Statement sets out 5 main components for the development of integrated epilepsy services;

3.1) Immediate Care
3.2) Continuing Care
3.3) Remission
3.4) Specialist Service Requirements and the Role of General Practice
3.5) Education and Monitoring
4. References


5. Acknowledgements

The Research Team would like to thank the members of the Steering Group for their valuable input throughout the course of the project.

Thanks must also go to the Joint Epilepsy Council for initiating and organising the project and to the Department of Health for providing funding through the Section 64 scheme.

Last but not least, thanks to Mike Moran, Dr Henry Smithson and Dr Malcolm Taylor who provided advice on the structure and content of the National Statement.
Introduction

1.1 Aims and scope of the National Statement

The aim of this National Statement is to provide a series of recommendations for attaining high quality National Health Service care for people with epilepsy in England.

The statement is principally aimed at facilitating commissioning and will therefore be of use to purchasers, providers and service users.

Epilepsy has the potential to affect individuals and their families in many areas of their lives, e.g. education, employment and relationships (Taylor, 2000; BEA, 2000). This National Statement reflects this by placing an emphasis on medical, social and psychological care.

Rationale

2.1 Background

The 1990s saw an increasing interest in the epilepsies and care provision. There were numerous publications (Service Development Kit, Epilepsy Care: Making it Happen, Adults with Poorly Controlled Epilepsy, CSAG Report, SIGN Guidelines) and this National Statement attempts to take all the information from this previous work and consolidate the evidence in one brief document. All the recommendations made here are based on the data collected and views expressed in this previous work with people with epilepsy, their families and professionals working in the field.

Epilepsy is the most common of the serious neurological conditions
(Brown et al, 1998)

In preparing this National Statement, the Clinical Standards Advisory Group Report (CSAG) and Scottish Intercollegiate Guidelines Network (SIGN) documents were initially consulted, both of which had a thorough literature search strategy of their own. Further MEDLINE searches were carried out and standard textbooks and other important reports (e.g. Epilepsy Task Force Survey) were also consulted.

2.2 The epilepsies and commissioning

Epilepsy is the most common of the serious neurological conditions (Brown et al, 1998). It affects over 300,000 people in the UK (Cockerell et al, 1994a). Its estimated incidence is around 50 - 80 per 100,000 persons per annum (Wallace et al, 1998; Hauser and Annegers, 1993; Brown et al, 1998). This means that in the average Primary Care Trust of 250,000 people between 125 - 200 will develop epilepsy per annum. The incidence is greater in children and older people (Hauser and Annegers, 1993; Brown et al, 1998). The prevalence of active epilepsy is 5-10 per 1,000 persons (Sander and Shorvon, 1996; CSAG 1999; Brown et al, 1993). It is as common as insulin dependent diabetes (Boyle et al 1998).

Around 70% of people have the potential to become seizure free (Annegers 1979; Hauser and Annegers, 1993; Griffin 1991; Wallace et al, 1997; Taylor, 2000). The other 30% will continue to have seizures despite optimum care.