

Provision of clinical services for people with epilepsy

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Epilepsy is one of the most common neurological conditions yet in the UK provision of care for people with epilepsy is patchy. Since 1948 there have been six government-sponsored reports into epilepsy services¹. The Clinical Standards Advisory Group (CSAG) report, published in 2000², stated that still 'there is a lack of focus for services for people with epilepsy and lack of co-ordination between primary care, secondary care, specialist centres and the voluntary sector'.

In 1997 the Scottish Intercollegiate Guidelines Network (SIGN) produced guidelines for the management of epilepsy³, and these were updated in 2003⁴. The National Sentinel Clinical Audit of epilepsy-related death was published in 2002, and reported that a majority of people had received inadequate secondary care and that many deaths were potentially or probably avoidable¹. In response to this, the Department of Health published its Action Plan⁵ which focused the attention of health departments on epilepsy. The report by the All Party Parliamentary Group (APPG) on epilepsy called for a review of the Action Plan and also for an assessment of its implementation⁶. Since the Action Plan, numerous government initiatives and reports have included epilepsy in their recommendations. Particularly relevant are the NICE guidelines on the diagnosis and management of the epilepsies in adults and children in primary and secondary care⁷, which are due to be updated, and the NICE technology appraisals on newer drugs for epilepsy^{8,9}. The APPG is concerned that the guidelines are not being implemented however⁶. NICE has also developed a commissioning guide for the accurate diagnosis of the epilepsies in adults¹⁰, and is planning to produce Quality Standards for epilepsy¹¹. The National Service Framework into long-term conditions mentions epilepsy¹². Other publications, including the Expert Patients Programme¹³, and the white paper 'Our health, our care, our say'¹⁴ encourage the participation of patients in their care. The National Primary and Care Trust Development Programme (NatPaCT) included a competency framework for epilepsy services encouraging the use of practice epilepsy registers, regular check-ups of people with epilepsy and effective links with secondary care providers¹⁵. Various non-government organisations have also published recommendations to improve epilepsy care.

Modern understanding of epilepsy began in the nineteenth century¹⁶ when it was recognised that epilepsy was a symptom of a variety of disorders. Despite the fact that many of the founding fathers of British neurology had an interest in epilepsy¹⁷, their successors became disinterested in the subject. Indeed, at the time of the inception of the National Health Service in 1948, there were about 50 neurologists in the UK, mainly in and around London, of whom only one or two had a major interest in epilepsy. By the time of the CSAG report there were about 330 consultant neurologists in the UK, relatively few of whom had a specialist interest in epilepsy. There are far fewer consultant neurologists in the UK than in France, the Netherlands or Italy¹⁸ and the APPG recommended substantial increases in the number of neurologists in England⁶.

The new contract for GPs was introduced in 2004, and brought about a major change in funding. The contract includes quality markers, and associated financial incentives, for the

management of various conditions, including epilepsy. Practices wishing to gain this funding should be able to produce a register of adults receiving drug treatment for epilepsy. They also receive funding for the percentage of patients aged 18 and over who have a record of seizure frequency, for those aged 18 and over who are seizure-free and for the number of women of childbearing age who have received information and counselling about reproductive issues, all in the previous 15 months¹⁹. In England in 2009–10, the average percentage of epilepsy points achieved was almost 95%²⁰. Intuitively it would seem that improved record keeping would translate into improved quality of care, and thence into improved quality of life for people with epilepsy; there are no randomised controlled trials available to support or refute this notion. The way in which the review is performed will impact on the effectiveness of the process. If the activity is seen merely as a ‘tick-box’ exercise, then little will change for the better for people with epilepsy. If, however, GPs undertake proper reviews and react to the problems they encounter, this may improve the lives of people with epilepsy. The APPG made many recommendations regarding this scheme, including that the criteria reflect optimal and not basic care and that a new indicator reflects the number of adults not seizure-free who have been referred to tertiary care, where appropriate⁶. Unfortunately only the recommendation about reproductive issues has been taken up in the most recent quality markers. It is currently not clear how the reorganisation of the NHS will affect people with epilepsy.

The Department of Health Action Plan suggested a specific framework to help develop more GPs and nurses with a special interest in neurology²¹. This is already happening in parts of the UK²². There is, however, no accredited qualification for GPs with a special interest in epilepsy and many Primary Care Trusts (PCTs) do not fund these posts⁶. Epilepsy specialist nurses are seen as pivotal to the care of people with epilepsy^{7,23}, but there are fears that the role is vulnerable.

Primary care

New diagnosis

The diagnosis of epilepsy is largely based on the history of seizures⁴, and the GP may well be the best person to take a detailed history from the patient and any eye-witnesses before salient features are forgotten. A GP with an average sized list can expect to see one or two people with new-onset epilepsy each year²⁴. Because of the potential problems of diagnosis, however, it is recommended that a consultant neurologist, or other specialist with an interest in epilepsy, should see people with a possible diagnosis of epilepsy promptly; the 2003 SIGN and 2004 NICE guidelines both suggest that the diagnosis should be made by an epilepsy specialist, and that patients should be seen within two weeks^{4,7}. The SIGN guidelines also suggest that the ‘shared care management system’ should ‘provide appropriate information’ once a provisional diagnosis has been made, and the individual referred to a specialist centre⁴. The individual should be fully informed of the specialist’s findings, as should the GP²⁴.

The Epilepsy Needs Revisited document²⁵ suggested that GPs should not usually initiate treatment, and the SIGN guidelines confirm this, stating that the decision to start antiepileptic drugs (AEDs) should be made by the individual and epilepsy specialist⁴. The NICE guidelines suggest that an epilepsy specialist should recommend the appropriate treatment, and also plan its continuation in partnership with the individual. It is important that treatment is initiated with the most appropriate AED at diagnosis as, once patients become seizure-free, they may be reluctant to change AEDs, regardless of side effects, particularly if driving licences have been obtained²⁶.

Once the diagnosis has been established, the primary care team can help the individual to understand the implications of epilepsy. The following checklist for the first review of the

patient by the primary healthcare team, after the diagnosis of epilepsy has been made, may be helpful²⁴:

- Discuss the diagnosis
- Review seizure frequency; consider the use of a seizure diary
- Discuss drugs – the benefits and side effects
- Discuss the impact on the patient's lifestyle
- Find out what the patient knows and fill in the gaps
- Provide addresses of patient organisations
- Discuss contraception and pregnancy with women
- Agree a timetable for follow up.

Active epilepsy

About 30% of people who develop epilepsy will continue to have seizures despite treatment with AEDs, and the Epilepsy Needs Revisited document suggested that most of these will require further specialist follow-up²⁵. It is to the GP, however, that most people will have ready access when problems arise. CSAG² recommended that, for people in whom seizure control is sub-optimal, a management plan should be formulated jointly by the hospital and general practice. This would help to alleviate the mismatch which could occur when the person's epilepsy is being looked after by secondary or tertiary care, but when the individual has access only to the GP when acute problems occur. During routine visits, GPs should monitor drug dosages, seizure frequency, adverse drug effects, adherence to AED regimen and any other problems². The NICE guidelines further propose that, for each person with epilepsy, there should be a comprehensive care plan, agreed between the individual and primary and secondary care providers, and which includes medical and lifestyle issues⁷. People should receive appropriate information and education about all aspects of epilepsy, and some can be encouraged to manage their epilepsy more effectively through the Expert Patients Programme¹³.

Controlled epilepsy

It is generally accepted that those no longer experiencing seizures can be returned to primary care with provision for re-referral when necessary. Primary care services for epilepsy, however, vary among practices, and many people receive little epilepsy care, their care being reactive rather than proactive²⁷. The NICE guidelines suggest that people should have a regular structured review, performed by either the GP or specialist depending on the circumstances and severity of epilepsy, which should occur at least once a year⁷. The GP should re-refer the person to secondary care if the seizures are inadequately controlled, or if there are specific medical or lifestyle issues, such as pregnancy or consideration of withdrawal of AEDs.

Those not under current review

There may be problems in attempting to review all people with epilepsy, particularly those who have not been reviewed for some years. People may not wish to be reminded of the diagnosis, which may have been denied or concealed¹⁶, and there may be anxiety about the prospect of change²⁸. The best time to offer a review may be when a prescription is due¹⁶. In keeping with the goal of person-centred medicine, it is suggested that the first requirement is to define the main problems as seen by the person; whether directly seizure related, AED side effects or psychosocial problems¹⁶. The correctness of the diagnosis should be challenged, the frequency and severity of seizures ascertained, and all aspects of AED therapy, including adherence to drug regimen, discussed.

It has been shown that reviewing people with epilepsy in general practice, reducing polytherapy and changing treatment, can improve seizure control in over one-quarter of

patients, and reduce side effects in almost one-quarter¹⁶. In many cases, however, re-referral to specialist care for these alterations may be more appropriate.

Specialist care

The CSAG report recommended that epilepsy care should be based on epilepsy centres. These would be well organised with good links to other services and with emphasis on shared care and communication between the centre and general practices².

The NICE guidelines do not specifically address models of care, nor recommend what form of service configuration can best provide the resources required. A Cochrane Review found only one study investigating the benefit of clinics held at a specialist epilepsy unit²⁹. The study had a weak design and the review concluded that there was no robust evidence for benefit of the specialist clinic. Nevertheless, several studies have shown that neurology opinions may contribute useful advice to, or change the diagnosis in, patients previously under the care of non-neurologists^{30,31}, and the Association of British Neurologists states that neurologists who specialise in epilepsy (or other conditions) are better at managing those conditions than neurologists without such a specialism¹⁸. Whatever form the clinics take, there is agreement that people needing specialist care for epilepsy should be treated by a specialist with an interest in epilepsy. A recent study from the north of England suggested that older people with epilepsy are less likely than younger people to be referred to specialist epilepsy services³².

New diagnosis

The function of the hospital service in people who develop seizures is to:

- Confirm the diagnosis
- Initiate treatment, if indicated
- Provide initial counselling and information to patients and their families
- Monitor the response to the initial treatment, and
- Refer the patient back to the GP if the condition is stable²⁵.

The NICE guidelines⁷ propose that the diagnosis of epilepsy should be established by specialist practitioners with training and expertise in epilepsy. (Misdiagnosis of epilepsy is common, occurring in up to one-quarter of patients referred to a specialist clinic³³ and in at least one-fifth of people from primary care who were assessed by a specialist³⁴; there may be physical, psychosocial and socioeconomic consequences of a misdiagnosis.) After a detailed history of the attack has been obtained from the patient and any eye-witnesses, a full physical examination, including cardiac, neurological and mental state, should be carried out. Appropriate investigations should be available where necessary. The guidelines stress that information on how to recognise a seizure and first-aid for seizures should be provided to the individual, to the family and to carers. Some information should be provided while the diagnosis is awaited. Once epilepsy is diagnosed, seizures and syndromes should be classified using a multi-axial diagnostic scheme. The decision to start AED treatment should be made after full discussion of the risks and benefits, taking account of the person's epilepsy syndrome, prognosis and lifestyle. Treatment (where appropriate) should be initiated by the specialist, who should also plan the continuation of treatment, and manage, or provide guidance for, withdrawal of AEDs. The National Service Framework (NSF) for Long-term Conditions¹² requires that people suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment.

Active epilepsy

Those with continuing seizures should benefit from continuing secondary care, with additional investigations and treatments being available. Video telemetry and high resolution MRI may be indicated, and the patient may need to try second-line or experimental drugs, or be assessed for epilepsy surgery²⁵. All people with epilepsy should be able to consult a tertiary care specialist (via the secondary care specialist) should the circumstances require this⁷. Suggested criteria for referral to tertiary care are:

- Epilepsy not controlled with medication within two years, or after two AEDs
- Unacceptable side effects of AEDs
- Presence of a unilateral structural lesion
- Psychological or psychiatric comorbidity
- Diagnostic doubt⁷

Controlled epilepsy

Although those adults who become seizure free will probably not need ongoing secondary care, it is important that re-referral can be swiftly instigated should seizures recur, or circumstances changes (e.g. impending pregnancy). NICE suggests that AED withdrawal should be discussed with adults who have been seizure free for at least two years; it is important that this decision is made by the patient and the specialist after a full discussion of the risks and benefits, and that the withdrawal be under the guidance of the specialist⁷. In children a regular structured review, occurring at least yearly, should be provided by a specialist⁷.

Accident and emergency care

A survey in Leeds in 1998 showed that fewer than a quarter of people with epilepsy-related emergencies seen in A&E were referred for neurological follow-up, noted to be under regular specialist follow-up or admitted to the neurology ward³⁵. A more recent audit of 38 persons with a first seizure seen in an A&E department found that, of 22 people discharged, either with an appointment to see a neurologist or a letter to the GP advising such referral, only 10 (45%) were seen by a neurologist³⁶. The mean wait was 21 weeks, and range 6–44 weeks.

The NICE guidelines recommend that A&E departments should develop protocols to ensure that people with suspected seizures are properly assessed and that, once initial screening has been performed by a suitable physician, referral to a specialist should follow whenever an epileptic seizure is suspected⁷.

Use of AEDs

Drug therapy is the most important part of the management of the epilepsies⁸. In the UK AEDs are generally not prescribed unless the person has had at least two unprovoked seizures, unless there are other factors such as certain EEG abnormalities which make recurrence after a first seizure extremely likely. Therapy with a single AED is recommended wherever possible, but some people will need to try several different AEDs before the seizures are fully controlled, and a minority will need to be treated with two or more AEDs⁸.

Since the late 1980s, ten ‘new’ AEDs have been licensed in the UK, and two recent NICE technology appraisals (newer drugs for epilepsy in adults⁸, and in children⁹) have been published. In adults the use of these newer drugs is recommended in those who have not benefited from the older drugs, or in whom the latter are unsuitable for a variety of reasons such as drug interactions or in women who may become pregnant.

The guideline for children also suggests other qualifications for newer AEDs, such as avoiding the introduction of sodium valproate in a young girl who may need to continue taking it for several years⁹. The UK SANAD study suggested that lamotrigine is an alternative to carbamazepine for people with partial onset seizures³⁷.

Investigations

EEG

In 1998 the Epilepsy Needs Revisited document suggested that every person with newly diagnosed epilepsy should have at least one standard EEG to assist in syndrome diagnosis²⁵. The SIGN guidelines state that EEG is not routinely indicated and should not be used to exclude a diagnosis of epilepsy, but can be used to support the classification⁴. It should be used in young people with generalised seizures to aid classification and detect a photoparoxysmal response. The NICE guidelines agree that an EEG should only be used to support a diagnosis of epilepsy, and should not be used to exclude the diagnosis in cases of probable syncope or non-epileptic attack⁷. Sleep or sleep-deprived EEGs, and video EEG monitoring may be required if diagnostic uncertainty persists.

Neuroimaging

In 1997 it was advised that best practice is to carry out MRI in all people with epilepsy, with the exception of those who have a definite electroclinical diagnosis of idiopathic generalised epilepsy, or benign epilepsy of childhood with centrottemporal spikes. It is particularly indicated where there is evidence of focal onset, evidence of a fixed deficit on examination, and difficulty in gaining or maintaining control of seizures³⁸. The SIGN guidelines suggest that MRI is the current reference standard for epilepsy, but is not routinely required in idiopathic generalised epilepsy with complete response to a first-line AED⁴. The NICE guidelines echo this advice, adding that MRI is also required in people who develop epilepsy under two years of age, or in adulthood⁷. MRI is also important in people with any suggestion of focal onset, and in those in whom seizures fail to respond to first-line medication. CT scanning is used where MRI is unavailable or contraindicated, and in some emergency situations⁷.

Surgery

Surgical treatment for epilepsy is sometimes suitable for people who have partial epilepsy resistant to drug treatment (having not gained seizure control with two appropriate AEDs in adequate dosage)⁴. Assessment for surgery should be carried out in a specialist unit⁴.

Information provision

Most epilepsy publications stress the importance of information provision for people with epilepsy^{2,24,25,39,40}. Much information is crucial to the health and safety of the person with epilepsy, while other information is important in encouraging adherence to the AED regime and reducing the stigma of epilepsy.

References

1. HANNA NJ, BLACK M, SANDER JW et al. The National Sentinel Clinical Audit of Epilepsy-Related Death: Epilepsy - Death in the Shadows. London: The Stationery Office, 2002.
2. CSAG. Services for Patients with Epilepsy. London: Department of Health, 2000.
3. SIGN. Diagnosis and Management of Epilepsy in Adults. Edinburgh: Royal College of Physicians, 1997.
4. SIGN. Diagnosis and Management of Epilepsy in Adults. Edinburgh: Royal College of Physicians, 2003.
5. Department of Health. Improving Services for People with Epilepsy. London: Department of Health, 2003.
6. All Party Parliamentary Group on Epilepsy. Wasted money wasted lives. London: The Stationery Office, 2007.

7. NICE. The diagnosis and management of the epilepsies in adults and children in primary and secondary care. Clinical guidelines CG20. London: NICE, 2004.
8. NICE. Newer drugs for epilepsy in adults. Technology appraisals, TA76. London: NICE, 2004.
9. NICE. Newer drugs for epilepsy in children. Technology appraisals TA79, London: NICE, 2004.
10. NICE. Commissioning a service for the accurate diagnosis of the epilepsies in adults. London: NICE, 2008.
11. Thirty-one new quality standards to be developed by NICE. http://www.nhsemployers.org/SiteCollectionDocuments/11-12_QOF807_6_Summary_of_11-12_QOF_indicators_changes_bt11032011.pdf, 2011.
12. Department of Health. National Service Framework for Long-term conditions. London: Department of Health, 2005.
13. Department of Health. Expert Patients Programme: A new approach to chronic disease management for the 21st century. London: Department of Health, 2005.
14. Department of Health. Our Health, Our Care, Our Say: a new direction for community services. London: Department of Health, 2006.
15. NatPaCT. Clinical quality: Epilepsy Services. NatPaCT, 2005.
16. TAYLOR MP. *Managing Epilepsy: a Clinical Handbook*. Oxford: Blackwell Science, 2000.
17. SANDER JW, BARCLAY J, SHORVON SD. The neurological founding fathers of the National Society for Epilepsy and of the Chalfont Centre for Epilepsy. *J Neurol Neurosurg Psychiatry* 1993;56:599-604.
18. HUMPHREY P, BATEMAN D, BRACEWELL M, COCK H, COMPSTON A, NICHOLS P. Acute Neurological Emergencies in Adults. London: Association of British Neurologists, 2002.
19. NHS Employers. Changes to QOF 2011. Available at: http://www.nhsemployers.org/SiteCollectionDocuments/11-12_QOF807_6_Summary_of_11-12_QOF_indicators_changes_bt11032011.pdf.
20. The Information Centre. Quality and Outcomes Framework (QOF) for April 2009– March 2010, England. Available at: <http://www.ic.nhs.uk/statistics-and-data-collections/supporting-information/audits-and-performance/the-quality-and-outcomes-framework/qof-2009-10/data-tables/england-level-data-tables>.
21. Department of Health. Guidelines for the appointment of General Practitioners with special interests in the delivery of clinical services. London: Department of Health, 2003.
22. ROGERS G. The future of epilepsy care in general practice: a role for the GPWsi? *Br J Gen Pract* 2002;52:872-873.
23. Clinical Standards Advisory Group. Services for Patients with Epilepsy. London: Department of Health, 2000.
24. HALL B, MARTIN E, SMITHSON WH. Epilepsy. A General Practice Problem. London: Royal College of General Practitioners, 1997.
25. BROWN S, BETTS T, CRAWFORD P, HALL B, SHORVON S, WALLACE S. Epilepsy needs revisited: a revised epilepsy needs document for the UK. *Seizure* 1998;7:435-446.
26. GOODWIN M, WADE D, LUKE B, DAVIES P. A survey of a novel epilepsy clinic. *Seizure* 2002;11:519-522.
27. CHAPPELL B, SMITHSON WH. Patient views on primary care services for epilepsy and areas where additional professional knowledge would be welcome. *Seizure* 1998;7:447-457.
28. ELWYN G, TODD S, HIBBS R et al. A 'real puzzle': the views of patients with epilepsy about the organisation of care. *BMC Fam Pract* 2003;4:4-9.
29. BRADLEY P, LINDSAY B. Care delivery and self-management strategies for adults with epilepsy. *Cochrane Database Syst Rev* 2008;Jan 23(1):CD006244.
30. HILLEN ME, SAGE JI. Proving the worth of neurologists. *Neurology* 1996;46:276-277.
31. STEIGER MJ, ENEVOLDSON TP, HAMMANS SR, GINSBERG L. Influence of obtaining a neurological opinion on the diagnosis and management of hospital inpatients. *J Neurol Neurosurg Psychiatry* 1996;61:653-654.
32. REUBER M, TORANE P, MACK C. Do older adults have equitable access to specialist epilepsy services? *Epilepsia* 2010;51:2341-2343.
33. SMITH D, DEFALLA BA, CHADWICK DW. The misdiagnosis of epilepsy and the management of refractory epilepsy in a specialist clinic. *Q J Med* 1999;92:15-23.
34. SCHEEPERS B, CLOUGH P, PICKLES C. The misdiagnosis of epilepsy: findings of a population study. *Seizure* 1998;7:403-406.
35. REUBER M, HATTINGH L, GOULDING PJ. Epileptological emergencies in accident and emergency: a survey at St James's university hospital, Leeds. *Seizure* 2000;9:216-220.
36. BHATT H, MATHARU MS, HENDERSON K, GREENWOOD R. An audit of first seizures presenting to an Accident and Emergency Department. *Seizure* 2005;14:58-61.
37. MARSON AG, AL-KHARUSI AM, ALWAIDH M et al. The SANAD study of effectiveness of carbamazepine, gabapentin, lamotrigine, oxcarbazepine, or topiramate for treatment of partial epilepsy: an unblinded randomised controlled trial. *Lancet* 2007;369:1000-1015.
38. Wallace HK, Shorvon SD, Hopkins A, O'Donoghue MF. Adults with poorly controlled epilepsy: Guidelines for treatment. London: Royal College of Physicians, 1997.
39. CHAPPELL B, HALL WW. Managing epilepsy in general practice: the dissemination and uptake of a free audit package, and collated results from 12 practices in England and Wales. *Seizure* 1997;6:9-12.
40. SMITH PE, LEACH JP. Epilepsy: time for review. *Q J Med* 2003;96:87-89.