

Provision of clinical services for people with epilepsy

G.S. BELL¹ and R.S.N LIU²

¹UCL Institute of Neurology, National Hospital for Neurology and Neurosurgery, Queen Square, London, and Epilepsy Society, Chalfont St Peter, Buckinghamshire, and ²Royal Free London NHS Foundation Trust, Hampstead, London

Epilepsy is the most common serious neurological condition in the UK yet provision of care for people with epilepsy is patchy. The Clinical Standards Advisory Group (CSAG) report, published in 2000¹, noted ‘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’. Epilepsy has been highlighted as a national priority for action since 2001.

In 1997 the Scottish Intercollegiate Guidelines Network (SIGN) produced guidelines for the management of epilepsy², which were updated in 2003 and 2005³. 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 estimated that 39% of adults’ and 59% of children’s epilepsy-related deaths were potentially or probably avoidable⁴. In response to this, the Department of Health published its Action Plan⁵ which focused the attention of health departments on epilepsy. Since the Action Plan, numerous government initiatives and reports have included epilepsy in their recommendations – most notably the NICE guidelines on the diagnosis and management of the epilepsies in adults and children in primary and secondary care. Key points of the NICE guidelines were later summarised in the 2013 Quality Standards in Epilepsy (QS26)⁶, which provide a blueprint for epilepsy care in the UK. Epilepsy was the first neurological condition to be given quality standards (Table 1).

1.	Adults presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within two weeks of presentation.
2.	Adults having initial investigations for epilepsy undergo the tests within four weeks of them being requested.
3.	Adults who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.
4.	Adults with epilepsy have an agreed and comprehensive written epilepsy care plan.
5.	Adults with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.
6.	Adults with a history of prolonged or repeated seizures have an agreed written emergency care plan.
7.	Adults who meet the criteria for referral to a tertiary care specialist are seen within four weeks of referral.
8.	Adults with epilepsy who have medical or lifestyle issues that need review are referred to specialist epilepsy services.
9.	Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

In their report ‘Epilepsy in England: time for change’ (2009), Epilepsy Action highlighted the wide variation in provision of epilepsy services, with many Trusts and PCTs failing to meet the recommendations made by NICE⁷. Problems included:

- Inadequate access to specialists in epilepsy. Over half of all Acute Trusts and 64% of PCTs did not employ an epilepsy specialist nurse; and almost half of Acute Trusts surveyed did not employ an epilepsy specialist
- Excessive waiting times for a first appointment (over 90% of Acute Trusts did not meet two-week waiting times)
- Inadequate access to diagnostic tests
- Lack of care plans and transitional services.

More recently in 2012 and 2014, two UK-wide epilepsy audits of hospitals with an emergency department (ED) provided site-specific quality standards benchmarked against all participating UK sites⁸. Although a small shift towards better care was seen between the first and second National audit, on each occasion a wide variation in quality was observed and much epilepsy care remained sub-optimal. Over half of individuals presenting to the ED were on monotherapy with one of the older antiepileptic drugs (AEDs) and were not under specialist review; and less than half the patients were referred onwards for specialist neurology input. What is evident is that there continues to be significant geographic and socioeconomic inequity in access to epilepsy care. Inadequate epilepsy care has significant financial ramifications as a result of unnecessary hospital admissions, epilepsy misdiagnosis, inappropriate use of emergency department resources and paramedic call-outs, and poor AED prescribing^{8,9}.

The National Service Framework, which sets out a programme for ten years to improve care of people with long-term conditions, mentions epilepsy¹⁰. Other publications, including the Expert Patients Programme¹¹, and the White Paper ‘Our health, our care, our say’¹² encourage the participation of patients in their care. The chronic disease management (CDM) model was set up as part of an international drive to improve the quality of long-term care while containing health care costs¹³ (Table 2). Components of this model are highly applicable to epilepsy care.

Self-management	Integrated care	Clinical guidelines	Clinical information systems
Knowledgeable patient	Improve continuity and coordination of care	Evidence-based treatment and care	Timely sharing and exchange of clinical information
Active patient participation in partnership with healthcare practitioners	Multi-professional collaboration	Enhance quality and safety	Web-based electronic patient records
Improve compliance and adopt healthier lifestyles	Primary and specialist care partnership	Improve consistency of care	Health service monitoring, evaluation and planning
	Role expansion, e.g. nurse specialists	More efficient use of healthcare resources	

Primary care

The General Medical Services (GMS) contract was introduced in 2004 and is the contract between general practices and NHS England for delivering primary care services to local communities. Around the same time the government introduced the Quality and Outcomes Framework (QOF) which rewards GPs for the provision of quality care and helps to standardise improvements in the delivery of primary medical services throughout England. Participation in QOF is voluntary. The framework includes quality markers, and associated financial incentives, for the management of conditions, including epilepsy. For epilepsy, GPs can accumulate points for which they receive payment by demonstrating that they maintain a register of adults receiving drug treatment for epilepsy (read code EP001).

Until 2014, practices also received funding for recording those aged 18 and over who were seizure free (EP002) and the number of women of childbearing age who had received information and counselling about reproductive issues (EP003) in the previous 15 months¹⁴. 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 was performed is likely to have impacted on the effectiveness of the process. If the activity was seen merely as a 'tick-box' exercise, then little would change for the better for people with epilepsy. If, however, GPs undertook proper reviews and reacted to the problems they encountered, this may have improved the lives of people with epilepsy.

Revised indicators for QOF 2014/15 became effective on 1 April 2014. Practices are required to establish and maintain an epilepsy register, but quality indicators EP002 and EP003 have been retired¹⁵.

GPs often perceive their knowledge of epilepsy as inadequate and barriers to implementation of effective epilepsy review in primary care include: lack of incentivisation; the small numbers of people with epilepsy attending GPs leads to a perception of deficient knowledge and expertise; and poor access to secondary services. The Department of Health Action Plan suggested a specific framework to help develop more GPs and nurses with a special interest in neurology¹⁶. There have been GPs with a special interest in epilepsy for some time in parts of the UK¹⁷, and there are around 40 to date. There is, however, no accredited qualification for GPs with a special interest in epilepsy.

New diagnosis

The diagnosis of epilepsy is largely based on the history of seizures³, 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 year¹⁸. Because of the potential problems of diagnosis, 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 2005 SIGN and 2012 NICE guidelines both suggest that the diagnosis should be made by an epilepsy specialist, and that patients should be seen within two weeks^{3,19}. 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 centre³. The individual should be fully informed of the specialist's findings, as should the GP¹⁸.

The Epilepsy Needs Revisited document²⁰ suggested that GPs should not usually initiate treatment. This is reinforced by national guidance stating that the decision to start AEDs should be made by the individual and the epilepsy specialist. The NICE guidelines suggest that an epilepsy specialist should recommend the appropriate treatment, and also plan its continuation in partnership with the individual. 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 helpful¹⁸:

- 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-up²⁰. It is to the GP, however, that most people will have ready access when problems arise. CSAG¹ 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 problems¹. 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 issues¹⁹. 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 Programme¹¹.

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. 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 year¹⁹. Many practices in primary care have built in templates for annual epilepsy reviews with the correct read codes and standardised templates have been incorporated into electronic patient records to facilitate teaching and to guide the review process.

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 concealed²¹, and there may be anxiety about the prospect of change²². The best time to offer a review may be when a prescription is due²¹. 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 problems²¹. 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-quarter²¹. In many cases, however, re-referral to specialist care for these alterations may be more appropriate.

Integrated epilepsy care and community epilepsy schemes

Epilepsy care has traditionally been fragmented, with poor channels of communication between primary and secondary care¹, and between epilepsy specialists and the wider multidisciplinary team. People with chronic epilepsy often have significant comorbidity requiring psychological support and the input of mental health and social care services. Uncoordinated care can lead to inconsistent advice for patients, inappropriate and unnecessary investigations and interventions, and delays in diagnosis and initiation of treatment²³. Improved integration of care is key to improving the quality, safety and efficiency of health services for people with chronic illness.

For some time, community epilepsy nurse specialists, community learning disability nurses and GPs with special interest in epilepsy have helped bridge the gap between primary and secondary care, providing a comprehensive epilepsy service in the community following initial diagnostic evaluation in secondary care. Epilepsy nurse specialists are integral to effective integrated care, evaluating need and access to multi-agency community services, providing information and support to patients, their families and carers, and improving patient knowledge and self-management. To date, the impact of nurse intervention on health outcomes such as impact on unplanned admissions, seizure outcome and cost is largely unexplored, but it is widely acknowledged that epilepsy specialist nurses enhance the integration of epilepsy care and improve patient experience.

There has been a recent move by some clinical commissioning groups (CCGs) to commission and develop more integrated community-based epilepsy services. The strategic vision of one such model (pilot study, Camden CCG) aims to provide a 'Step up and step down service' between primary and secondary care services. Individuals will be seen by epilepsy specialists and an epilepsy specialist nurse in the community, allowing improved communication with GPs and better implementation of epilepsy care plans. People with stable epilepsy and those with complex care needs will be stepped down into the community service, allowing greater access to allied health professionals and improved communication across services. More responsive and proactive care should result in reduced unplanned admissions due to epilepsy. It is anticipated that delivering care in the context of integrated health and social care provision with regular MDT meetings will better address the wider burden of epilepsy (such as social exclusion, anxiety and depression), while offering improved psychosocial support, and better access to employment advice and local support networks.

Integral to effective integrated care is timely sharing and dissemination of clinical information. There is a move towards electronic patient records, which have been in use for some time in primary care, although adoption into secondary care has been slower. A unified care record system is required to enhance coordinated patient care and allow data to be captured and interrogated. Improved integration across primary, secondary and tertiary care and social services should result in improved sharing of information and ultimately improved patient experience

Specialist care

After diagnosis, 20–40% of people with epilepsy will need follow-up in a specialist centre²⁴. 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 practices¹.

The NICE guidelines do not specifically address models of care, or 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 unit²⁵. 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^{26,27}, 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 specialism²⁸. 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 study from the north of England suggested that older people with epilepsy are less likely than younger people to be referred to specialist epilepsy services²⁹.

The transition and transfer of epilepsy care for adolescents is specifically endorsed by NICE¹⁹, SIGN³ and the NSF¹⁰. Transition from paediatric to adolescent services is a major milestone for an adolescent with a chronic illness such as epilepsy, with adjustments in their care and social needs as well as an evolving relationship with their parents and clinicians. Although ‘transfer’ and ‘transition’ are often used interchangeably, transition is a more dynamic process implying a planned and structured move from paediatric to adult care, involving preparation and discussion with the young person, while transfer often represents a single event of passing their medical care either back to their GP or to an adult or specific adolescent service.

Specialist epilepsy care should provide provision for special groups, e.g. adolescents, patients with learning disability and women with epilepsy requiring preconception advice. Such services could conceivably be held either in the community or in specialist units and funding may come from either hospital Trusts or Clinical Commissioning Groups.

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 stable²⁰.

The NICE guidelines¹⁹ 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 clinic³⁰ and in at least one-fifth of people from primary care who were assessed by a specialist³¹; 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 eyewitnesses, 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.

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 surgery or neurostimulation²⁰. All people with epilepsy should be able to consult a tertiary care specialist (via the secondary care specialist) should the circumstances require this¹⁹. 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 doubt¹⁹.

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 change (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 specialist¹⁹. In children a regular structured review, occurring at least yearly, should be provided by a specialist¹⁹.

Accident and emergency care

In line with the findings of the NASH reports, a survey in Leeds in 1998 showed that fewer than one-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 ward³². 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 neurologist³³. The mean wait was 21 weeks (range 6–44 weeks).

The NICE guidelines recommend that A&E departments should develop first seizure protocols to ensure that people with suspected seizures are properly assessed and that, once initial screening has been performed by a suitable physician, urgent referrals to a specialist are made¹⁹.

Patient education and self-management

Most epilepsy publications stress the importance of information provision for people with epilepsy^{1,18,20,34,35}. Empowering individuals to take a more active role in their care is likely to improve their understanding of their condition, develop greater awareness and management of their triggers, encourage adoption of healthier and safer lifestyles and use scarce health services more efficiently. Improved partnership between the individual and clinician in devising a care plan should help to increase treatment adherence. It has been reported that inadequate adherence to AED regimens occurs in 30–60% of patients³⁶. Self-management programmes, e.g. MOSES (Modular Service Package Epilepsy) have been shown to improve knowledge of epilepsy, coping with epilepsy, seizure frequency and tolerability of AEDs³⁷.

Conclusion

In response to ever increasing burdens on our healthcare system and the wide variability in the quality of epilepsy care across the UK, there has to be a change in the way epilepsy and other long-term conditions are managed. Management needs to move away from the episodic reactive model of epilepsy care to a more proactive model that averts or delays unplanned admissions, promotes patient participation through improved self-management and improves the quality of life of those with epilepsy. Although much progress has been made in developing quality standards in epilepsy, in reality, guidelines are often poorly supported and implemented. Transforming epilepsy care requires individual and importantly organisational change in developing new models of integrated care that cross organisational boundaries and provide more pro-active patient-centric care.

References

1. CSAG Services for Patients with Epilepsy. Department of Health, 2000.
2. SIGN. Diagnosis and Management of Epilepsy in Adults. Royal College of Physicians, Edinburgh, 1997.
3. SIGN. Diagnosis and management of epilepsy in adults. Royal College of Physicians, Edinburgh, 2003.
4. HANNA NJ, BLACK M, SANDER JW et al. The National Sentinel Clinical Audit of Epilepsy-Related Death: Epilepsy – death in the shadows. The Stationery Office, 2002.
5. Department of Health. Improving services for people with epilepsy. Department of Health, London, 2003.
6. NICE. Quality standard for the epilepsies in adults. NICE, 2013.
7. Epilepsy Action. Epilepsy in England: time for change. Epilepsy England, 2009.
8. DIXON PA, KIRKHAM JJ, MARSON AG et al. National Audit of Seizure management in Hospitals (NASH): results of the national audit of adult epilepsy in the UK. *BMJ Open* 2015; 5:e007325.
9. JUAREZ-GARCIA A, STOKES T, SHAW B et al. The costs of epilepsy misdiagnosis in England and Wales. *Seizure* 2006; 15:598-605.
10. Department of Health. National Service Framework for long-term conditions. Department of Health, 2005.
11. Department of Health. Expert Patients Programme: A new approach to chronic disease management for the 21st century. Department of Health, 2005.
12. Department of Health. Our health, our care, our say: a new direction for community services. Department of Health, 2006.
13. FITZSIMONS M, NORMAND C, VARLEY J et al. Evidence-based models of care for people with epilepsy. *Epilepsy Behav* 2012; 23:1-6.
14. NHS Employers. Changes to QOF 2011. NHS, 2011.
15. NHS Employers. GMS Contract Quality and Outcomes Framework. NHS, 2014.
16. Department of Health. Guidelines for the appointment of general practitioners with special interests in the delivery of clinical services. Department of Health, 2003.
17. ROGERS G. The future of epilepsy care in general practice... a role for the GPWsi? *Br J Gen Pract* 2002; 52:872-873.
18. HALL B, MARTIN E, SMITHSON WH. Epilepsy. A General Practice Problem. Royal College of General Practitioners, 1997.
19. NICE. The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. NICE 2012.
20. BROWN S, BETTS T, CRAWFORD P et al. Epilepsy needs revisited: a revised epilepsy needs document for the UK. *Seizure* 1998; 7:435-446.
21. TAYLOR MP. Managing Epilepsy: A Clinical Handbook. Oxford: Blackwell Science, 2000.
22. 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.
23. MARCHIBRODA JM. The impact of health information technology on collaborative chronic care management. *J Manag Care Pharm* 2008; 14:S3-11.
24. BROWN S, BETTS T, CHADWICK D et al. An epilepsy needs document. *Seizure* 1993; 2:91-103.
25. Bradley PM, Lindsay B. Care delivery and self-management strategies for adults with epilepsy. *Cochrane Database Syst Rev* 2008;CD006244.
26. HILLEN ME, SAGE JI. Proving the worth of neurologists. *Neurology* 1996; 46:276-277.
27. STEIGER MJ, ENEVOLDSON TP, HAMMANS SR et al. Influence of obtaining a neurological opinion on the diagnosis and management of hospital inpatients. *J Neurol Neurosurg Psychiatry* 1996; 61:653-654.
28. HUMPHREY P, BATEMAN D, BRACEWELL M et al. Acute neurological emergencies in adults. Association of British Neurologists, London, 2002.
29. REUBER M, TORANE P, MACK C. Do older adults have equitable access to specialist epilepsy services? *Epilepsia* 2010; 51:2341-2343.
30. SMITH D, DEFALLA BA, CHADWICK DW. The misdiagnosis of epilepsy and the management of refractory epilepsy in a specialist clinic. *QJM* 1999; 92:15-23.
31. SCHEEPERS B, CLOUGH P, PICKLES C. The misdiagnosis of epilepsy: findings of a population study. *Seizure* 1998; 7:403-406.
32. 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.

33. BHATT H, MATHARU MS, HENDERSON K et al. An audit of first seizures presenting to an Accident and Emergency Department. *Seizure* 2005; 14:58-61.
34. 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.
35. SMITH PE, LEACH JP. Epilepsy: time for review. *QJM* 2003; 96:87-89.
36. FRASER RT, JOHNSON EK, MILLER JW et al. Managing epilepsy well: self-management needs assessment. *Epilepsy Behav* 2011; 20:291-298.
37. MAY TW, PFAFFLIN M. The efficacy of an educational treatment program for patients with epilepsy (MOSES): results of a controlled, randomized study. *Modular Service Package Epilepsy. Epilepsia* 2002; 43:539-549.