Review of epilepsy out-patients is often inadequate. Time constraints encourage a largely reactive approach to ‘follow-ups’, with little questioning of existing diagnoses or exploration of the patient’s agenda, and undue emphasis on counting seizures, adjusting medication, and restating lifestyle and driving restrictions. Compared to new cases, follow-ups in secondary care are more likely to be delegated to less experienced team members: seeing a different doctor at each visit is dispiriting to both parties.

Yet patients with epilepsy certainly require detailed and long-term follow up, not least because the diagnosis is too often incorrect, particularly in non-specialist hands. Epilepsy is diagnosed predominantly on clinical grounds, and where there is doubt, it may be necessary to retake the history (with witness accounts) over several visits. Review appointments also provide an opportunity to check patients’ knowledge, understanding, expectations and beliefs about epilepsy and its lifestyle implications. Further, epilepsy generally requires long-term medication, and this also requires long-term supervision. The choice of treatment, and the need for medication at all, deserves repeated reconsideration. The lessons from felbamate (aplastic anaemia), vigabatrin (visual field constriction), and anti-epileptic teratogenicity, demonstrate the dangers of complacency about the long-term side-effects of anti-epileptic medication.

Existing primary care guidelines recommend annual review of all patients with epilepsy, with re-referral to specialist services when appropriate. However, it appears increasingly necessary to make regular specialist review available to all patients with epilepsy, even those not actively seeking medical attention. Such specialist review would have three main aims: to check diagnoses, to optimize clinical management and to provide information.

Epilepsy is often overdiagnosed in people with recurrent blackouts: other common conditions such as syncope and psychogenic attacks may be to blame. Around 20% of ‘epilepsy’ patients referred to specialist centres, or reviewed in the community, do not have a sustainable diagnosis of epilepsy, and many, including females of reproductive age, will have received potentially toxic medications unnecessarily. Even when correct, a diagnosis of epilepsy is incomplete without an attempt to define an epileptic syndrome. Different syndromes carry different implications for management, prognosis, and the necessary extent of investigation. Advances in imaging now offer the opportunity to refine existing diagnoses by identifying underlying structural disorders in the majority of patients with focal epilepsies.

Treatment choices for epilepsy have broadened considerably in recent years, with eight new anti-epileptic drugs licensed in the UK since 1989, and more to come. With such a range of treatment, freedom from seizures without medication side-effects is now an achievable target for most epileptic patients. Surgery also has an increasing role, especially for mesial temporal sclerosis or isolated cortical dysplasia, yet remains generally underused. There must be many people suitable for such surgery, not currently under specialist follow-up, who are unaware of this potentially curative option.

Informing, empowering, and addressing expectations are also important reasons for review. Empowered patients participate more in clinical decisions and adhere better to prescription plans. There may also be a need to challenge the expectations and beliefs of both patients and doctors. For example, one annual seizure may seem acceptable to a clinician used to patients with frequent attacks, yet remains disastrous for the individual, sustaining anxiety and stigma, threatening employment, and necessitating continued loss of their driving licence. Medication-related sedation can also too easily be accepted (by doctor and patient) as a price worth paying for seizure control. Furthermore, self-imposed or clinician-imposed lifestyle restrictions are not always appropriate to the real risks of seizure.
Realistically, the review process, collaborating with primary care, should first target specific groups. Patients taking vigabatrin are an obvious example, since they require reassessment, regular visual field perimetry and consideration of alternative anti-epileptic medication, owing to their 40% risk of irreversible visual field constriction.9 The fact that it took 9 years from licensing to identify such a common and serious problem offers no reassurance as to the long-term safety of other, newer drugs. Children and teenagers might particularly benefit from review, since a more vigorous approach to their clinical management is justified.10 Complete seizure control, achieved prior to adult social and vocational responsibilities, can potentially avoid the long-term social handicaps of epilepsy. Information previously provided to parents about a child’s epilepsy, must be covered again with the teenager as an individual. Furthermore, teenagers can participate in, even lead, discussions and decisions about their clinical management.

Young women especially should be offered review, checking knowledge of drug interactions with oral contraception, teratogenicity, and the need for pre-conceptual folate supplements. Women contemplating pregnancy require balanced and reliable information about the teratogenic risks of their medication. Unfortunately, such data are currently lacking, and our advice must be based to some extent upon opinion and conjecture. Nevertheless, prospective observational data from the UK Epilepsy and Pregnancy Register show an alarming trend towards valproate being more associated with major congenital malformations than either carbamazepine or lamotrigine.11 There are also suggestions, awaiting prospective evaluation, of increased risk of neurodevelopmental delay among children exposed in utero to anti-epileptic medication.12,13 Despite the absence of conclusive proof and the inherent difficulties in researching this area,14 a case could be made for targeting young women for review, particularly those on valproate, to inform their decisions about long-term treatment.

The Clinical Standards Advisory Group (CSAG) report on epilepsy services (2000)15 highlighted deficiencies in the provision of specialist epilepsy review, and the point has been powerfully re-stated by the recent report on the National Sentinel Clinical Audit of Epilepsy-Related Deaths UK (2002).16 However, the existing lack of a uniform structured provision for epilepsy patients restrains improvements and expansion of the service. There are an estimated 25 000 new epilepsy cases per year in the UK (incidence 0.04%17): assuming that 80% of ‘possible epilepsy’ referrals have other conditions,3 125 000 new cases already require specialist epilepsy assessment each year. Additional provision of specialist review for the existing 300 000 patients with epilepsy in the UK (point prevalence 0.5%18) is clearly underdeliverable at present.

UK neurology consultants are relatively scarce (currently 400 adult and paediatric neurologists for 60 million population), and the promised increases in specialist numbers are likely to be limited and slow in coming. Although some specialist expansion is essential to deliver improved quality of long-term care, other approaches are worth considering. Extending the role of epilepsy nurse specialists, and increasing their numbers as recommended by CSAG,15 would be a useful start. Specialist nurses might also help in supporting epilepsy managed clinical networks, integrating services and encouraging partnerships between groups of hospitals and primary care. It must also be recognized that patients with epilepsy (and other chronic conditions) are themselves ‘experts’, often having acquired the life skills to cope with a chronic condition. Given the wider use of care plans and the support of specialist nurses, patients with epilepsy have the potential to become confident partners with professionals in their care.19

Despite the existing constraints, regular, if infrequent, review of all patients prescribed anti-epileptic medication for seizures must be built into every epilepsy specialist service. We should be asking not only how such review might be provided, but how patients have managed so long without it.

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