Implementing new guidelines on epilepsy management

A clinical audit of sudden unexpected deaths in epilepsy conducted jointly by NICE, the chief medical officer and patient groups (2002) and used to inform the NICE guidelines and its appraisal of drugs used to treat epilepsy (NICE, 2004c; 2004d), revealed disturbing findings about the effects of inadequate services. These included:

- 59 per cent (13/22) of child deaths due to epilepsy in 1999-2000 were potentially or probably avoidable;
- Care was deficient in 77 per cent (17) of these cases;
- 39 per cent (62/158) of adult deaths were potentially or probably avoidable;
- Care was deficient in 54 per cent of such cases (Box 2).

People with epilepsy are at up to three times greater risk of premature death than the general population. Although it is not known what causes unexpected deaths, the most important risk factor is the occurrence of unexpected deaths during sleep. The risk is greater in people who have a specific epilepsy syndrome, particularly absence seizures.


New guidance has been released by the National Institute for Clinical Excellence on the diagnosis and management of epilepsies in adults, children and young people. Appropriate treatment and management can result in up to 70 per cent of people with epilepsy living seizure free. However, there are concerns regarding the shortage of specialists to implement the new guidance.

Moves to improve services available to the 400,000 people in England and Wales with epilepsy require a substantial increase in resources if the National Institute for Clinical Excellence’s (2004a; 2004b) priorities are to be achieved. As reported in Nursing Times (Strachan-Bennett, 2004), current services fall way below NICE recommendations.

There are two sets of guidelines (one for adults and one for children/young people. They set priorities (Box 1), focusing on ensuring management is a partnership between patients and health professionals. People with established epilepsy should have individualised care plans and be reviewed regularly to ensure treatment is effective, and referred appropriately if not.

Those with suspected epilepsy should receive prompt referral for diagnosis, to exclude other conditions, while special consideration should be given to women of child-bearing age, as drugs can have implications for contraception, pregnancy and breastfeeding. Services must also consider the needs of special groups:

- Care of people with learning disabilities should be undertaken by a specialist working with the multi-disciplinary team to ensure seizures can be distinguished from stereotypical and other behaviour patterns;
- People from minority ethnic groups should receive care that considers their cultural and communication needs;
- Older people should receive the same level of monitoring as the general population;
- The transfer of adolescents from paediatric to adult services is managed to ensure a smooth transition.

However, preliminary results of a recent survey by the organisation Epilepsy Action (as yet unpublished) suggest there is a great deal of ground to be made up. For example, only 15 per cent of respondents had a care plan, a key requirement for effective management of the condition. It is also estimated that one-quarter of cases are misdiagnosed, so patients do not receive the appropriate treatment.

**AUTHOR** Ann Shuttleworth, BA, is a freelance health care journalist.

**DIAGNOSIS**
- Patients with a suspected first seizure should be seen within two weeks by a specialist doctor
- Seizure types, epilepsy syndrome aetiology and co-morbidity should be determined

**MANAGEMENT**
- Care should be provided in partnership with patients and their partners/carers, and take account of race, culture and specific needs
- Patients need comprehensive individualised care plans, agreed between the patient, family and/or carer and all relevant professionals
- Drug therapy should be individualised according to the condition, individual lifestyle and preferences

**REVIEW AND REFERRAL**
- Patients should have an annual review, conducted by a specialist or generalist, depending on how well the condition is controlled and/or specific lifestyle issues
- At the review, patients should have access to information on their condition and voluntary organisations, counselling and possible referrals
- If seizures are uncontrolled, patients should be referred to tertiary services within four weeks

**WOMEN OF CHILDBEARING AGE**
- Women/partners should be given information and counselling on contraception, pregnancy, caring for children, breastfeeding and menopause

**REFERENCES**


seizures. However, with appropriate treatment and management up to 70 per cent of people with epilepsy have the potential to be seizure free.

Who will implement the guidelines?
A range of additional medical professionals will be required, in primary and tertiary care, to establish the network of services NICE has called for. However, there is a chronic shortage of appropriately qualified specialists. According to the National Society for Epilepsy, the shortage of specialist neurologists is widely recognised, but neuroradiologists are also in short supply. These practitioners interpret MRI scans to identify potential candidates for curative surgery.

The shortage of epilepsy specialists cannot be addressed quickly, as new specialists need to be trained, but the situation can be improved by passing routine management and review of people whose epilepsy is stable to other appropriately trained professionals. In primary care the Department of Health has published a framework for the development of GPs with special interest (GPwSI) in epilepsy, who will be trained to act as a resource for their area, providing clinical care, education and leadership to other primary care professionals. The new GP contract also offers practices financial incentives for offering specific services in the management of a number of complex conditions, including epilepsy.

The NICE guidelines also acknowledge that epilepsy specialist nurses should be an integral part of the network of care. Specialist nurses can play a key role in helping patients manage their epilepsy by monitoring their condition, providing education to patients, their families, other health professionals and organisations such as schools and employers, and assisting in setting up epilepsy clinics in GP practices. However, as with doctors, there is an acute shortage. Although national figures are not available, Gavin Barlow, Sapphire Scheme coordinator at the organisation Epilepsy Action, estimates there are approximately 130 in the UK, and says this is far from adequate. ‘Three or four hundred wouldn’t go amiss,’ he says. ‘Epilepsy is something that is neglected in many areas of the country.’

Epilepsy Action supported NICE in producing the new guidelines and has a key role in tackling the shortage of epilepsy specialist nurses (ESNs) by providing start-up funding for new posts via its Sapphire Nurses Scheme. These nurses work closely with specialist consultants but run their own clinics, providing a range of services:

- Acting as a specialist resource in the diagnosis, treatment and care of people with epilepsy;
- Promoting good practice;
- Establishing and participating in multidisciplinary training and education programmes for professionals, and promoting wider understanding of epilepsy;
- Encouraging the setting up of specialist epilepsy clinics in GP practices;
- Assisting people attending A&E because of seizures.

To date Epilepsy Action has funded 69 Sapphire nurses, paying salary and travel costs full time for a year or sharing with the employing trust for two years. Other costs such as administration are borne by the trust, which must also give a written undertaking to continue funding the post indefinitely after the Sapphire sponsorship ends.

Bringing on stream over 200 new ESNs would be a huge undertaking for an organisation like Epilepsy Action. ‘We certainly couldn’t cope if we received 100 requests next week as a result of the NICE guidelines, as we are dependent on getting money from our sponsors,’ says Mr Barlow. ‘However, getting trusts to give funding commitment is a long process. It usually takes at least six months of negotiation, and has taken as long as two years in some cases, so provided the requests came in stages I would hope we could manage.’

Mr Barlow believes ESNs are hugely beneficial. ‘These nurses can cut waiting lists as they, instead of the consultant, can see many stable patients,’ he explains. ‘They are a point of contact for patients and families to talk to, and are more accessible than consultants. They are also very good at educating others about the condition – for example they often go to schools to give talks on it.’

Funding
Although the resources required to implement the NICE guidelines have significant funding implications, the Joint Epilepsy Council (2004) believes the measures would be cost-neutral. The council, an umbrella body for 24 epilepsy organisations in the UK and Ireland, says 80,000 people have seizures that could be prevented if they received the level of care provided in the best treatment centres. It estimates eradicating inequalities in care would save over £200m annually – the combined cost of misdiagnosis and spending on disability benefits for people who could be free of seizures if their condition were managed effectively.

Conclusion
Good management of patients with epilepsy can result in a significant reduction in seizures, improving both quantity of quality of life. Nurses have an important role to play in establishing the network of services called for in the NICE Epilepsies guidelines.

Keywords ■ Medicine ■ Epilepsy ■ NICE guidance

References

National Institute for Clinical Excellence (2004a) The Epilepsies: Diagnosis and Management of the Epilepsies in Adults in Primary and Secondary Care. London: NICE.


National Institute for Clinical Excellence (2004c) Newer Drugs for Epilepsy in Adults. London: NICE.


This article has been double-blind peer-reviewed.

For related articles on this subject and links to relevant websites see www.nursingtimes.net