# Updated advice for nurses who care for patients with epilepsy

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# Welcome

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# Introduction

n January 2012, the National Institute for Health and Clinical Excellence (NICE) updated its pharmacological recommendations for the NHS on the management of the epilepsies in adults and children. The updated clinical guideline also includes new advice on the use of the ketogenic diet. It replaces NICE clinical guideline 20, as well as NICE technology appraisals 76 and 79.

A key reason behind the update is the increase in anti-epileptic drugs (AEDs) now being prescribed in the UK; for example, four have been licensed in the last eight years, and there has been variation across the NHS regarding when, how and in what order they should be considered for use (see Table 1 for NICE's definition of "older" and "newer" AEDs).

Previously it has been estimated that the annual cost of established epilepsies was £2 billion, including direct and indirect costs. With an increase in treatment costs likely in coming years, it is essential that the NHS is equipped with advice on which AEDs are proven to be clinically and cost effective for the different types of epilepsy syndrome and seizure. Also, it is important that nurses have up-to-date advice for particular patient groups, such as pregnant and breastfeeding women, the elderly, and for childhood absences and infantile spasms. Similarly, health professionals should be aware of specific advice they should give for patients

## DEFINITION OF EPILEPSY

Epilepsy is a common neurological disorder characterised by recurring seizures. The condition presents by way of seizures, which depend on the area of the brain affected, the pattern and speed of epileptic discharges through the brain, the cause and the age of the individual. Different types of epilepsy have different causes.

Epilepsy has been estimated to affect between 362,000 and 415,000 people in England, although accurate estimates of incidence and prevalence are difficult to achieve because there can be challenges and inaccuracies in identification and diagnosis.

Two-thirds of people with active epilepsy have their epilepsy controlled satisfactorily with AEDs. Other approaches may include surgery. Optimal management improves health outcomes and can also help to minimise other, often detrimental, impacts on social, educational and employment activity.

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#### TABLE 1. "OLDER" AND "NEWER" AEDS

Older AEDs included in NICE's clinical guideline 20 (2004)	Newer AEDs included in NICE's clinical guideline 20 (2004) and technology appraisals 76 and 79	Newer AEDs included in NICE's clinical guideline 137 (2012)
Acetazolamide	Gabapentin	Eslicarbazepine
Carbamazepine	Felbamate	Lacosamide
Clobazam	Lamotrigine	Pregabalin
Clonazepam	Levetiracetam	Rufinamide
Ethosuximide	Oxcarbazepine	Zonisamide
Phenobarbitone	Piracetam	
Phenytoin	Stiripentol	
Primidone	Tiagabine	
Sodium valproate	Topiramate	
Sulthiame	Vigabatrin	

regarding the use of AEDs; for example during pregnancy, alongside contraception, as well as for people who have learning disabilities, repeated seizures in the community and status epilepticus.

#### WHAT NICE RECOMMENDS

Below are some of the key changes to the guideline, under headings which are of relevance or interest to nurses. The recommendations regarding the diagnosis of epilepsy remain unchanged from the original version of the guideline and so are not detailed in this article – for further information about this, please visit: www.nice.org.uk/CG137.

#### Working with patients

• When possible, choose which AED to offer on the basis of the presenting epilepsy

syndrome. If the epilepsy syndrome is not clear at presentation, base the decision on the presenting seizure type(s).

 Consistent supply to the child, young person or adult with epilepsy of a particular manufacturer's AED preparation is recommended, unless the prescriber, in consultation with the child, young person, adult and their family and/or carers as appropriate, considers that this is not a concern. Different preparations of some AEDs may vary in bioavailability or pharmacokinetic profiles and care needs to be taken to avoid reduced effect or excessive side effects. Consult the summary of product characteristics (SPC) and 'British national formulary' (BNF; available at http://bnf.org) on the bioavailability and pharmacokinetic profiles of



individual AEDs, but note that these do not give information on comparing bioavailability of different generic preparations.

- When prescribing sodium valproate to women and girls of present and future childbearing potential, discuss the possible risk of malformation and neurodevelopmental impairments in an unborn child, particularly with high doses of this AED or when using as part of polytherapy.
- Prescribers should consult the Summary of Product Characteristics (SPC) and British National Formulary (BNF) when prescribing AEDs for women and girls who are breastfeeding. The decision regarding AED therapy and breastfeeding should be made between the woman or girl and the prescriber, and be based on the risks and benefits of breastfeeding

against the potential risks of the drug affecting the child.

#### Cost-effective prescribing

Offer carbamazepine or lamotrigine as first-line treatment to children, young people and adults with newly diagnosed focal seizures. Oxcarbazepine, sodium valproate or levetiracetam are recommended as options if carbamazepine and lamotrigine are unsuitable or not tolerated. However levetiracetam should only be recommended provided the acquisition cost of levetiracetam falls to at least 50% of June 2011 value documented in the National Health Service Drug Tariff for England and Wales. This is because at June 2011 costs levetiracetam is not considered to be cost effective.

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#### Evidence-based practice

- The guideline provides guidance on the pharmacological management of different epilepsies including the familiar syndromes and those rarer or more complex syndromes. For the syndromes, such as Dravets, infantile spasms, Lennox-Gastaut, Landau-Kleffner and myoclonic astactic epilepsies, the updated guidance advises professionals to refer to or discuss these patients with tertiary paediatric epilepsy specialists.
- For other epilepsy syndromes and epilepsy seizure types, the updated guideline advises on which AEDs should be offered first and what should be considered if the first drug is not appropriate, ineffective or causes excessive side effects for the individual.
- The guideline continues to recommend monotherapies as the first line treatment, but where this is not possible, it advises on adjunctive therapies, providing best evidence on which AEDs should be considered.
- Adjunctive treatment should be considered if the second well-tolerated AED is ineffective.

#### Health and safety

- A high level of vigilance should be maintained for treatment-emergent adverse effects (e.g. bone health and neuropsychiatric issues).
- Healthcare professionals should be aware of the teratogenic risks in prescribing sodium valproate for girls/women of child bearing potential.



## Managing prolonged or repeated seizures in the community

- Buccal midazolam should be administered as the first line treatment.
- Rectal diazepam should be considered where it is preferred or when buccal midazolam is not available.
- Buccal midazolam and rectal diazepam should be prescribed when the person



has had previous episodes of prolonged or serial convulsive seizures.

 Buccal midazolam should be administered by a clinical person unless specific family members and carers have been trained in its use.

#### THE KETOGENIC DIET

The ketogenic diet is a high-fat, low carbohy-

drate and protein diet designed to mimic the biochemical response of the body to starvation when ketone bodies become the main fuel for the brain's energy demands. It has long been used in the treatment of refractory epilepsy in children, although the exact mechanism of action is unclear. NICE advises that children and young people with epilepsies whose seizures have not responded to appropriate AEDs should be referred to a tertiary paediatric epilepsy specialist for consideration of the use of a ketogenic diet.

There are no data on the use of the ketogenic diet in adults. This may reflect the fact that the diet has been shown to be ineffective and the results unpublished, or, as is more likely, that the diet has never been used in this age group. The updated guideline calls for more research into the effectiveness of the ketogenic diet in adults with epilepsy.

#### CONCLUSION

The updated guideline advises on the pharmacological treatments that should be considered for patients who have seizures and diagnosed epilepsies. The revised recommendations are relevant to both nurse prescribers and nurses who do not currently prescribe. This bulletin touches on some of the key recommendations which have been updated surrounding the pharmacological treatments. For further information (e.g. regarding diagnosis), please visit: www.nice.org.uk/CG137.

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