

## OVERVIEW

In England and Wales there are between 260,000 and 416,000 people with active epilepsy. The incidence of epilepsy is around 50 per 100,000 per annum. The aim of these guidelines is to provide guidance about the diagnosis, initial antiepileptic drug (AED) treatment, management of provoked seizures and the management of people with learning disability and epilepsy. This guideline also makes recommendations relating to contraception, pregnancy and the menopause; models of care for epilepsy and provision of information for patients and carers. Furthermore, this guidance had been developed to help achieve the outcomes set out in "The NHS Outcomes Framework 2011/12" for example reducing the amount of unplanned time spent in hospital for patients with epilepsy.

## MODELS OF CARE

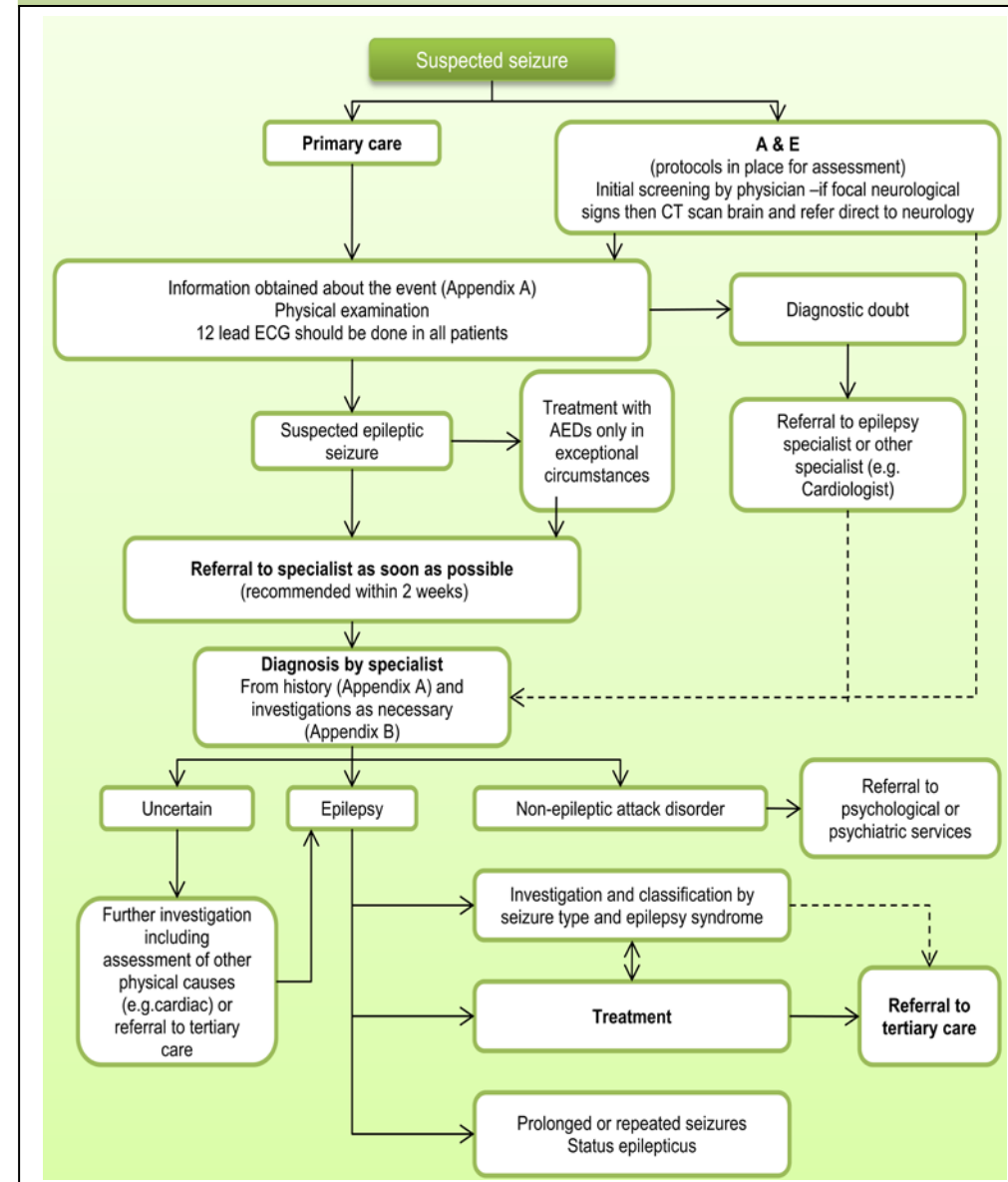
A **structured management system** for epilepsy should be established in primary care. As with other chronic diseases, an **annual review** is desirable.

The shared care management system adopted should seek to:

- Identify all patients with epilepsy, register/record basic demographic data, validate the classification of seizures and syndromes.
- make the provisional diagnosis in patients, provide appropriate information and refer to a specialist centre.
- monitor seizures, aiming to improve control by adjustments of medication or referral to hospital services.
- minimize side effects of medications and their interactions.
- Facilitate structured withdrawal from medication where appropriate, and if agreed by the patient.
- Introduce non-clinical interventions, and disseminate information to help improve quality of life for patients with epilepsy.
- address specific women's issues and needs of patients with learning disabilities.

- Services should be provided in acute hospitals to enable probable recent onset seizures to be seen within two weeks of onset.
- Hospitals should provide services to review people with drug-resistant epilepsy.
- Subspeciality epilepsy clinics should be available to meet the needs of specific groups of patients (epilepsy in learning disability, in pregnancy, in adolescence and in potential surgical candidates).
- Each epilepsy teams should include epilepsy nurse specialists.

## DIAGNOSIS, CLASSIFICATION AND INVESTIGATION



## TREATMENT ALGORITHM

### Starting antiepileptic drug (AED) treatment

The decision to start AEDs should be made by the patient and an epilepsy specialist. AEDs should be offered after a first tonic-clonic seizure if:

- the patient has had previous myoclonic, absence or partial seizures.
- the EEG shows unequivocal epileptic discharges.
- the patient has a congenital neurological deficit.
- the patient considers the risk of recurrence unacceptable.



### Choice of AED monotherapy

Partial and secondary generalized seizures	Primary generalized seizures	Uncertain seizure types
Carbamazepine Lamotrigine Levetiracetam Oxcarbazepine Sodium valproate	Sodium valproate Lamotrigine	Sodium valproate Lamotrigine

Drug treatment should only be started by a neurologist or epilepsy specialist

The side effect and interaction profiles should direct the choice of drug for the individual patient



### Epilepsy resistant to monotherapy

- Review diagnosis of epilepsy and adherence to medication
- Consider combination therapy when:
  - Treatment with two first line AEDs has failed
  - The first well-tolerated drug substantially improves seizure control, but fails to produce seizure freedom at maximal dosage.
  - The choice of drugs in combination should be matched to the patient's seizure type(s) and should be limited to two or at most three AEDs.
- Gabapentin, lacosamide, lamotrigine, levetiracetam, pregabalin, topiramate, zonisamide (alphabetical order) may be considered as adjunctive therapy dependent on patient and seizure type.



### Surgical referral

- Consider if epilepsy is drug resistant, failing to respond to at least two AEDs separately or in combination

## TREATMENT CONTINUED

### Provoked seizures

**Metabolic disturbances/ drugs**  
**Alcohol withdrawal**  
**Acute brain insult/ neurosurgery**

Correct/withdraw the provocative factor.  
Give benzodiazepines in the short term.  
Prophylactic AED treatment is not indicated  
Withdraw AEDs used to treat provoked seizures (*unless unprovoked seizures occur later*).  
AED treatment is not indicated

**Concussive convulsions**

### AED blood levels

- Are NOT routinely indicated (SIGN 2006)
- Can be useful for
  - Adjustment of phenytoin dose
  - Assessment of adherence and toxicity

### AED side effects

Commence AEDs in doses no higher than recommended by manufacturers.  
Warn patient of risks of potential side effects.  
Give instructions to seek urgent medical attention for rash, bruising or somnolence with vomiting.  
Give advice to minimize risk of osteoporosis (see below)  
No need to routinely monitor liver function tests and full blood count although these tests should be done prior to starting treatment.

### AED withdrawal

- Discuss after at least two years seizure freedom.
- Factors to be discussed include: chances of seizure recurrence, driving, employment risks and fear of further seizures and concerns about prolonged AED treatment.
- Withdraw drugs slowly, usually over a few months after consultation with ESN or specialist.

### Psychological treatment of epilepsy

Psychological treatments are not an alternative to pharmacological treatments, but their use can be considered in patients with poorly controlled seizures.

### Vitamin D and bone density

Phenytoin, phenobarbitone, carbamazepine and sodium valproate have been associated with reduced bone mineral density and increased fracture rates which are characteristic of osteoporosis. Vitamin D supplementation should be considered in patients who receive long term treatment with these drugs.

## GENERIC PRESCRIBING IN PATIENTS WITH EPILEPSY SHOULD BE AVOIDED

Changing the formulation or brand of AED is NOT recommended because different preparations may vary in bioavailability or have different pharmacokinetic profiles and, thus, increased potential for reduced effect or excessive side effects.

**Table 1 Main adverse reactions of AEDs, which may be serious and rarely life threatening**

AED	Main adverse reactions	Life threatening
Carbamazepine	Idiosyncratic (rash), sedation, headache, ataxia, nystagmus, diplopia, tremor, impotence, hyponatraemia, cardiac arrhythmia	AHS**, hepatic failure, haematological
Clobazam	Severe sedation, fatigue, drowsiness, behavioural and cognitive impairment, restlessness, aggressiveness, hypersalivation and coordination disturbances. Tolerance and withdrawal syndrome	No
Clonazepam	As for clobazam	No
Gabapentin	Weight gain, peripheral oedema, behavioural changes, impotence, viral infection	Acute pancreatitis, hepatitis, Stevens-Johnson syndrome, acute renal failure
Lacosamide	Dizziness, diplopia, headache, nausea	No
Lamotrigine	Idiosyncratic (rash), tics, insomnia, dizziness, diplopia, headache, ataxia, asthenia	AHS**, hepatic failure, haematological
Levetiracetam	Irritability, behavioural and psychotic changes, asthenia, dizziness, somnolence, headache	Hepatic failure, hepatitis***
Oxcarbazepine	Idiosyncratic (rash), headache, dizziness, weakness, nausea, somnolence, ataxia and diplopia, hyponatraemia	AHS**, haematological
Phenobarbital	Idiosyncratic (rash), severe drowsiness, sedation, impairment of cognition and concentration, hyperkinesias and agitation in children, shoulder-hand syndrome	AHS**, hepatic failure, haematological
Phenytoin	Idiosyncratic (rash), ataxia, drowsiness, lethargy, sedation, encephalopathy, gingival hyperplasia, hirsutism, dysmorphism, rickets, osteomalacia	AHS**, hepatic failure, haematological
Pregabalin	Weight gain, myoclonus, dizziness, somnolence, ataxia, confusion	Renal failure, congestive heart failure
Topiramate	Somnolence, anorexia, fatigue, nervousness, difficulty with concentration/attention, memory impairment, psychomotor slowing, metabolic acidosis, weight loss, language dysfunction, renal calculi, acute angle-closure glaucoma and other ocular	Hepatic failure, anhidrosis
Valproate	Nausea, vomiting, dyspepsia, weight gain, tremor, hair loss, hormonal in women	Hepatic and pancreatic failure
Vigabatrin	Irreversible visual field defects, fatigue, weight gain	No
Zonisamide	Idiosyncratic, drowsiness, anorexia, irritability, photosensitivity, weight loss, renal calculi	AHS**, anhidrosis

\*\*Anticonvulsant hypersensitivity syndrome (AHS), anhidrosis and hepatic/pancreatic failure occur more often in children than in adults. AHS is a potentially fatal but rare reaction that can manifest as a rash, fever, tender lymphadenopathy, hepatitis or eosinophilia. There is usually cross-sensitivity between AEDs, which have the potential to cause AHS; these AEDs should be avoided in patients who have developed idiosyncratic reactions to one or another drug. The appearance of a rash is an early indicator that mandates the immediate discontinuation of the responsible agent because it may progress to Stevens-Johnson syndrome and AHS.

## LEARNING DISABILITY AND EPILEPSY

In the management of people with learning disability and epilepsy:

- Allow adequate time for the consultation
- Ensure the patient is accompanied by the carer familiar with the seizure types, frequency, possible side effects of medication, general health and behavior
- Provide information in an accessible form
- Liaise with other health professional involved
- If midazolam is needed for serial or prolonged seizures:
  - Give recognized training to carers with retraining every two years
  - Draw up and regularly review care plan, agreed between GP and specialist service
- All individuals with epilepsy and learning disability should have a risk assessment including
  - Bathing and showering
  - Preparing food
  - Using electrical equipment
  - Managing prolonged or serial seizures
  - The impact of epilepsy in social settings
  - SUDEP
  - The suitability of independent living, where the rights of the individual are balanced with the role of the carer.

## EPILEPSY IN THE ELDERLY

In the management of elderly people with epilepsy:

- Nearly all de-novo seizures are focal in onset with or without secondary generalization. Underlying factors can often be identified e.g. tumor, dementia, cerebrovascular disease
- Complex partial seizures presenting as confusion may be misdiagnosed as psychiatric symptoms
- Post-ictal confusion can be prolonged in elderly patients
- Elderly patients are particularly sensitive to AED adverse event so low doses are recommended
- Drugs with a high propensity for neurotoxicity should be avoided
- In patients with multiple concomitant medications AEDs that do not have drug-drug interactions are preferred

## REFERENCES

(Scottish Intercollegiate Guidelines Network (SIGN) 2003. Epilepsy Quick Reference Guide. National Institute for Clinical Excellence. The Epilepsies: The diagnosis and management of the epilepsies in adults and children in primary and secondary care. Panayiotopolous, Principles of Anti-Epileptic Drug Therapy 2008  
Brodie, Schachter & Kwan (2005) Epilepsy  
DVLA At a glance guide to current medical standards of fitness to drive 2011

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## EPILEPSY IN WOMEN

Women with epilepsy, who are of childbearing age, need additional advice about such issues as contraception, pregnancy and breastfeeding

- Advice on contraception should be given before young women are sexually active.
- When the combined oral contraceptive is given with an enzyme-inducing AED, a minimum of 50micrograms should be used. Also women should be warned that the pill's efficacy may be reduced. If breakthrough bleeding occurs the dose should be increased. Taking the combined oral contraceptive pill and lamotrigine can result in a significant reduction in lamotrigine levels and lead to loss of seizure control. When a woman starts or stops taking oral contraceptives, the dose of lamotrigine may need to be adjusted.
- Information about the risk of epilepsy and AEDs in pregnancy and the need for folate and vitamin K should be given to all women of childbearing age and repeated at review appointments.
- Pregnancies in women with epilepsy should be supervised in an obstetric clinic with access to a physician in epilepsy.

## DRIVING REGULATIONS

### THE CURRENT EPILEPSY REGULATIONS FOR GROUP 1 AND GROUP 2 ENTITLEMENT

#### GROUP 1

- A person who has suffered an epileptic attack whilst **awake** must refrain from driving for at least **one** year from the date of the attack before a driving licence may be issued.
- A person who has suffered an attack whilst **asleep** must also refrain from driving for at least **one** year from the date of the attack. However, if they have had an attack whilst asleep more than three years previously and have had no attacks whilst awake since that original attack whilst asleep, then they may be licensed even though attacks whilst asleep may continue to occur. If an attack whilst awake subsequently occurs, then the formal epilepsy regulations apply and require at least **one** year off driving from the date of the attack.

#### AND in both cases

- 3) i) so far as practicable, the person complies with advised treatment and check-ups for epilepsy, and
- ii) the driving of a vehicle by such a person should not be likely to cause danger to the public.

#### GUIDANCE FOR CLINICIANS ADVISING PATIENTS TO SURRENDER THEIR DRIVING LICENCE IN THE CASE OF BREAK-THROUGH SEIZURES IN THOSE WITH ESTABLISHED EPILEPSY:

In the event of a seizure, the patient must be advised not to drive unless they are able to meet the conditions of the asleep concessions. The patient should also be advised to notify the DVLA. In exceptional cases (e.g. seizure secondary to prescribing error), the clinician is advised to discuss the circumstances individually with the Medical Adviser at the DVLA before advising the patient on the appropriate licensing procedure.

## INFORMATION FOR PATIENTS AND CARERS

Information should be given in an appropriate manner with sufficient time to answer questions. The type of information given should be recorded in the patient notes

The following checklist should be used to help healthcare professionals to give patients and carers the information they need in an appropriate format:

### General epilepsy information

- Explanation of what epilepsy is\*
- Probable cause
- Explanation of investigational procedures
- Classification of seizures\*
- Syndrome
- Epidemiology
- Prognosis\*
- Genetics
- Sudden Unexpected Death in Epilepsy(SUDEP)

### Antiepileptic drugs

- Choice of drugs\*
- Efficacy\*
- Side effects\*
- Adherence\*
- Drug interactions\*
- Free prescriptions\*

### Possible psychological consequences

- Perceived stigma\*
- Memory loss\*
- Depression
- Anxiety
- Maintaining mental well being
- Self esteem\*
- Sexual difficulties

### Issues for women

- contraception\*
- pre-conception\*
- pregnancy and breastfeeding\*
- menopause

### Seizure triggers

- lack of sleep\*
- alcohol and recreational drugs
- stress\*
- photosensitivity

### Lifestyle

- driving regulations
- employment
- education (e.g. ES guidelines for teachers)

### Support organizations

- Addresses and telephone numbers of national and local epilepsy organizations.

### First Aid

- General guidelines\*
- *Status epilepticus*

\*essential information

## USEFUL CONTACTS AND WEBSITES

Epilepsy Action

National Society for epilepsy

Helpline 0808 800 5050

[www.epilepsy.org.uk](http://www.epilepsy.org.uk)

Helpline 01494 601 400

[www.epilepysociety.org.uk](http://www.epilepysociety.org.uk)

Epilepsy specialist nurse

DVLA

01422 222568

[www.dft.gov.uk/dvla](http://www.dft.gov.uk/dvla)

## APPENDIX A

Important points in history taking in a patient suspected of having had one or more seizures

### Features of the suspected seizure event

Before the event

- Precipitating or provoking factors
- Preceding symptoms
- Duration of symptoms
- 

During the event

- Motor symptoms
- Sensory symptoms
- Level of awareness/ responsiveness
- Tongue biting or other injury
- Urinary incontinence
- Duration of the event
- 

After the event

- Level of alertness
- Confusion
- Duration of symptoms
- 

Pattern of events

- Duration
- Frequency
- Stereotyped or variable

### Patient's History

Previous medical history

- Birth history
- Childhood febrile convulsion(s)
- Severe head trauma of other neurological insult
- Psychiatric illness
- 

Family history

Drug history

- Prescribed medication
- Over-the-counter medication
- Illicit drugs
- Alcohol use

A witness account can be very useful in aiding diagnosis (see appendix D). Also, with the increased availability of video recording with mobile phones. A recording of the actual event(s) can be a great help in reaching an accurate diagnosis

## APPENDIX B

### Investigations

#### Electroencephalography (EEG)

- EEG should not be used to exclude epilepsy.
- EEG can be used to support the diagnosis in patients in whom the clinical history indicates a significant probability of an epileptic seizure or epilepsy.
- EEG should be used to support the classification of epileptic seizures and epilepsy syndromes when there is clinical doubt
- EEG should be performed in young people with generalized seizures to aid classification and to detect a photoparoxysmal response

#### Brain imaging

- Indicated unless there is a confident diagnosis of an idiopathic generalized epilepsy with response to AED treatment
- Magnetic resonance imaging (MRI) is the modality of choice to identify underlying structural pathology.
- Computed tomography (CT) has a role in the urgent assessment of seizures, or when MRI is contraindicated

**Video EEG** and other specialist investigations should be available for patients who present diagnostic difficulties

## APPENDIX C

### Factors lowering seizure threshold

#### Common

- Sleep deprivation
- Alcohol withdrawal
- Television flicker
- Epileptogenic drugs
- Systemic infection
- Head trauma
- Recreational drugs
- Antiepileptic non-compliance
- Menstruation

#### Occasional

- Dehydration
- Barbiturate withdrawal
- Benzodiazepine withdrawal
- Hyperventilation
- Flashing lights
- Diet and missed meals
- Specific 'reflex' triggers
- Stress
- Intense exercise

## CHECKLIST FOR COMPLETION OF AN EYEWITNESS REPORT

- Keep a record of the dates and times that `seizures' occur.
- Where was the person and what were they doing before the seizures?
- Did you notice any mood changes, such as excitement, anxiety or anger?
- Did the person mention any unusual sensations, such as odd taste or smell?
- Did the seizure occur without warning?
- What drew your attention to the person having a seizure (e.g. a cry, a fall, or body movements such as eyes rolling or head turning)?
- Did the person lose consciousness or appear confused?
- Did the person change colour (e.g. become pale, flushed or `blue')? If so, where (e.g. face, lips or hands)?
- Did the person's breathing alter (e.g. become noisy or difficult)?
- Did any part of their body stiffen, jerk or twitch? If so, which?
- Was there incontinence?
- Did they bite their cheek or tongue?
- Did the person do anything unusual such as mumble, wander about, fumble with their clothes or any objects?
- How long did the `seizure' last?
- How was the person after the `seizure'?
- Did the person feel tired, need to sleep? If so, for how long?
- How long was it before the person was able to resume normal activities?
- Did you notice anything else?

## STATUS EPILEPTICUS

### Prevention

Carers should treat serial or prolonged seizures in the community with rectal diazepam according to an agreed protocol (protocol must include advice on when to transfer to hospital).

### Patients with generalized tonic-clonic status epilepticus

IMMEDIATE MEASURES

- Secure airway
- Give oxygen
- Assess cardiac and respiratory function
- Secure intravenous(IV) access in large veins
- Collect blood for bedside blood glucose monitoring and full blood count, urea and electrolytes, liver function tests, calcium, glucose, clotting, AED levels and storage for later analyses.

Give lorazepam 4mg IV (or diazepam 10mg IV if lorazepam is unavailable)

No response?

Repeat after maximum of 10 minutes in hospital

Delay in IV access in community?

Give 10-20mg diazepam rectally

### Determine aetiology

- Any suggestion of hypoglycaemia: give 50ml 50% glucose IV
- Any suggestion of alcohol abuse or impaired nutritional status: give thiamine IV (as 2 pairs ampoules Pabrinex)
- Give usual AED treatment orally or by nasogastric tube (or IV if necessary for phenytoin, sodium valproate and Phenobarbital)

If status persists

WITHIN 30 MINUTES

- Give fosphenytoin 18mg/Kg phenytoin equivalent IV, up to 150mg/min; or phenytoin 18mg/Kg IV, 50mg/min, both with ECG monitoring; or Phenobarbital 15mg/Kg IV, 100mg/min
- Call ITU to inform of patient

If status persists

>30 MINUTES

- administer general anaesthesia and admit to ITU
- monitor using EEG to assess seizure activity
- refer for specialist advice