The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care (partial update of NICE clinical guideline 20)

NICE guideline
Draft for consultation, August 2010

If you wish to comment on this version of the guideline, please be aware that all the supporting information and evidence is contained in the full version.
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This guidance is a partial update of NICE clinical guideline 20 (published October 2004) and will replace it. This guidance also updates NICE technology appraisal 76 (published March 2004) and NICE technology appraisal 79 (published April 2004) and will replace them.

New recommendations have been added for the pharmacological treatment of people with epilepsy, including the use of ketogenic diet.

Where recommendations are shaded in grey and end [2004] the evidence has not been updated since the original guideline. Yellow shading in these recommendations indicates where wording changes have been made for the purposes of clarification only.

You are invited to comment on the new and updated recommendations in this guideline only. These are marked as [2011] if the evidence has been reviewed but no change has been made to the recommendation or [new 2011] if the evidence has been reviewed and the recommendation has been added or updated.

Appendix F contains recommendations from the 2004 guideline that NICE proposes deleting in the 2011 update. This is because the evidence has been reviewed and the recommendation has been updated or because NICE has updated other relevant guidance and has replaced the original recommendations. Where there are replacement recommendations, details are provided. Where there is no replacement recommendation, an explanation for the proposed deletion is given. You are invited to comment on the deleted recommendations as part of the consultation on the 2011 update.

The original NICE guideline and supporting documents are available from www.nice.org.uk/guidance/CG20
Introduction

Epilepsy is a common neurological disorder characterised by recurring seizures. Different types of epilepsy have different causes. Accurate estimates of incidence and prevalence are difficult to achieve because identifying people who may have epilepsy is difficult. Epilepsy has been estimated to affect between 260,000 and 416,000 people in England and Wales. Incidence is estimated to be 50 per 100,000 per year and the prevalence of active epilepsy in the UK is estimated to be 5–10 cases per 1000. Two-thirds of people with active epilepsy have their epilepsy controlled satisfactorily with anti-epileptic drugs (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. ‘The epilepsies’, NICE clinical guideline 20 (2004), stated that the annual estimated cost of established epilepsies was £2 billion (direct and indirect costs).

Newer and more expensive AEDs are now being prescribed, and with an increase in treatment costs likely in coming years it is essential to ensure that AEDs with proven clinical and cost effectiveness are identified. The evidence used to develop NICE clinical guideline 20 and the existing NICE technology appraisal guidance on epilepsy (‘Newer drugs for epilepsy in adults’, NICE technology appraisal guidance 76 [2004] and ‘Newer drugs for epilepsy in children’, NICE technology appraisal guidance 79 [2004]) showed no difference in effectiveness between newer and older AEDs, or between the newer drugs (as monotherapy) for seizure control. However, a recent large multicentre trial (the SANAD trial) evaluating newer drugs in newly diagnosed epilepsy (accepting some limitations) suggested that sodium valproate should be the drug of choice in generalised and unclassifiable epilepsies, and lamotrigine in partial epilepsies. We therefore considered it necessary to review new evidence regarding AEDs within an update of the NICE clinical guideline published in 2004.

The guideline will assume that prescribers will use a drug’s summary of product characteristics to inform decisions made with individual patients.
This guideline recommends some drugs for indications for which they do not have a UK marketing authorisation at the date of publication, if there is good evidence to support that use. Where recommendations have been made for the use of drugs outside their licensed indications ('off-label use'), these drugs are marked with an asterisk.
1 Patient-centred care

This guideline offers best practice advice on the care of adults and children with epilepsy.

Treatment and care should take into account patients’ needs and preferences. People with epilepsy should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. If patients do not have the capacity to make decisions, healthcare professionals should follow the Department of Health’s advice on consent (available from www.dh.gov.uk/consent) and the code of practice that accompanies the Mental Capacity Act (summary available from www.publicguardian.gov.uk). In Wales, healthcare professionals should follow advice on consent from the Welsh Assembly Government (available from www.wales.nhs.uk/consent).

If the patient is under 16, healthcare professionals should follow the guidelines in ‘Seeking consent: working with children’ (available from www.dh.gov.uk/consent).

Good communication between healthcare professionals and patients is essential. It should be supported by evidence-based written information tailored to the patient’s needs. Treatment and care, and the information patients are given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English.

If the patient agrees, families and carers should have the opportunity to be involved in decisions about treatment and care.

Families and carers should also be given the information and support they need.

Care of young people in transition between paediatric and adult services should be planned and managed according to the best practice guidance.

Adult and paediatric healthcare teams should work jointly to provide assessment and services to young people with epilepsy. Diagnosis and management should be reviewed throughout the transition process, and there should be clarity about who is the lead clinician to ensure continuity of care.
Key priorities for implementation

The following recommendations have been identified as priorities for implementation.

**Diagnosis**
- All individuals with a recent onset suspected seizure should be seen urgently\(^1\) by a specialist\(^2\). This is to ensure precise and early diagnosis and initiation of therapy as appropriate to their needs. \([2004]\)

**Management**
- Healthcare professionals should adopt a consulting style that enables the individual with epilepsy, and their family and/or carers as appropriate, to participate as partners in all decisions about their healthcare, and take fully into account their race, culture and any specific needs. \([2004]\)
- All individuals with epilepsy should have a comprehensive care plan that is agreed between the individuals, their family and/or carers as appropriate, and primary and secondary care providers. \([2004]\)
- The AED (anti-epileptic drug) treatment strategy should be individualised according to the seizure type, epilepsy syndrome, co-medication and co-morbidity, the individual’s lifestyle, and the preferences of the individual, their family and/or carers as appropriate. \([2004]\)

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\(^1\) The Guideline Development Group considered that ‘urgently’ meant being seen within 2 weeks.

\(^2\) For adults, a specialist is defined throughout as a medical practitioner with training and expertise in epilepsy. For children, a specialist is defined throughout as a paediatrician with training and expertise in epilepsy.
Prolonged or repeated seizures and convulsive status epilepticus

- Use buccal midazolam* as first-line treatment in adults and children with prolonged or repeated seizures. Use rectal diazepam if buccal midazolam* is not available. If intravenous access is already established and resuscitation facilities are available, offer intravenous lorazepam. [new 2011]
- Only prescribe rectal diazepam or buccal midazolam* for adults and children who have had a previous episode of prolonged or repeated convulsive seizures. [new 2011]

Special considerations for women of childbearing potential

- Women with epilepsy and their partners, as appropriate, must be given accurate information and counselling about contraception, conception, pregnancy, caring for children, breastfeeding and menopause. [2004]

Review and referral

- All individuals with epilepsy should have a regular structured review. In children, this review should be carried out at least yearly (but may be between 3 and 12 months by arrangement) by a specialist. In adults, this review should be carried out at least yearly by either a generalist or specialist, depending on how well the epilepsy is controlled and/or the presence of specific lifestyle issues. [2004]
- At the review, individuals should have access to: written and visual information; counselling services; information about voluntary organisations; epilepsy specialist nurses; timely and appropriate investigations; referral to tertiary services, including surgery, if appropriate. [2004]
- If seizures are not controlled and/or there is diagnostic uncertainty or treatment failure, individuals should be referred to tertiary services soon for further assessment. [2004]
Guidance

The following guidance is based on the best available evidence. The full guideline ([hyperlink to be added for final publication]) gives details of the methods and the evidence used to develop the guidance.

In this guideline, adults are defined as aged 18 years and older and children as aged 28 days to 17 years. Young people are defined as being 12 to 17 years of age. However, it is recognised that there is a variable age range (15–19 years) at which care is transferred between child and adult health services by local healthcare trusts and primary care organisations.

Anti-epileptic drugs will be referred to in this document as AEDs.

1.1 Principle of decision making

1.1.1 Healthcare professionals should adopt a consulting style that enables the individual with epilepsy, and their family and/or carers as appropriate, to participate as partners in all decisions about their healthcare, and take fully into account their race, culture and any specific needs. [2004]

1.2 Coping with epilepsy

1.2.1 People with epilepsy and their families and/or carers should be empowered to manage their condition as well as possible. [2004]

1.2.2 Adults should receive appropriate information and education about all aspects of epilepsy. This may be best achieved and maintained through structured self-management plans. [2004]

1.2.3 In children, self-management of epilepsy may be best achieved through active child-centred training models and interventions. [2004]

1.2.4 Healthcare professionals should highlight the Expert Patients Programme (www.expertpatients.co.uk) to individuals with epilepsy who wish to manage their condition more effectively. [2004]
1.3 Information

1.3.1 Individuals with epilepsy and their families and/or carers should be given, and have access to sources of, information about (where appropriate):

- epilepsy in general
- diagnosis and treatment options
- medication and side effects
- seizure type(s), triggers and seizure control
- management and self-care
- risk management
- first aid, safety and injury prevention at home and at school or work
- psychological issues
- social security benefits and social services
- insurance issues
- education and healthcare at school
- employment and independent living for adults
- importance of disclosing epilepsy at work, if relevant (if further information or clarification is needed, voluntary organisations should be contacted)
- road safety and driving
- prognosis
- sudden death in epilepsy (SUDEP)
- status epilepticus
- lifestyle, leisure and social issues (including recreational drugs, alcohol, sexual activity and sleep deprivation)
- family planning and pregnancy
- voluntary organisations, such as support groups and charitable organisations, and how to contact them. [2004]
1.3.2 The time at which this information should be given will depend on the certainty of the diagnosis, and the need for confirmatory investigations. [2004]

1.3.3 Information should be provided in formats, languages and ways that are suited to the individual’s requirements. Consideration should be given to developmental age, gender, culture and stage of life of the individual. [2004]

1.3.4 If individuals and families and/or carers have not already found high-quality information from voluntary organisations and other sources, healthcare professionals should inform them of different sources (using the Internet, if appropriate: see, for example, the website of the Joint Epilepsy Council of the UK and Ireland, www.jointepilepsycouncil.org.uk). [2004]

1.3.5 Adequate time should be set aside in the consultation to provide information, which should be revisited on subsequent consultations. [2004]

1.3.6 Checklists should be used to remind both individuals and healthcare professionals about information that should be discussed during consultations. [2004]

1.3.7 Everyone providing care or treatment for individuals with epilepsy should be able to provide essential information. [2004]

1.3.8 The person with epilepsy and their family and/or carers as appropriate should know how to contact a named individual when information is needed. This named individual should be a member of the healthcare team and be responsible for ensuring that the information needs of the individual and/or their family and/or carers are met. [2004]

1.3.9 The possibility of having seizures should be discussed, and information on epilepsy should be provided before seizures occur,
for people at high risk of developing seizures (such as after severe brain injury), people with a learning disability, or people who have a strong family history of epilepsy. [2004]

1.3.10 People with epilepsy should be given appropriate information before they make important decisions (for example, regarding pregnancy or employment). [2004]

Sudden death in epilepsy (SUDEP)

1.3.11 Information on SUDEP should be included in literature on epilepsy to show why preventing seizures is important. Tailored information on the individual’s relative risk of SUDEP should be part of the counselling checklist for people with epilepsy and their families and/or carers. [2004]

1.3.12 The risk of SUDEP can be minimised by:

• optimising seizure control
• being aware of the potential consequences of nocturnal seizures. [2004]

1.3.13 Tailored information and discussion between the individual with epilepsy, their family and/or carers (as appropriate) and healthcare professionals should take account of the small but definite risk of SUDEP. [2004]

1.3.14 Where families and/or carers have been affected by SUDEP, healthcare professionals should contact families and/or carers to offer their condolences, invite them to discuss the death, and offer referral to bereavement counselling and a SUDEP support group. [2004]
### 1.4 Following a first seizure

1.4.1 Individuals presenting to an Accident and Emergency department following a suspected seizure should be screened initially. This should be done by an adult or paediatric physician with onward referral to a specialist\(^4\) when an epileptic seizure is suspected or there is diagnostic doubt. [2004]

1.4.2 Protocols should be in place that ensure proper assessment in the emergency setting for individuals presenting with an epileptic seizure (suspected or confirmed). [2004]

1.4.3 The information that should be obtained from the individual and/or family or carer after a suspected seizure is contained in appendix D. [2004]

1.4.4 The information that should be obtained from the child and/or parent or carer after a suspected seizure is contained in appendix D. [2004]

1.4.5 It is recommended that all people having a first seizure should be seen as soon as possible\(^5\) by a specialist in the management of the epilepsies to ensure precise and early diagnosis and initiation of therapy as appropriate to their needs. [2004]

1.4.6 It is recommended that all children who have had a first non-febrile seizure should be seen as soon as possible\(^5\) by a specialist in the management of the epilepsies to ensure precise and early diagnosis and initiation of therapy as appropriate to their needs. [2004]

1.4.7 At the initial assessment for a recent onset seizure, the specialist should have access to appropriate investigations. [2004]

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\(^4\) For adults, a specialist is defined throughout as a medical practitioner with training and expertise in epilepsy. For children, a specialist is defined throughout as a paediatrician with training and expertise in epilepsy.

\(^5\) The GDG considered that with a recent onset suspected seizure, referrals should be urgent, meaning that patients should be seen within 2 weeks.
1.4.8 In an individual presenting with an attack, a physical examination should be carried out. This should address the individual’s cardiac, neurological and mental status, and should include a developmental assessment where appropriate. [2004]

1.4.9 Essential information on how to recognise a seizure, first aid, and the importance of reporting further attacks should be provided to a person who has experienced a possible first seizure, and their family/carer/parent as appropriate. This information should be provided while the individual is awaiting a diagnosis and should also be provided to their family and/or carers. [2004]

1.5 Diagnosis

1.5.1 The diagnosis of epilepsy in adults should be established by a specialist medical practitioner with training and expertise in epilepsy. [2004]

1.5.2 The diagnosis of epilepsy in children should be established by a specialist paediatrician with training and expertise in epilepsy. [2004]

1.5.3 Individuals and their families and/or carers should be given an opportunity to discuss the diagnosis with an appropriate healthcare professional. [2004]

1.5.4 A detailed history should be taken from the individual and an eyewitness to the attack, where possible, to determine whether or not an epileptic seizure is likely to have occurred. [2004]

1.5.5 The clinical decision as to whether an epileptic seizure has occurred should then be based on the combination of the description of the attack and different symptoms. Diagnosis should not be based on the presence or absence of single features. [2004]

1.5.6 It may not be possible to make a definite diagnosis of epilepsy. If the diagnosis cannot be clearly established, further investigations
(see section 1.6) and/or referral to a tertiary centre (see section 1.10.3) should be considered. Follow-up should always be arranged. [2004]

1.5.7 Where non-epileptic attack disorder is suspected, suitable referral should be made to psychological or psychiatric services for further investigation and treatment. [2004]

1.5.8 Prospective recording of events, including video recording and written descriptions, can be very helpful in reaching a diagnosis. [2004]

1.6 Investigations

1.6.1 Information should be provided to individuals and families and/or carers as appropriate on the reasons for tests, their results and meaning, the requirements of specific investigations, and the logistics of obtaining them. [2004]

1.6.2 All investigations for children should be performed in a child-centred environment. [2004]

Electroencephalogram (EEG)

1.6.3 Individuals requiring an EEG should have the test performed soon after it has been requested. [2004]

1.6.4 An EEG should be performed only to support a diagnosis of epilepsy in adults in whom the clinical history suggests that the seizure is likely to be epileptic in origin. [2004]

1.6.5 An EEG should be performed only to support a diagnosis of epilepsy in children. If an EEG is considered necessary, it should be performed after the second epileptic seizure but may, in certain circumstances, as evaluated by the specialist, be considered after a first epileptic seizure. [2004]

6 The Guideline Development Group considered that ‘soon’ meant being seen within 4 weeks.
1.6.6 An EEG should not be performed in the case of probable syncope because of the possibility of a false-positive result. [2004]

1.6.7 The EEG should not be used to exclude a diagnosis of epilepsy in an individual in whom the clinical presentation supports a diagnosis of a non-epileptic event. [2004]

1.6.8 The EEG should not be used in isolation to make a diagnosis of epilepsy. [2004]

1.6.9 An EEG may be used to help determine seizure type and epilepsy syndrome in individuals in whom epilepsy is suspected. This enables individuals to be given the correct prognosis. [2004]

1.6.10 In individuals presenting with a first unprovoked seizure, unequivocal epileptiform activity shown on EEG can be used to assess the risk of seizure recurrence. [2004]

1.6.11 For individuals in whom epilepsy is suspected, but who present diagnostic difficulties, specialist investigations should be available. [2004]

1.6.12 Repeated standard EEGs may be helpful when the diagnosis of the epilepsy or the syndrome is unclear. However, if the diagnosis has been established, repeat EEGs are not likely to be helpful. [2004]

1.6.13 Repeated standard EEGs should not be used in preference to sleep or sleep-deprived EEGs. [2004]

1.6.14 When a standard EEG has not contributed to diagnosis or classification, a sleep EEG should be performed. [2004]

1.6.15 In children, a sleep EEG is best achieved through sleep deprivation or the use of melatonin. [2004]

1.6.16 Long-term video or ambulatory EEG may be used in the assessment of individuals who present diagnostic difficulties after clinical assessment and standard EEG. [2004]
1.6.17 Provocation by suggestion may be used in the evaluation of non-epileptic attack disorder. However, it has a limited role and may lead to false positive results in some individuals. [2004]

1.6.18 Photic stimulation and hyperventilation should remain part of standard EEG assessment. The individual and family and/or carer should be made aware that such activation procedures may induce a seizure and they have a right to refuse. [2004]

**Neuroimaging**

1.6.19 Neuroimaging should be used to identify structural abnormalities that cause certain epilepsies. [2004]

1.6.20 MRI should be the imaging investigation of choice in individuals with epilepsy. [2004]

1.6.21 MRI is particularly important in those:

- who develop epilepsy before the age of 2 years or in adulthood
- who have any suggestion of a focal onset on history, examination or EEG (unless clear evidence of benign focal epilepsy)
- in whom seizures continue in spite of first-line medication. [2004]

1.6.22 Individuals requiring MRI should have the test performed soon. [2004]

1.6.23 Neuroimaging should not be routinely requested when a diagnosis of idiopathic generalised epilepsy has been made. [2004]

1.6.24 CT should be used to identify underlying gross pathology if MRI is not available or is contraindicated, and for children in whom a general anaesthetic or sedation would be required for MRI but not CT. [2004]

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7 The Guideline Development Group considered that ‘soon’ meant being seen within 4 weeks.
1.6.25 In an acute situation, CT may be used to determine whether a seizure has been caused by an acute neurological lesion or illness. [2004]

**Other tests**

1.6.26 Measurement of serum prolactin is not recommended for the diagnosis of epilepsy. [2004]

1.6.27 In adults, appropriate blood tests (for example, plasma electrolytes, glucose, calcium) to identify potential causes and/or to identify any significant co-morbidity should be considered. [2004]

1.6.28 In children, other investigations, including blood and urine biochemistry, should be undertaken at the discretion of the specialist to exclude other diagnoses, and to determine an underlying cause of the epilepsy. [2004]

1.6.29 A 12-lead ECG should be performed in adults with suspected epilepsy. [2004]

1.6.30 In children, a 12-lead ECG should be considered in cases of diagnostic uncertainty. [2004]

1.6.31 In cases of diagnostic uncertainty, a referral to a cardiologist should be considered. [2004]

**Neuropsychological assessment**

1.6.32 Neuropsychological assessment should be considered in individuals in whom it is important to evaluate learning disabilities and cognitive dysfunction, particularly in regard to language and memory. [2004]
1.6.33 Referral for a neuropsychological assessment is indicated:

- when an individual with epilepsy is having educational or occupational difficulties
- when an MRI has identified abnormalities in cognitively important brain regions
- when an individual complains of memory or other cognitive deficits and/or cognitive decline. [2004]

1.7 Classification

1.7.1 Epileptic seizures and epilepsy syndromes in individuals should be classified using a multi-axial diagnostic scheme. The axes that should be considered are: description of seizure (ictal phenomenology); seizure type; syndrome and aetiology. [2004]

1.7.2 The seizure type(s) and epilepsy syndrome, aetiology, and co-morbidity should be determined, because failure to classify the epilepsy syndrome correctly can lead to inappropriate treatment and persistence of seizures. [2004]

1.7.3 Individuals with epilepsy should be given information about their seizure type(s) and epilepsy syndrome, and the likely prognosis. [2004]

1.8 Management

1.8.1 People with epilepsy should have an accessible point of contact with specialist services. [2004]

1.8.2 All people with epilepsy should have a comprehensive care plan that is agreed between the individual, family and/or carers where appropriate, and primary care and secondary care providers. This should include lifestyle issues as well as medical issues. [2004]

1.8.3 Epilepsy specialist nurses (ESNs) should be an integral part of the network of care of individuals with epilepsy. The key roles of the ESNs are to support both epilepsy specialists and generalists, to
ensure access to community and multi-agency services and to provide information, training and support to the individual, families, carers and, in the case of children, others involved in the child’s education, welfare and well-being. [2004]

1.8.4 Healthcare professionals have a responsibility to educate others about epilepsy so as to reduce the stigma associated with it. They should provide information about epilepsy to all people who come into contact with people with epilepsy, including school staff, social care professionals and others. [2004]

1.9 Pharmacological treatment

Note: see appendix E for further details of pharmacological treatment.

1.9.1 General information about pharmacological treatment

1.9.1.1 Information that is provided about anti-epileptic drugs (AEDs) needs to be in the context of that provided by the manufacturer, for example, indications, side effects and licence status. [2004]

1.9.1.2 The AED treatment strategy should be individualised according to the seizure type, epilepsy syndrome, co-medication and co-morbidity, the individual’s lifestyle, and the preferences of the individual and their family and/or carers as appropriate (see appendix E). [2004]

1.9.1.3 The diagnosis of epilepsy needs to be critically evaluated if events continue despite an optimal dose of a first-line AED. [2004]

1.9.1.4 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. [2004]

1.9.1.5 It is recommended that individuals should be treated with a single antiepileptic drug (monotherapy) wherever possible. If the initial treatment is unsuccessful, then monotherapy using another drug
can be tried. Caution is needed during the changeover period. [2004]

1.9.1.6 If an AED has failed because of adverse effects or continued seizures, a second drug should be started (which may be an alternative first-line or second-line drug) and built up to an adequate or maximum tolerated dose and then the first drug should be tapered off slowly. [2004]

1.9.1.7 If the second drug is unhelpful, either the first or second drug may be tapered, depending on relative efficacy, side effects and how well the drugs are tolerated before starting another drug. [2004]

1.9.1.8 It is recommended that combination therapy (adjunctive or ‘add-on’ therapy) should only be considered when attempts at monotherapy with AEDs have not resulted in seizure freedom. If trials of combination therapy do not bring about worthwhile benefits, treatment should revert to the regimen (monotherapy or combination therapy) that has proved most acceptable to the individual, in terms of providing the best balance between effectiveness in reducing seizure frequency and tolerability of side effects. [2004]

1.9.2 Initiation of pharmacological treatment

1.9.2.1 AED therapy should only be started once the diagnosis of epilepsy is confirmed, except in exceptional circumstances that require discussion and agreement between the prescriber, the specialist and the individual and their family and/or carers as appropriate. [2004]

1.9.2.2 AED therapy should be initiated in adults on the recommendation of a specialist. [2004]

1.9.2.3 AED therapy in children should be initiated by a specialist. [2004]
<table>
<thead>
<tr>
<th>Section</th>
<th>Text</th>
</tr>
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<tbody>
<tr>
<td>1.9.2.4</td>
<td>The decision to initiate AED therapy should be taken between the individual, their family and/or carers (as appropriate) and the specialist after a full discussion of the risks and benefits of treatment. This discussion should take into account details of the individual’s epilepsy syndrome, prognosis and lifestyle. [2004]</td>
</tr>
<tr>
<td>1.9.2.5</td>
<td>Treatment with AED therapy is generally recommended after a second epileptic seizure. [2004]</td>
</tr>
<tr>
<td>1.9.2.6</td>
<td>AED therapy should be considered and discussed with individuals and their family and/or carers as appropriate after a first unprovoked seizure if:</td>
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<tr>
<td></td>
<td>• the individual has a neurological deficit</td>
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<td></td>
<td>• the EEG shows unequivocal epileptic activity</td>
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<td></td>
<td>• the individual and/or their family and/or carers consider the risk of having a further seizure unacceptable</td>
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<td></td>
<td>• brain imaging shows a structural abnormality. [2004]</td>
</tr>
<tr>
<td>1.9.2.7</td>
<td>It should be recognised that some individuals (through their families and/or carers, in some instances) may choose not to take AED therapy following a full discussion of the risks and benefits. [2004]</td>
</tr>
<tr>
<td>1.9.3</td>
<td>Pharmacological treatment of focal seizures</td>
</tr>
<tr>
<td>1.9.3.1</td>
<td>Offer carbamazepine, lamotrigine, oxcarbazepine or sodium valproate as first-line treatment to adults and children with newly diagnosed focal seizures, unless contraindicated. If the first AED is ineffective or not tolerated, offer an alternative from these four AEDs. If the second well-tolerated AED is ineffective, consider adjunctive treatment. [new 2011]</td>
</tr>
<tr>
<td>1.9.3.2</td>
<td>Only offer levetiracetam to adults and children with focal seizures if first-line treatments (see recommendation 1.9.3.1) are contraindicated. [new 2011]</td>
</tr>
</tbody>
</table>
Adjunctive treatment in adults and children with refractory focal seizures

1.9.3.3 Offer clobazam*, gabapentin*, lamotrigine, oxcarbazepine or topiramate as adjunctive treatment to adults and children with focal seizures if first-line treatments (see recommendations 1.9.3.1 and 1.9.3.2) are ineffective or not tolerated. [new 2011]

1.9.3.4 Discuss management with, or offer referral to, a tertiary epilepsy specialist if adjunctive treatment with AEDs listed in recommendation 1.9.3.3 is ineffective or not tolerated in adults and children with focal seizures. Other AEDs that may be considered are eslicarbazepine*, lacosamide, levetiracetam, phenobarbital, phenytoin, pregabalin*, tiagabine and zonisamide*. [new 2011]

1.9.3.5 Only offer vigabatrin to adults and children who are receiving tertiary epilepsy specialist care, because of the potential for serious adverse effects. [new 2011]

1.9.4 Pharmacological treatment of idiopathic generalised epilepsy (IGE)

First-line treatment in adults and children with IGE

1.9.4.1 Offer sodium valproate as first-line treatment to adults and children with newly diagnosed IGE. Offer lamotrigine or topiramate if sodium valproate is contraindicated or not tolerated. Be aware that lamotrigine can exacerbate myoclonic seizures. [new 2011]

Adjunctive treatment in adults and children with IGE

1.9.4.2 Offer levetiracetam as adjunctive treatment to adults and children with IGE if first-line treatments (see recommendation 1.9.4.1) are ineffective or not tolerated. [new 2011]

* Please see appendix E for licensing details.
1.9.5 Pharmacological treatment of absence seizures

*(childhood absence epilepsy, juvenile absence epilepsy
and other absence epilepsy syndromes)*

**First-line treatment in adults and children with absence seizures**

1.9.5.1 Offer ethosuximide or sodium valproate as first-line treatment to
adults and children with absence seizures, unless they have also
experienced generalised tonic-clonic seizures when sodium
valproate should be offered first. *[new 2011]*

1.9.5.2 Offer lamotrigine* to adults and children with absence seizures if
ethosuximide and sodium valproate have been ineffective or not
tolerated. *[new 2011]*

1.9.5.3 Do not offer carbamazepine, oxcarbazepine, phenytoin, tiagabine
or vigabatrin to adults and children with absence seizures.
*[new 2011]*

1.9.6 Pharmacological treatment of juvenile myoclonic epilepsy

*(JME)*

**First-line treatment in adults and children with JME**

1.9.6.1 Offer sodium valproate as first-line treatment to adults and children
with newly diagnosed JME. Offer lamotrigine* or topiramate* if
sodium valproate is contraindicated or not tolerated. Offer
topiramate if sodium valproate is ineffective. Be aware that
lamotrigine can exacerbate myoclonic seizures. *[new 2011]*

**Adjunctive treatment in adults and children with JME**

1.9.6.2 Offer levetiracetam as adjunctive treatment to adults and children
with JME if first-line treatments (see recommendation 1.9.6.1) are
ineffective or not tolerated. *[new 2011]*

* Please see appendix E for licensing details.
1.9.7 Pharmacological treatment of myoclonic seizures

First-line treatment in adults and children with myoclonic seizures

1.9.7.1 Offer sodium valproate as first-line treatment to adults and children with newly diagnosed myoclonic seizures. Offer topiramate* if sodium valproate is contraindicated, ineffective or not tolerated. [new 2011]

Adjunctive treatment in adults and children with myoclonic seizures

1.9.7.2 Offer levetiracetam as adjunctive treatment to adults and children with myoclonic seizures if first-line treatments (see recommendation 1.9.7.1) are ineffective or not tolerated. If treatment is ineffective or not tolerated discuss with, or refer to, a tertiary epilepsy specialist, and consider offering clobazam*, clonazepam, piracetam or zonisamide*. [new 2011]

1.9.8 Pharmacological treatment of newly diagnosed primary generalised tonic-clonic (PGTC) seizures

First-line treatment in adults and children with newly diagnosed PGTC seizures

1.9.8.1 Offer carbamazepine, lamotrigine, oxcarbazepine* or sodium valproate as first-line treatment to adults and children with PGTC seizures, unless they have also had myoclonic and/or absence seizures, when sodium valproate should be offered first. [new 2011]

Adjunctive treatment in adults and children with newly diagnosed PGTC seizures

1.9.8.2 Offer clobazam*, lamotrigine, levetiracetam or topiramate as adjunctive treatment to adults and children with PGTC seizures if first-line treatments (see recommendation 1.9.8.1) are ineffective or not tolerated. [new 2011]

1.9.8.3 Do not offer tiagabine and vigabatrin to adults and children with PGTC seizures. [new 2011]

* Please see appendix E for licensing details.
1.9.9 Pharmacological treatment of infantile spasms

First-line treatment in children with infantile spasms

1.9.9.1 Discuss with, or refer to, a tertiary paediatric epilepsy specialist when a child presents with infantile spasms. [new 2011]

1.9.9.2 Offer a steroid (prednisolone or tetracosactide*) or vigabatrin as first-line treatment to children with infantile spasms that are not due to tuberous sclerosis. [new 2011]

1.9.9.3 Offer vigabatrin as first-line treatment to children with infantile spasms due to tuberous sclerosis. If vigabatrin is ineffective, offer a steroid (prednisolone or tetracosactide*). [new 2011]

1.9.10 Pharmacological treatment of Lennox-Gastaut syndrome

First-line treatment in children with Lennox-Gastaut syndrome

1.9.10.1 Offer sodium valproate as first-line treatment to children with Lennox-Gastaut syndrome. [new 2011]

Adjunctive treatment in adults and children with Lennox-Gastaut syndrome

1.9.10.2 Offer lamotrigine as adjunctive treatment to adults and children with Lennox-Gastaut syndrome if first-line treatment with sodium valproate is ineffective or not tolerated. [new 2011]

1.9.10.3 Discuss with a tertiary epilepsy specialist if adjunctive treatment in adults and children with Lennox-Gastaut syndrome is ineffective or not tolerated. Other AEDs that may be considered are rufinamide and topiramate. [new 2011]

1.9.10.4 Do not offer carbamazepine or oxcarbazepine to adults and children with Lennox-Gastaut syndrome. [new 2011]

1.9.10.5 Only offer felbamate* to adults and children with Lennox-Gastaut syndrome in centres providing tertiary epilepsy specialist care and when treatment with all of the AEDs listed in recommendations

* Please see appendix E for licensing details.
1.9.10.2 and 1.9.10.3 have proved ineffective or not tolerated. [new 2011]

1.9.11 Pharmacological treatment of severe myoclonic epilepsy of infancy (SMEI)

First-line treatment in children with SMEI
1.9.11.1 Consider sodium valproate or topiramate* as first-line treatment in children with SMEI. [new 2011]

Adjunctive treatment in children with SMEI
1.9.11.2 Refer children with SMEI in whom first-line treatment has proved ineffective or not tolerated to a tertiary paediatric epilepsy specialist for consideration of stiripentol as adjunctive treatment. [new 2011]

1.9.11.3 Do not offer carbamazepine, lamotrigine, oxcarbazepine, phenytoin or vigabatrin to children with SMEI. [new 2011]

1.9.12 Other epilepsy syndromes
1.9.12.1 Refer to a tertiary paediatric epilepsy specialist all children with continuous spike and wave during slow sleep (CSWS), Landau–Kleffner syndrome (LKS) or a myoclonic-astatic epilepsy (MAE). [new 2011]

1.9.13 Pharmacological treatment of benign partial epilepsies of childhood (benign epilepsy with centrotemporal spikes [BECTS] or benign epilepsy with occipital paroxysms [BEOP])

First-line treatment in children with BECTs or BEOP
1.9.13.1 Discuss with the child and their family and/or carers whether AED treatment for BECTs or BEOP in the individual circumstance is indicated. [new 2011]

* Please see appendix E for licensing details.
1.9.13.2 Offer carbamazepine*, lamotrigine*, oxcarbazepine* or sodium valproate as first-line treatment to children with BECTs or BEOP when treatment is indicated. Offer levetiracetam* if first-line treatments are contraindicated. [new 2011]

1.9.14 Continuation of pharmacological treatment

1.9.14.1 Continuing AED therapy should be planned by the specialist. It should be part of the individual’s agreed treatment plan, which should include details of how specific drug choices were made, drug dosage, possible side effects, and action to take if seizures persist. [2004]

1.9.14.2 The needs of the individual and their family and/or carers as appropriate should be taken into account when healthcare professionals take on the responsibility of continuing prescribing. [2004]

1.9.14.3 If management is straightforward, continuing AED therapy can be prescribed in primary care if local circumstances and/or licensing allow. [2004]

1.9.14.4 The prescriber must ensure that the individual and their family and/or carers as appropriate are fully informed about treatment including action to be taken after a missed dose or after a gastrointestinal upset. [2004]

1.9.14.5 Adherence to treatment can be optimised with the following:

- educating individuals and their families and/or carers in the understanding of their condition and the rationale of treatment
- reducing the stigma associated with the condition (see also section 1.2)
- using simple medication regimens

* Please see appendix E for licensing details.
positive relationships between healthcare professionals, the individual with epilepsy and their family and/or carers. [2004]

1.9.14.6 Regular blood test monitoring in adults is not recommended as routine, and should be done only if clinically indicated. [2004]

1.9.14.7 Regular blood test monitoring in children is not recommended as routine, and should be done only if clinically indicated and recommended by the specialist. [2004]

1.9.14.8 Indications for monitoring of AED blood levels are:

- detection of non-adherence to the prescribed medication
- suspected toxicity
- adjustment of phenytoin dose
- management of pharmacokinetic interactions
- specific clinical conditions, for example, status epilepticus, organ failure and pregnancy. [2004]

1.9.14.9 Examples of blood tests for adults include:

- before surgery – clotting studies in those on valproate
- full blood count, electrolytes, liver enzymes, vitamin D levels, and other tests of bone metabolism (for example, serum calcium and alkaline phosphatase) every 2–5 years for adults taking enzyme-inducing drugs. [2004]

1.9.14.10 Asymptomatic minor abnormalities in test results are not necessarily an indication for changes in medication. [2004]

1.9.15 Withdrawal of pharmacological treatment

1.9.15.1 The decision to continue or withdraw medication should be taken by the individual, their family and/or carers as appropriate, and the specialist after a full discussion of the risks and benefits of withdrawal. At the end of the discussion individuals, and their family and/or carers as appropriate, should understand the individual’s
risk of seizure recurrence on and off treatment. This discussion should take into account details of the individual’s epilepsy syndrome, prognosis and lifestyle. [2004]

1.9.15.2 Withdrawal of AEDs must be managed by, or be under the guidance of, the specialist. [2004]

1.9.15.3 The risks and benefits of continuing or withdrawing AED therapy should be discussed with individuals, and their families and/or carers as appropriate, who have been seizure free for at least 2 years (see appendix H of the full guideline). [2004]

1.9.15.4 When AED treatment is being discontinued in an individual who has been seizure free, it should be carried out slowly (at least 2–3 months) and one drug should be withdrawn at a time. [2004]

1.9.15.5 Particular care should be taken when withdrawing benzodiazepines and barbiturates (may take up to 6 months or longer) because of the possibility of drug-related withdrawal symptoms and/or seizure recurrence. [2004]

1.9.15.6 There should be a failsafe plan agreed with individuals and their families and/or carers as appropriate, whereby if seizures recur, the last dose reduction is reversed and medical advice is sought. [2004]

1.10 Referral for complex or refractory epilepsy

1.10.1 All individuals with epilepsy should have access via their specialist to a tertiary service when circumstances require. [2004]

1.10.2 Information should be provided to individuals and families and/or carers as appropriate about the reasons for considering surgery. The benefits and risks of the surgical procedure under

Appendix H of the full guideline provides tables for the prognosis for remission of seizures in adults.
consideration should be fully explained before the individual's informed consent is obtained. [2004]

1.10.3 If seizures are not controlled and/or there is diagnostic uncertainty or treatment failure, individuals should be referred to tertiary services soon\(^9\) for further assessment. Referral should be considered when one or more of the following criteria are present:

- the epilepsy is not controlled with medication within 2 years
- management is unsuccessful after two drugs
- the individual is aged under 2 years
- an individual experiences, or is at risk of, unacceptable side effects from medication
- there is a unilateral structural lesion
- there is psychological and/or psychiatric co-morbidity
- there is diagnostic doubt as to the nature of the seizures and/or seizure syndrome. [2004]

1.10.4 In children, the diagnosis and management of epilepsy within the first few years of life may be extremely challenging. For this reason, children with suspected epilepsy should be referred to tertiary services early, because of the profound developmental, behavioural and psychological effects that may be associated with continuing seizures. [2004]

1.10.5 Behavioural or developmental regression or inability to identify the epilepsy syndrome in an individual should result in immediate referral to tertiary services. [2004]

1.10.6 Individuals with specific syndromes such as Sturge–Weber syndrome, the hemispheric syndromes, Rasmussen’s encephalitis and hypothalamic hamartoma should be referred to a tertiary epilepsy service. [2004]

\(^9\) The Guideline Development Group considered that ‘soon’ meant being seen within 4 weeks.
1.10.7 Psychiatric co-morbidity and/or negative baseline investigations should not be a contraindication for referral to a tertiary centre. [2004]

1.10.8 The tertiary service should include a multidisciplinary team, experienced in the assessment of individuals with complex epilepsy, and have adequate access to investigations and treatment by both medical and surgical means. [2004]

1.10.9 The expertise of multidisciplinary teams involved in managing complex epilepsy should include psychology, psychiatry, social work, occupational therapy, counselling, neuroradiology, clinical nurse specialists, neurophysiology, neurology, neurosurgery and neuroanaesthesia. Teams should have MRI and video telemetry facilities available to them. [2004]

1.10.10 The neurosurgeon in the multidisciplinary team should have specialist experience of and/or training in epilepsy surgery and have access to invasive EEG recording facilities. [2004]

1.11 Psychological interventions

1.11.1 Psychological interventions (relaxation, cognitive behaviour therapy, biofeedback) may be used in conjunction with AED therapy in adults where either the individual or the specialist considers seizure control to be inadequate with optimal AED therapy. This approach may be associated with an improved quality of life in some individuals. [2004]

1.11.2 Psychological interventions (relaxation, cognitive behaviour therapy) may be used in children with drug-resistant focal epilepsy. [2004]

1.11.3 Psychological interventions may be used as adjunctive therapy. They have not been proven to affect seizure frequency and are not an alternative to pharmacological treatment. [2004]
1.12 **Ketogenic diet**

1.12.1 The ketogenic diet should not be recommended for adults with epilepsy. [2004]

1.12.2 Refer children with epilepsy whose seizures have not responded to appropriate AEDs to a tertiary paediatric epilepsy specialist for consideration of the use of a ketogenic diet. [new 2011]

1.13 **Vagus nerve stimulation (VNS)**

1.13.1 Vagus nerve stimulation is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults who are refractory to antiepileptic medication but who are not suitable for resective surgery. This includes adults whose epileptic disorder is dominated by partial seizures (with or without secondary generalisation) or generalised seizures. [2004]

1.13.2 Vagus nerve stimulation is indicated for use as an adjunctive therapy in reducing the frequency of seizures in children who are refractory to antiepileptic medication but who are not suitable for resective surgery. This includes children whose epileptic disorder is dominated by partial seizures (with or without secondary generalisation) or generalised seizures. [2004]

1.14 **Prolonged or repeated seizures and convulsive status epilepticus**

1.14.1 Follow local or national protocols for treating status epilepticus in children. [new 2011]

1.14.2 **First-line treatment for people with prolonged or repeated generalised, convulsive (tonic-clonic, tonic or clonic) seizures in the community**

1.14.2.1 Give immediate emergency care and treatment to adults and children who have prolonged (lasting 5 minutes or more) or...

10 Evidence from NICE interventional procedure guidance 50 (March 2004).
repeated (three or more in an hour) convulsive seizures in the community. [new 2011]

1.14.2.2 Use buccal midazolam* as first-line treatment in adults and children with prolonged or repeated seizures. Use rectal diazepam if buccal midazolam* is not available. If intravenous access is already established and resuscitation facilities are available, offer intravenous lorazepam. [new 2011]

1.14.2.3 Only prescribe rectal diazepam or buccal midazolam* for adults and children who have had a previous episode of prolonged or repeated convulsive seizures. [new 2011]

1.14.2.4 Inform individuals and their families and/or carers that buccal midazolam* is currently unlicensed. [2011]

1.14.2.5 Treatment should be administered by trained clinical personnel or, if specified by an individually agreed protocol drawn up with the specialist, by family members or carers with appropriate training. [2004]

1.14.2.6 Care must be taken to secure the individual’s airway and assess his or her respiratory and cardiac function. [2004]

1.14.2.7 Depending on response to treatment, the person’s situation and any personalised care plan, call an ambulance, particularly if:

- the seizures continue for 5 minutes without response to emergency medication
- there is a high risk of recurrence
- this is the first episode requiring emergency treatment
- there are concerns or difficulties monitoring the person’s condition. [new 2011]

* Please see appendix E for licensing details.
1.15 Treatment for adults and children with convulsive status epilepticus in hospitals

1.15.1 Convulsive status epilepticus

1.15.1.1 For adults and children with ongoing generalised tonic-clonic seizures (status epilepticus) who are in hospital, immediately:

- secure airway
- give high-concentration oxygen
- assess cardiac and respiratory function
- check blood glucose levels using a finger prick test
- secure intravenous access in a large vein. [new 2011]

1.15.1.2 Use intravenous lorazepam as a first-line treatment in hospital in adults and children with ongoing generalised tonic-clonic seizures (status epilepticus). Use buccal midazolam* if unable to secure immediate intravenous access. Use only a maximum of two doses of the first-line treatment (including pre-hospital treatment). [new 2011]

1.15.1.3 If seizures continue, use intravenous phenobarbital, phenytoin or sodium valproate as second-line treatment in hospital in adults and children with ongoing generalised tonic-clonic seizures (status epilepticus). [new 2011]

1.15.2 Refractory convulsive status epilepticus

1.15.2.1 Follow local or national protocols for treating refractory status epilepticus in secondary care. [2011]

1.15.2.2 Use propofol* or thiopental* in adults with refractory status epilepticus. Adequate monitoring, including blood levels of thiopental, and critical life systems support is required. [2011]

* Please see appendix E for licensing details.
1.15.2.3 Use midazolam or thiopental* in children with refractory status epilepticus. Adequate monitoring, including blood levels of thiopental, and critical life systems support is required. [2011]

1.15.2.4 As the treatment pathway progresses, the expertise of an anaesthetist/intensivist should be sought. [2004]

1.15.2.5 If either the whole protocol or intensive care is required in children, a tertiary paediatric epilepsy centre should be consulted. [2004]

1.15.2.6 Regular medication should be continued at optimal doses and the reasons for status epilepticus should be investigated. [2004]

1.15.2.7 An individual treatment pathway should be formulated for people who have recurrent convulsive status epilepticus. [2004]

1.16 Women with epilepsy

1.16.1 Information and advice for women and young girls with epilepsy

1.16.1.1 In order to enable informed decisions and choice, and to reduce misunderstandings, women with epilepsy and their partners, as appropriate, must be given accurate information and counselling about contraception, conception, pregnancy, caring for children and breastfeeding, and menopause. [2004]

1.16.1.2 Information about contraception, conception, pregnancy, or menopause should be given to girls and women in advance of sexual activity, pregnancy or menopause, and the information should be tailored to their individual needs. This information should also be given, as needed, to people who are closely involved with

* Please see appendix E for licensing details.
girls and women with epilepsy. These may include an individual’s family and/or carers. [2004]

1.16.1.3 All healthcare professionals who treat, care for, or support women with epilepsy should be familiar with relevant information and the availability of counselling. [2004]

1.16.1.4 Discuss with women of childbearing potential the risk of AEDs causing malformations and neurodevelopmental delay to an unborn child. Assess the risks and benefits of treatment with individual drugs. There are limited data on risks to the unborn child associated with newer drugs. Risk of continued use of sodium valproate to the unborn child should specifically be discussed. [new 2011]

1.16.1.5 Discuss with girls of childbearing potential (including young girls who are likely to need treatment into their childbearing years) and their parents and/or carer the risk of AEDs causing malformations and neurodevelopmental delay to an unborn child. Assess the risks and benefits of treatment with individual drugs. There are limited data on risks to the unborn child associated with newer drugs. Risk of continued use of sodium valproate to the unborn child should specifically be discussed. [new 2011]

1.16.1.6 Be aware of the latest data on the risks to the unborn child associated with AED therapy when prescribing for women and girls of childbearing potential. [2011]

1.16.1.7 All women on AEDs should be offered 5 mg per day of folic acid before any possibility of pregnancy. [2004]

1.16.2 Contraception

1.16.2.1 In women of childbearing potential, the possibility of interaction with oral contraceptives should be discussed and an assessment made as to the risks and benefits of treatment with individual drugs. [2004]
1.16.2.2 In girls of childbearing potential, including young girls who are likely to need treatment into their childbearing years, the possibility of interaction with oral contraceptives should be discussed with the child and/or her carer, and an assessment made as to the risks and benefits of treatment with individual drugs. [2004]

1.16.2.3 In women of childbearing potential, the risks and benefits of different contraceptive methods, including hormone-releasing IUDs, should be discussed. [2004]

1.16.2.4 If a woman taking enzyme-inducing AEDs chooses to take the combined oral contraceptive pill, a minimum initial dose of 50 micrograms of oestrogen is recommended. If breakthrough bleeding occurs, the dose of oestrogen should be increased to 75 micrograms or 100 micrograms per day, and ‘tricycling’ (taking three packs without a break) should be considered. [2004]

1.16.2.5 The progesterone-only pill is not recommended as reliable contraception in women taking enzyme-inducing AEDs. [2004]

1.16.2.6 Women taking enzyme-inducing AEDs who choose to use depot injections of progesterone should be informed that a shorter repeat injection interval is recommended (10 weeks instead of 12 weeks). [2004]

1.16.2.7 The progesterone implant is not recommended in women taking enzyme-inducing AEDs. [2004]

1.16.2.8 The use of additional barrier methods should be discussed with women taking enzyme-inducing AEDs and oral contraception or having depot injections of progesterone. [2004]

1.16.2.9 If emergency contraception is required for women taking enzyme-inducing AEDs, the dose of levonorgestrel should be increased to 1.5 mg and 750 micrograms 12 hours apart. [2004]
1.16.2.10 Discuss with women who are taking lamotrigine that taking the combined oral contraceptive pill with lamotrigine can result in a significant reduction of 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. [new 2011]

1.16.2.11 Follow guidance in the ‘British national formulary’ (available at www.bnf.org) on the interactions between AEDs and hormonal contraception. [new 2011]

1.16.3 Pregnancy

1.16.3.1 Women with epilepsy need accurate information during pregnancy, and the possibility of status epilepticus and SUDEP should be discussed with all women who plan to stop AED therapy (see section 1.9.15). [2004]

1.16.3.2 All pregnant women with epilepsy should be encouraged to notify their pregnancy, or allow their clinician to notify the pregnancy, to the UK Epilepsy and Pregnancy Register (www.epilepsyandpregnancy.co.uk). [2004]

1.16.3.3 The clinician should discuss with the woman the relative benefits and risks of adjusting medication to enable her to make an informed decision. Where appropriate, the woman’s specialist should be consulted. [2004]

1.16.3.4 Women with generalised tonic–clonic seizures should be informed that the fetus may be at relatively higher risk of harm during a seizure, although the absolute risk remains very low, and the level of risk may depend on seizure frequency. [2004]

1.16.3.5 Women should be reassured that there is no evidence that simple partial, complex partial, absence and myoclonic seizures affect the pregnancy or developing foetus adversely unless they fall and sustain an injury. [2004]
1.16.3.6 Women should be reassured that an increase in seizure frequency is generally unlikely in pregnancy or in the first few months after birth. [2004]

1.16.3.7 Generally, women may be reassured that the risk of a tonic–clonic seizure during the labour and the 24 hours after birth is low (1–4%). [2004]

1.16.3.8 Routine monitoring of AED levels in pregnancy is not recommended. If seizures increase, or are likely to increase, monitoring of AED levels may be useful to plan or anticipate the extent of change of dose adjustment needed. [2004]

1.16.3.9 Women with epilepsy should be informed that although they are likely to have healthy pregnancies, their risk of complications during pregnancy and labour is higher than for women without epilepsy. [2004]

1.16.3.10 Care of pregnant women should be shared between the obstetrician and the specialist. [2004]

1.16.3.11 Pregnant women who are taking AEDs should be offered a high-resolution ultrasound scan to screen for structural anomalies. This scan should be performed at 18–20 weeks’ gestation by an appropriately trained ultrasonographer, but earlier scanning may allow major malformations to be detected sooner. [2004]

1.16.3.12 The risk of seizures during labour is low, but it is sufficient to warrant the recommendation that delivery should take place in an obstetric unit with facilities for maternal and neonatal resuscitation and treating maternal seizures. [2004]

1.16.3.13 All children born to mothers taking enzyme-inducing AEDs should be given 1 mg of vitamin K parenterally at delivery. [2004]
1.16.3.14 Genetic counselling should be considered if one partner has epilepsy, particularly if the partner has idiopathic epilepsy and a positive family history of epilepsy. [2004]

1.16.3.15 Although there is an increased risk of seizures in children of parents with epilepsy, individuals with epilepsy should be given information that the probability that a child will be affected is generally low. However, this will depend on the family history. [2004]

1.16.3.16 Advanced planning, including the development of local protocols for care, should be implemented in obstetric units that deliver babies of women with epilepsy. [2004]

1.16.3.17 Joint epilepsy and obstetric clinics may be convenient for mothers and healthcare professionals but there is insufficient evidence to recommend their routine use. [2004]

1.16.3.18 It is, however, important that there should be regular follow-up, planning of delivery, and liaison between the specialist or epilepsy team and the obstetrician or midwife. [2004]

1.16.3.19 Aim for seizure freedom before conception and during pregnancy (particularly for women and girls with generalised tonic-clonic seizures) but consider the risk of adverse effects of AEDs and use the lowest effective dose of AED for each individual. [new 2011]

1.16.4 Breastfeeding

1.16.4.1 All women with epilepsy should be encouraged to breastfeed, except in very rare circumstances. Breastfeeding for most women taking AEDs is generally safe and should be encouraged. However, each mother needs to be supported in the choice of feeding method that bests suits her and her family. [2004]

1.16.4.2 Prescribers should consult Appendix 5 of the British National Formulary when prescribing AEDs for women who are
breastfeeding. The decision on whether to continue AED therapy should be made between the woman and the prescriber, and be based on the risks and benefits of breastfeeding against the potential risks of the drug affecting the child. [2004]

1.16.5  **After the birth**
1.16.5.1 Parents of new babies or young children should be informed that introducing a few simple safety precautions may significantly reduce the risk of accidents and minimise anxiety. An approaching birth can be an ideal opportunity to review and consider the best and most helpful measures to start to ensure maximum safety for both mother and baby. [2004]

1.16.5.2 Information should be given to all parents about safety precautions to be taken when caring for the baby (see appendix D of the full guideline). [2004]

1.16.5.3 Parents should be reassured that the risk of injury to the infant caused by maternal seizure is low. [2004]

1.17  **People with learning disabilities (see also sections 1.16 and 1.18)**

1.17.1  **Diagnosis (see also section 1.5)**
1.17.1.1 It can be difficult to diagnose epilepsy in people with learning disabilities, and so care should be taken to obtain a full clinical history. Confusion may arise between stereotypic or other behaviours and seizure activity. [2004]

1.17.1.2 It is important to have an eye witness account supplemented by corroborative evidence (for example, a video account), where possible. [2004]

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11 Appendix D of the full guideline provides a checklist for the information needs of women with epilepsy, and practical information for mothers with epilepsy.
1.17.1.3 Clear, unbiased reporting is essential. Witnesses may need education to describe their observations accurately. [2004]

1.17.2 Investigations (see also section 1.6)

1.17.2.1 Those with learning disabilities may require particular care and attention to tolerate investigations. [2004]

1.17.2.2 Facilities should be available for imaging under anaesthesia, if necessary. [2004]

1.17.2.3 In the child presenting with epilepsy and learning disability, investigations directed at determining an underlying cause should be undertaken. [2004]

1.17.3 Management (see section 1.8)

1.17.3.1 Enable adults and children who have learning disabilities, and their family and/or carers where appropriate, to take an active part in developing a personalised care plan for treating their epilepsy. [new 2011]

1.17.3.2 Allow additional time for consultation to achieve effective management of epilepsy in adults and children with learning difficulties. [new 2011]

1.17.3.3 In making a management plan for an individual with learning disabilities and epilepsy, particular attention should be paid to the possibility of adverse cognitive and behavioural effects of AED therapy. [2004]

1.17.3.4 The recommendations on choice of treatment and the importance of regular monitoring of effectiveness and tolerability are the same for those with learning disabilities as for the general population. [2004]
1.17.3.5 Do not discriminate against adults and children with learning difficulties and offer the same investigations and therapies as for the general population. [new 2011]

1.17.3.6 Every therapeutic option should be explored in individuals with epilepsy in the presence or absence of learning disabilities. [2004]

1.17.3.7 Healthcare professionals should be aware of the higher risks of mortality for people with learning disabilities and epilepsy and discuss these with individuals, their families and/or carers. [2004]

1.17.3.8 All individuals with epilepsy and learning disabilities 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. [2004]

1.18 Young people with epilepsy (see also section 1.16)

1.18.1 The physical, psychological and social needs of young people with epilepsy should always be considered by healthcare professionals. Attention should be paid to their relationships with family and friends, and at school. [2004]

1.18.2 Healthcare professionals should adopt a consulting style that allows the young person with epilepsy to participate as a partner in the consultation. [2004]

1.18.3 Decisions about medication and lifestyle issues should draw on both the expertise of the healthcare professional and the
experiences, beliefs and wishes of the young person with epilepsy as well as their family and/or carers. [2004]

1.18.4 During adolescence a named clinician should assume responsibility for the ongoing management of the young person with epilepsy and ensure smooth transition of care to adult services, and be aware of the need for continuing multi-agency support. [2004]

1.18.5 Multidisciplinary services provided jointly by adult and paediatric specialists have a key role in the care of the young person with epilepsy. This can facilitate the transition from paediatric to adult services and aid in the dissemination of information. [2004]

1.18.6 Before the transition to adult services is made, diagnosis and management should be reviewed and access to voluntary organisations, such as support groups and epilepsy charities, should be facilitated. [2004]

1.18.7 The information given to young people should cover epilepsy in general and its diagnosis and treatment, the impact of seizures and adequate seizure control, treatment options including side effects and risks, and the risks of injury. Other important issues to be covered are the possible consequences of epilepsy on lifestyle and future career opportunities and decisions, driving and insurance issues, social security and welfare benefit issues, sudden death and the importance of adherence to medication regimes. Information on lifestyle issues should cover recreational drugs, alcohol, sexual activity and sleep deprivation (see section 1.3). [2004]

1.18.8 The diagnosis and management of epilepsy should be reviewed during adolescence. [2004]
1.19 **Older people with epilepsy**

1.19.1 Do not discriminate against older people and offer the same investigations and therapies as for the general population. [new 2011]

1.19.2 Pay particular attention to pharmacokinetic and pharmacodynamic issues with polypharmacy and comorbidity in older people with epilepsy. Consider using lower doses of AEDs and if using carbamazepine, offer modified-release carbamazepine preparations. [new 2011]

1.20 **People from black and minority ethnic groups**

1.20.1 People from black and minority ethnic groups may have different cultural and communication needs and these should be considered during diagnosis and management. The need for interpretation should be considered alongside other means of ensuring that an individual’s needs are appropriately met. [2004]

1.20.2 An interpreter should have both cultural and medical knowledge. Interpreters from the family are generally not suitable because of issues such as confidentiality, privacy, personal dignity, and accuracy of translation. [2004]

1.20.3 Information, including information about employment rights and driving, should be available in an appropriate format or through other appropriate means for people who do not speak or read English. [2004]

1.21 **Review**

1.21.1 Adults and children with epilepsy should have a regular structured review and be registered with a general medical practice. [2004]

1.21.2 Adults should have a regular structured review with their GP, but depending on the individual’s wishes, circumstances and epilepsy, the review may be carried out by the specialist. [2004]
1.21.3 Children should have a regular structured review with a specialist. [2004]

1.21.4 For adults, the maximum interval between reviews should be 1 year but the frequency of review will be determined by the individual’s epilepsy and their wishes. [2004]

1.21.5 For children, the maximum interval between reviews should be 1 year, but the frequency of reviews should be determined by the individual’s epilepsy and their wishes and those of the family and/or carers. The interval between reviews should be agreed between the individual, their family and/or carers as appropriate, and the specialist, but is likely to be between 3 and 12 months. [2004]

1.21.6 Adults should have regular reviews. In addition, access to either secondary or tertiary care should be available to ensure appropriate diagnosis, investigation and treatment if the individual or clinician view the epilepsy as inadequately controlled. [2004]

1.21.7 Adults with well-controlled epilepsy may have specific medical or lifestyle issues (for example, pregnancy or drug cessation) that may need the advice of a specialist. [2004]

1.21.8 If the structured review is to be conducted by the specialist, this may be best provided in the context of a specialist clinic. [2004]

1.21.9 Treatment should be reviewed at regular intervals to ensure that individuals with epilepsy are not maintained for long periods on treatment that is ineffective or poorly tolerated and that concordance with prescribed medication is maintained. [2004]

1.21.10 Annual review should include an enquiry about side effects and a discussion of the treatment plan to ensure concordance and adherence to medication. [2004]

1.21.11 At the review, individuals should have access to: written and visual information; counselling services; information about voluntary
organisations; epilepsy specialist nurses; timely and appropriate
investigations; referral to tertiary services including surgery, where
appropriate. [2004]
2 Notes on the scope of the guidance

NICE guidelines are developed in accordance with a scope that defines what the guideline will and will not cover. The scope of this guideline is available from [www.nice.org.uk](http://www.nice.org.uk) [NICE to add details].

The guideline addresses the diagnosis, treatment and management of epilepsy in children, adolescents, adults and older people. It does not cover the diagnosis, treatment or management of epilepsy in neonates or the diagnosis or management of febrile convulsions.

The guideline makes recommendations concerning the care provided by healthcare professionals who have direct contact with, or make decisions concerning, the care of people with epilepsy. It deals with care in primary, secondary and tertiary centres, and integrated care for epilepsy may span all these sectors. The delivery of tertiary procedures, such as surgical techniques, is not included. The guideline will also be relevant to, but does not cover the practice of, those working in the occupational health services, social services, educational services or the voluntary sector.

In 2011 the pharmacological management sections of the guideline were updated.
How this guideline was developed

NICE commissioned the National Clinical Guideline Centre to develop this guideline. The Centre established a Guideline Development Group (see appendix A), which reviewed the evidence and developed the recommendations. An independent Guideline Review Panel oversaw the development of the guideline (see appendix B).

There is more information about how NICE clinical guidelines are developed on the NICE website (www.nice.org.uk/HowWeWork). A booklet, ‘How NICE clinical guidelines are developed: an overview for stakeholders, the public and the NHS’ (fourth edition, published 2009), is available from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1739).

3 Implementation

NICE has developed tools to help organisations implement this guidance (see www.nice.org.uk/guidance/CG[XX]).

4 Research recommendations

The Guideline Development Group has made the following recommendations for research, based on its review of evidence, to improve NICE guidance and patient care in the future.

4.1 Newly diagnosed seizures (focal and generalised) – monotherapy

How do the newer AEDs compare in efficacy to the standard AEDs in the treatment of newly diagnosed epilepsy?

- Focal seizures: carbamazepine, eslicarbazepine, lamotrigine, lacosamide, levetiracetam, pregabalin and zonisamide.
- Generalised seizures: lamotrigine, levetiracetam, sodium valproate and zonisamide.
**Why this is important**

Levetiracetam and other AEDs licensed for the treatment of focal and generalised seizures since publication of the original guideline in 2004 have not been evaluated as first-line monotherapy.

Research should include:

- A prospective randomised controlled trial.
- All ages.
- Primary outcome of seizure freedom.
- Secondary outcomes should include seizure-reduction, quality of life and cognitive outcome.
- An attempt to obtain some data on pharmaco-resistance.

**4.2 Epilepsy syndromes**

What is the initial and add-on AEDs of choice in the treatment of the epilepsy syndromes with onset in childhood, for example, myoclonic-astatic epilepsy and SMEI?

**Why this is important**

Despite the need to diagnose individual epilepsy syndromes, there is little evidence base for the most appropriate initial or add-on AEDs in the treatment of the rarer epilepsies.

Research should include:

- Multicentre randomised controlled comparative trials with centralised national data collection.
- The ketogenic diet as one of the randomised treatments.
- Primary outcome of seizure freedom.
- Secondary outcome measures including seizure-reduction, quality of life and cognitive outcome.
- An attempt to obtain some data on pharmaco-resistance.
- The possibility to include all children with specific epilepsy syndromes for consideration in the trial.
4.3  **Infantile spasms**

Does treatment response relate to cause in infantile spasms? Does early treatment success in seizure control and resolution of the hypsarrhythmic EEG influence the long-term developmental and cognitive outcome more than the underlying cause of the spasms?

**Why this is important**

The UK Infantile Spasms Study (UKISS)\(^{12}\) study demonstrated 14-day outcome efficacy of steroids over vigabatrin although this excluded children with tuberous sclerosis. This study provided no specific sub-group analysis based on the cause of the spasms. There was no analysis on the effect of treatment lag on the study findings. Further data are available on behavioural outcome at 14 months and 5 years with regard to different treatments but with no analysis based on cause or treatment lag. Further developmental and cognitive outcomes would be useful, including response by specific cause and by treatment lag (delay).

Research should include:

- Prospective randomised design; this should include sub-group analyses based on both cause and treatment lag (delay); this will necessitate large numbers of patients and will need to be multicentre, possibly involving Western Europe.
- EEG outcomes.
- Developmental status at presentation, and at follow-up.
- An attempt to obtain some data on pharmaco-resistance.

4.4 Treatment of refractory status epilepticus

What is the most effective and safest anticonvulsant to treat refractory convulsive status epilepticus (RCSE)?

Why this is important
Convulsive status epilepticus that is refractory or resistant to first-line drug treatment is rare and often complicated by irreversible neurological and intellectual sequelae, including death. Reasons for these complications include the underlying cause of RCSE and its duration but also its management. The majority, if not all patients with RCSE will be managed on an intensive care unit (ICU). There are no agreed drugs or treatment protocols for treating RCSE. The three most commonly used anticonvulsants are thiopentone, midazolam and propofol (although this latter drug is rarely used in children). There are very limited and all anecdotal data on the treatment and outcome of RCSE in adults and children. A two-year audit of all children with RCSE treated on a paediatric intensive care unit in England, Wales and Scotland has recently been completed. This will provide unique epidemiological data on paediatric RCSE and its current management. These data will facilitate the design of a randomised controlled trial of specific drug treatments and protocols.

Research should include:

- A multi-centre, randomised comparative trial on intensive care units – this could involve adult and paediatric care units (it will not be able to be a blinded study, and randomisation may have to exclude propofol for children).

- Primary outcome should be cessation of the RCSE.

- Secondary outcomes should include a recurrence with a designated period (12 hours), mortality and morbidity.

- Cost data should include treatment costs and days on intensive care.
4.5 AEDs and pregnancy

What is the malformation rate and longer-term neurodevelopmental outcome of children born to mothers who have taken the AEDs in pregnancy?

Why this is important

Pregnancy registers are increasing the data that are available on established AEDs; however, these registers may give malformation rates but do not provide controlled long-term data on neurodevelopmental outcome.

Research should include:

- Measures of maternal outcome, including seizure frequency and quality of life.
- Major and minor rates of congenital malformations.
- Prospective neurodevelopmental (including cognitive) and behavioural outcomes in children born to women with epilepsy; these should be undertaken on a long-term basis and ideally using a cohort study, followed from birth and until adult life.

5 Other versions of this guideline

5.1 Full guideline

The full guideline, 'The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care (a partial update of clinical guideline 20)', contains details of the methods and evidence used to develop the guideline. It is published by the National Clinical Guideline Centre, and is available from our website (www.nice.org.uk/guidance/CG[XX]/FullGuidance).

5.2 Quick reference guide

A quick reference guide for healthcare professionals is available from www.nice.org.uk/guidance/CG[XX]/QuickRefGuide

For printed copies, phone NICE publications on 0845 003 7783 or email publications@nice.org.uk (quote reference number N[XXXX]).
5.3 ‘Understanding NICE guidance’

A summary for patients and carers (‘Understanding NICE guidance’) is available from www.nice.org.uk/guidance/CG[XX]/PublicInfo.

For printed copies, phone NICE publications on 0845 003 7783 or email publications@nice.org.uk (quote reference number N[XXXX]).

We encourage NHS and voluntary sector organisations to use text from this booklet in their own information about epilepsy.

6 Related NICE guidance

Published


Under development

NICE is developing the following guidance (details available from www.nice.org.uk):

- Transient loss of consciousness in adults. NICE clinical guideline.

Publication expected August 2010.

7 Updating the guideline

NICE clinical guidelines are updated so that recommendations take into account important new information. New evidence is checked 3 years after publication, and healthcare professionals and patients are asked for their views; we use this information to decide whether all or part of a guideline needs updating. If important new evidence is published at other times, we may decide to do a more rapid update of some recommendations. Please see our website for information about updating the guideline.
Appendix A: The Guideline Development Group,
National Clinical Guideline Centre and NICE project
team

Guideline Development Group (2011, partial update)
Dr Amanda Freeman
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Hospital, Portsmouth.

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Dr Tanzeem Raza
Consultant Physician, Royal Bournemouth Hospital

Mr William Harkness
Consultant Neurological Surgeon, Great Ormond Street Hospital for Children, London
Guideline Development Group co-opted experts

For this guideline, the GDG was assisted by a number of co-opted experts, who were chosen because of their knowledge in a particular area.

2011 Guideline (partial update)

Dr Aza JJ Abdulla
Consultant Physician and Geriatrician, Department of Elderly Medicine, South London Healthcare NHS Trust. Princess Royal University Hospital, Kent

Professor Frank Besag
Consultant Neuropsychiatrist, Children’s Learning Disability Service
Twinwoods Health Resource Centre, Bedford

Dr Michael Marsh
Consultant in Obstetrics and Gynaecology, King's College Hospital, London

2004 Guideline

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Occupational Therapist, Frenchay Hospital, Bristol

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Nichole Taske
Technical Lead

Stefanie Reken
Health Economist

Michelle Wallwin
Editor
Appendix B: The Guideline Review Panel

The Guideline Review Panel is an independent panel that oversees the development of the guideline and takes responsibility for monitoring adherence to NICE guideline development processes. In particular, the panel ensures that stakeholder comments have been adequately considered and responded to. The panel includes members from the following perspectives: primary care, secondary care, lay, public health and industry.

2011 Guideline (partial update)
To be completed

2004 Guideline
Mr Barry Stables
Patient member

Dr Imogen Stephens
Joint Director of Public Health, Western Sussex Primary Care Trust

Dr Kevork Hopayian
General Practitioner, Suffolk

Professor Mike Drummond (Chair)
Director, Centre for Health Economics, University of York

Dr Robert Walker
Clinical Director, West Cumbria Primary Care
Appendix C: Outline care algorithms

Adults
**Children**

1. Suspected seizure
   - Primary care
   - Information obtained about the event
     - Physical examination
   - A&E (protocols in place for assessment)
     - Initial screening by paediatrician
   - Diagnostic doubt
   - Referral to specialist as soon as possible
     - (The GDG recommended within 2 weeks)
   - Diagnosis by specialist
     - with investigations as necessary
       - (see box A)
   - Uncertain
     - Further investigation including assessment of other physical causes
       - (e.g., cardiac) or referral to tertiary care
       - (see box A)
   - Epilepsy
     - Investigation and classification by seizure type and epilepsy syndrome
       - by specialist
       - (see box A)
     - Treatment
       - (see box A)
     - Referral to tertiary care
       - (see box A)
   - Non-epileptic attack disorder
   - Referral to psychological or psychiatric services
   - Young women and girls with epilepsy
     - (see box A)
   - Special groups
     - Children with learning disabilities
     - Black and ethnic minority groups
     - Young people with epilepsy
     - (see box A)

Regular structured review for all
(see box A)

**KEY:** —— As necessary
1

Box A Cross reference for algorithms

| Treatment with AEDs only in exceptional circumstances | 24 |
| Diagnosis and investigations | 16–17 |
| Further investigation | 17–21 |
| Investigation and classification by seizure type and epilepsy syndrome | 18–21 |
| Referral to tertiary care | 32–34 |
| Treatment | 22–35 |
| Prolonged or repeated seizures; status epilepticus | 35–38 |
| Women or girls with epilepsy | 38–44 |
| Special groups | 44–48 |
| Regular structured review | 48–50 |
| Appropriate information | 12–14 |
Appendix D: Differential diagnosis of epilepsy in adults and children

*Differential diagnosis of epilepsy in adults*
Abnormal movements predominate
- Generalised convulsive movements
- Drop attacks
- Transient focal motor attacks
- Facial muscle and eye movements
- Episodic phenomena in sleep

Disturbed awareness, thoughts, and sensations predominate
- Loss of awareness
- Transient focal sensory attacks
- Psychic experiences
- Aggressive or vocal outbursts
- Prolonged confusional or fugue states

Abnormal movements
- Epilepsy
- Syncope with secondary jerking movements
- Primary cardiac or respiratory abnormalities, presenting with secondary anoxic seizures
- Involuntary movement disorders and other neurological conditions
- Hyperekplexia
- Non-epileptic attack disorder (NEAD)

Disturbed awareness, thoughts, and sensations
- Epilepsy
- Syncope
- Cardiac disorders
- Microsleeps
- Panic attacks
- Hypoglycaemia
- Other neurological disorders
- Non-epileptic attack disorder (NEAD)

- Somatosensory attacks: epileptic seizure, transient ischaemic attack, hyperventilation
- Transient vestibular symptoms: peripheral vestibular disease, epilepsy
- Visual symptoms: migraine, transient ischaemic attack, epilepsy

- Epilepsy
- Migraine
- Panic attacks
- Drug induced flashbacks
- Hallucinations or illusions caused by loss of a primary sense
- Psychotic hallucinations and delusions
- Non-epileptic attack disorder (NEAD)

- Related to learning disability
- Epilepsy
- Villostal

- Acute encephalopathy
- Non-convulsive status epilepticus
- Intermittent psychosis
- Transient global amnesia
- Hysterical fugue
Differential diagnosis of epilepsy in children
History of Event / Attack
- Frequency
- Timing
- Triggers
- Warning beforehand
- Colour change
- Alteration in conscious level
- Motor phenomena
- Duration of attack
- Symptoms following attack

What is the trigger for the attack?
- Only during sleep?
- Related to feeding?
- With a fever?
- On initiation of movement?
- With excitement/emotion?
- Following unpleasant/painful stimuli?
- Boredom/concentration

What is the colour change?
- Pallor
- Cyanosis
- Flushing

What is the predominant motor phenomenon?
- Repetitive stereotyped spasm?
- Hypertonia?
- Hypotonia (include FALLS)?
- Dystonia?
- Unsteadiness?

What is the trigger for the attack?
- Cardiac arrhythmias
- Syncope
- Cata-plexy
- Akine-sin (drop) attacks (usually only with other seizure types)
- Infantile spasms
- Benign myoclonus of infancy
- Reflex seizures
- Behavioural stereotypes

What is the predominant motor phenomenon?
- Paroxysmal dystonia/dyskinesia
- Drug reactions

What is the trigger for the attack?
- Cardiac arrhythmias
- Syncope
- Cata-plexy
- Akine-sin (drop) attacks
- Infantile spasms
- Benign myoclonus of infancy
- Reflex seizures
- Behavioural stereotypes

What is the trigger for the attack?
- Paroxysmal dystonia/dyskinesia
- Drug reactions

What is the trigger for the attack?
- Cardiac arrhythmias
- Syncope
- Cata-plexy
- Akine-sin (drop) attacks
- Infantile spasms
- Benign myoclonus of infancy
- Reflex seizures
- Behavioural stereotypes
Appendix E: Pharmacological treatment

The tables that follow provide a summary reference guide to pharmacological treatment. They were updated in 2011. Licensing details are listed under table 3. All drugs are listed in alphabetical order.
Table 1 Drug options by seizure type

<table>
<thead>
<tr>
<th>Seizure type</th>
<th>First-line drugs</th>
<th>Adjunctive drugs</th>
<th>Other drugs that may be considered</th>
<th>Drugs to be avoided (may worsen seizures)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generalised tonic–clonic</td>
<td>Carbamazepine</td>
<td>Clobazam</td>
<td></td>
<td>Tiagabine, Vigabatrin</td>
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<tr>
<td></td>
<td>Lamotrigine</td>
<td>Lamotrigine</td>
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<td></td>
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<tr>
<td></td>
<td>Oxcarbazepine</td>
<td>Levetiracetam</td>
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<tr>
<td></td>
<td>Sodium valproate</td>
<td>Topiramate</td>
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</tr>
<tr>
<td>Absence</td>
<td>Ethosuximide</td>
<td>Lamotrigine</td>
<td></td>
<td>Carbamazepine, Oxcarbazepine, Phenytoin, Tiagabine, Vigabatrin</td>
</tr>
<tr>
<td></td>
<td>Sodium valproate</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Myoclonic</td>
<td>Sodium valproate</td>
<td>Levetiracetam</td>
<td>Clobazam, Clonazepam, Piracetam, Zonisamide, (after discussion with, or referral to a tertiary epilepsy specialist)</td>
<td></td>
</tr>
<tr>
<td>Focal with/without secondary generalisation</td>
<td>Carbamazepine, Lamotrigine, Oxcarbazepine, Sodium valproate</td>
<td>Clobazam, Gabapentin, Lamotrigine, Oxcarbazepine, Topiramate</td>
<td>Levetiracetam, (as first-line drug), Eslicarbazeine, Lacosamide, Levetiracetam, Phenobarbital, Phenytoin, Pregabalin, (after discussion with, or referral to a tertiary epilepsy specialist), Tiagabine, Zonisamide, (as adjunctive drug), Vigabatrin, (only in tertiary epilepsy specialist care)</td>
<td></td>
</tr>
<tr>
<td>Epilepsy syndrome</td>
<td>First-line drugs</td>
<td>Adjunctive drugs</td>
<td>Other drugs</td>
<td>Drugs to be avoided (may worsen seizures)</td>
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<td>------------------------------------------</td>
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<tr>
<td>Childhood absence epilepsy</td>
<td>Ethosuximide</td>
<td>Lamotrigine</td>
<td>Carbamazepine Oxcarbazepine Phenytoin Tiagabine Vigabatrin</td>
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<tr>
<td></td>
<td>Sodium valproate</td>
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<tr>
<td></td>
<td>Lamotrigine</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Juvenile absence epilepsy</td>
<td>Ethosuximide</td>
<td>Lamotrigine</td>
<td>Carbamazepine Oxcarbazepine Phenytoin Tiagabine Vigabatrin</td>
<td></td>
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<tr>
<td></td>
<td>Sodium valproate</td>
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<tr>
<td>Juvenile myoclonic epilepsy</td>
<td>Lamotrigine</td>
<td>Levetiracetam</td>
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<tr>
<td></td>
<td>Sodium valproate</td>
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<tr>
<td></td>
<td>Topiramate</td>
<td></td>
<td></td>
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<tr>
<td>Generalised tonic–clonic seizures only</td>
<td>Lamotrigine</td>
<td>Levetiracetam</td>
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<tr>
<td></td>
<td>Sodium valproate</td>
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<tr>
<td></td>
<td>Topiramate</td>
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<tr>
<td>Idiopathic Generalised Epilepsies</td>
<td>Lamotrigine</td>
<td>Levetiracetam</td>
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<tr>
<td></td>
<td>Sodium valproate</td>
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<tr>
<td></td>
<td>Topiramate</td>
<td></td>
<td></td>
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<tr>
<td>Infantile spasms</td>
<td>Steroid (prednisolone or tetracosactide) (when infantile spasms are not due to tuberous sclerosis) Vigabatrin (when infantile spasms due to tuberous sclerosis)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benign epilepsy with centrotemporal spikes</td>
<td>Carbamazepine Lamotrigine Levetiracetam Oxcarbazepine Sodium valproate</td>
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<td></td>
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<td>Benign epilepsy with occipital paroxysms</td>
<td>Carbamazepine Lamotrigine Levetiracetam Oxcarbazepine Sodium valproate</td>
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<tr>
<td>Condition</td>
<td>Treatment Options</td>
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<td></td>
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<tr>
<td>---------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Severe myoclonic epilepsy of infancy</td>
<td>Sodium valproate, Topiramate, Strипентол (after referral to a tertiary epilepsy specialist), Carbamazepine, Lamotrigine, Oxcarbazepine, Phenytoin, Vigabatrin</td>
<td></td>
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<tr>
<td>Continuous spike wave of slow sleep</td>
<td>Referral to a tertiary epilepsy specialist</td>
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<tr>
<td>Lennox–Gastaut syndrome</td>
<td>Sodium valproate, Lamotrigine, Rufinamide, Topiramate, Felbamate* (after discussion with a tertiary epilepsy specialist), Carbamazepine, Oxcarbazepine</td>
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<tr>
<td>Landau–Kleffner syndrome</td>
<td>Referral to a tertiary epilepsy specialist</td>
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<tr>
<td>Myoclonic-astatic epilepsy</td>
<td>Referral to a tertiary epilepsy specialist</td>
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</tbody>
</table>

* Please see appendix E for licensing details.
**Licensing indications**

Detailed below are drugs that have been recommended but which do not currently have licensed indications for these seizures types or syndromes or particular populations.

<table>
<thead>
<tr>
<th>Seizure type/syndrome</th>
<th>Drug</th>
<th>Details of licensing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment of refractory focal seizures</td>
<td>Clobazam</td>
<td>At the time of publication, clobazam did not have UK marketing authorisation for use in children younger than 3 years of age (BNF). This was because of insufficient experience of the use of this drug in children younger than 3 years of age to enable any dosage recommendation to be made (SPC).</td>
</tr>
<tr>
<td>Treatment of refractory focal seizures</td>
<td>Gabapentin</td>
<td>At the time of publication, gabapentin did not have UK marketing authorisation for use in children younger than 6 years of age and at doses over 50 mg/kg daily in children younger than 12 years of age (BNF). The use of gabapentin was not recommended in this age group owing to the lack of sufficient supporting data (SPC).</td>
</tr>
<tr>
<td>Treatment of refractory focal seizures</td>
<td>Eslicarbazepine</td>
<td>At the time of publication, eslicarbazepine did not have UK marketing authorisation for use in children younger than 18 years of age. It was not recommended owing to a lack of data on safety and efficacy (SPC).</td>
</tr>
<tr>
<td>Treatment of refractory focal seizures</td>
<td>Pregabalin</td>
<td>At the time of publication, pregabalin did not have UK marketing authorisation for use in children (BNF). Pregabalin is not recommended for use in children younger than 12 years of age and adolescents (12–17 years of age) owing to insufficient data on safety and efficacy (SPC).</td>
</tr>
<tr>
<td>Treatment of refractory focal seizures</td>
<td>Zonisamide</td>
<td>At the time of publication, zonisamide did not have UK marketing authorisation for use in children younger than 18 years of age owing to insufficient data on safety and efficacy (SPC).</td>
</tr>
<tr>
<td>Absence seizures</td>
<td>Lamotrigine</td>
<td>At the time of publication lamotrigine had UK marketing authorisation for monotherapy of typical absence</td>
</tr>
<tr>
<td>Seizure Type</td>
<td>Drug</td>
<td>Details</td>
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<tr>
<td>Juvenile myoclonic epilepsy</td>
<td>Lamotrigine</td>
<td>At the time of publication, lamotrigine did not have UK marketing authorisation for use in juvenile myoclonic epilepsy. It had authorisation for partial seizures, PGTC seizures and seizures associated with Lennox-Gastaut.</td>
</tr>
<tr>
<td>Juvenile myoclonic epilepsy</td>
<td>Topiramate</td>
<td>At the time of publication, topiramate did not have UK marketing authorisation for use in juvenile myoclonic epilepsy. It had authorisation for partial seizures, PGTC seizures and seizures associated with Lennox-Gastaut.</td>
</tr>
<tr>
<td>Myoclonic seizures</td>
<td>Zonisamide</td>
<td>At the time of publication, zonisamide did not have UK marketing authorisation for use in children younger than 18 years of age owing to insufficient data on safety and efficacy (SPC).</td>
</tr>
<tr>
<td>PGTC</td>
<td>Oxcarbazepine</td>
<td>At the time of publication, oxcarbazepine did not have UK marketing authorisation for PGTC seizures. It had authorisation for partial with or without secondarily generalised tonic-clonic seizures.</td>
</tr>
<tr>
<td>PGTC</td>
<td>Clobazam</td>
<td>At the time of publication, clobazam did not have UK marketing authorisation for use in children younger than 3 years of age (BNF). There was insufficient experience of the use in children younger than 3 years of age to enable any dosage recommendation to be made (SPC).</td>
</tr>
<tr>
<td>Infantile spasms</td>
<td>ACTH (tetracosactide)</td>
<td>At the time of publication, ACTH (tetracosactide) did not have UK marketing authorisation for infantile spasms. Depot ampoules are not recommended in infants and children younger than 3 years of age owing to the presence of benzyl alcohol in the formulation (SPC).</td>
</tr>
<tr>
<td>Lennox-Gastaut Syndrome</td>
<td>Felbamate</td>
<td>At the time of publication, felbamate did not have UK marketing authorisation. There was no SPC available.</td>
</tr>
<tr>
<td>SMEI</td>
<td>Topiramate</td>
<td>At the time of publication, topiramate did not have UK marketing authorisation for use in SMEI but did have authorisation for generalised</td>
</tr>
<tr>
<td>Treatment Area</td>
<td>Drug</td>
<td>Information</td>
</tr>
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<td>----------------</td>
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<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Tonic-clonic seizures, partial seizures and seizures associated with Lennox-Gastaut syndrome</td>
<td>Carbamazepine</td>
<td>At the time of publication, carbamazepine did not have UK marketing authorisation for BECTS/BEOP but had authorisation for partial and generalised tonic-clonic seizures.</td>
</tr>
<tr>
<td>Tonic-clonic seizures, partial seizures and seizures associated with Lennox-Gastaut syndrome</td>
<td>Lamotrigine</td>
<td>At the time of publication, clobazam did not have UK marketing authorisation for BECTS/BEOP but had authorisation for partial and primary and generalised tonic-clonic seizures, seizures associated with Lennox-Gastaut and typical absence seizures.</td>
</tr>
<tr>
<td>Tonic-clonic seizures, partial seizures and seizures associated with Lennox-Gastaut syndrome</td>
<td>Oxcarbazepine</td>
<td>At the time of publication, oxcarbazepine did not have UK marketing authorisation for BECTS/BEOP but had authorisation for partial seizures with or without generalised tonic-clonic seizures.</td>
</tr>
<tr>
<td>Tonic-clonic seizures, partial seizures and seizures associated with Lennox-Gastaut syndrome</td>
<td>Levetiracetam</td>
<td>At the time of publication, levetiracetam did not have UK marketing authorisation for BECTS/BEOPS but had authorisation for partial seizures with or without secondary generalisation and adjunctive therapy for myoclonic and PGTC seizures.</td>
</tr>
<tr>
<td>Status epilepticus</td>
<td>Propofol</td>
<td>At the time of publication, propofol did not have UK marketing authorisation for status epilepticus but had authorisation for other conditions. Diprivan 2%, Propofol-Lipuro 2%, and Propoven 2% were not licensed for use in children younger than 3 years of age; Diprofusor TCI (‘target controlled infusion’) system was not licensed for use in children (BNF).</td>
</tr>
<tr>
<td>Status epilepticus</td>
<td>Thiopental</td>
<td>At the time of publication, thiopental did not have UK marketing authorisation for status epilepticus or by intravenous infusion (BNF). It is authorised for convulsive states (75 mg to 125 mg or 3 ml to 5 ml of a 2.5% intravenous infusion) (SPC).</td>
</tr>
<tr>
<td>Status epilepticus</td>
<td>Midazolam</td>
<td>At the time of publication, buccal liquid and injection did not have UK marketing authorisation for children with status epilepticus (Children's BNF).</td>
</tr>
<tr>
<td>Status epilepticus</td>
<td>Diazepam</td>
<td>At the time of publication, diazepam did not have UK marketing authorisation for status epilepticus (Children's BNF).</td>
</tr>
<tr>
<td>BECTS, benign partial epilepsies of childhood; BEOP, benign epilepsy with occipital paroxysms; BNF, British national formulary; PGTC, primary generalised tonic-clonic; SMEI, severe myoclonic epilepsy of infancy; SPC, summary of product characteristics.</td>
<td>not have UK marketing authorisation for Rectubes and Stesolid Rectal Tubes or for use in children younger than 1 year.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix F: Recommendations to be deleted

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Replaced by</th>
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</table>
| 1.8.13A The newer AEDs gabapentin, lamotrigine, levetiracetam, oxcarbazepine, tiagabine, topiramate and vigabatrin, within their licensed indications, are recommended for the management of epilepsy in people who have not benefited from treatment with the older antiepileptic drugs such as carbamazepine or sodium valproate, or for whom the older antiepileptic drugs are unsuitable because:  
  - there are contraindications to the drugs  
  - they could interact with other drugs the person is taking (notably oral contraceptives)  
  - they are already known to be poorly tolerated by the individual  
  - the person is a woman of childbearing potential. | This recommendation has been replaced with new recommendations listed from sections 1.9.3 to 1.9.13 |
| 1.8.13C The newer AEDs gabapentin, lamotrigine, oxcarbazepine, tiagabine, topiramate, and vigabatrin (as an adjunctive therapy for partial seizures), within their licensed indications, are recommended for the management of epilepsy in children who have not benefited from | This recommendation has been replaced with new recommendations listed from sections 1.9.3 to 1.9.13 |
treatment with the older antiepileptic
drugs such as carbamazepine or
sodium valproate, or for whom the
older antiepileptic drugs are
unsuitable because:

- there are contraindications to the
drugs
- they could interact with other drugs
the child is taking (notably oral
contraceptives)
- they are already known to be
poorly tolerated by the child
- the child is currently of childbearing
potential or is likely to need
treatment into her childbearing
years.

1.8.14 C Vigabatrin is recommended
as a first-line therapy for the
management of infantile spasms.

1.9.9.2 Offer a steroid (prednisolone
or tetracosactide*) or vigabatrin as
first-line treatment to children with
infantile spasms that are not due to
tuberous sclerosis. [*new 2011]*

1.9.9.3 Offer vigabatrin as first-line
treatment to children with infantile
spasms due to tuberous sclerosis. If
vigabatrin is ineffective, offer a steroid
(prednisolone or tetracosactide*).
[*new 2011]*

* Please see appendix E for licensing details.
<table>
<thead>
<tr>
<th>1.8.48C</th>
<th>The ketogenic diet may be considered as an adjunctive treatment in children with drug-resistant epilepsy.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.12.2</td>
<td>Refer children with epilepsy whose seizures have not responded to appropriate AEDs to a tertiary paediatric epilepsy specialist for consideration of the use of a ketogenic diet. [new 2011]</td>
</tr>
<tr>
<td>1.9.1</td>
<td>An individual who has prolonged convulsive seizures (lasting 5 minutes or more) or serial seizures (three or more seizures in an hour) in the community should receive urgent care and treatment.</td>
</tr>
<tr>
<td>1.14.2.1</td>
<td>Give immediate emergency care and treatment to adults and children who have prolonged (lasting 5 minutes or more) or repeated (three or more in an hour) convulsive seizures in the community. [new 2011]</td>
</tr>
<tr>
<td>1.9.2</td>
<td>Rectal diazepam is safe and effective in first-line treatment of prolonged seizures and is recommended in the majority of cases.</td>
</tr>
<tr>
<td>1.9.3</td>
<td>For many individuals and in many circumstances, buccal midazolam* is more acceptable than rectal diazepam and is easier to administer. It should be used according to an agreed protocol drawn up by the specialist and only used following training.</td>
</tr>
<tr>
<td>1.14.2.2</td>
<td>Use buccal midazolam* as first-line treatment in adults and children with prolonged or repeated seizures. Use rectal diazepam if buccal midazolam* is not available. If intravenous access is already established and resuscitation facilities are available, offer intravenous lorazepam. [new 2011]</td>
</tr>
</tbody>
</table>

* Please see appendix E for licensing details.
1.9.7 Depending on response and the individual’s situation, emergency services should be contacted, particularly if:

- seizures develop into status epilepticus
- there is a high risk of recurrence
- this is the first episode
- there may be difficulties monitoring the individual’s condition.

1.14.2.7 Depending on response to treatment, the person’s situation and any personalised care plan, call an ambulance, particularly if:

- the seizures continue for 5 minutes without response to emergency medication
- there is a high risk of recurrence
- this is the first episode requiring emergency treatment
- there are concerns or difficulties monitoring the person’s condition. [new 2011]

1.10.1 In hospital, individuals with generalised tonic–clonic status epilepticus should be managed immediately, as follows (with local protocols being in place – see suggested guideline in Appendix C¹ of the full guideline):

- secure airway
- give oxygen
- assess cardiac and respiratory function
- secure intravenous (IV) access in a large vein.

1.15.1.1 For adults and children with ongoing generalised tonic-clonic seizures (status epilepticus) who are in hospital, immediately:

- secure airway
- give high-concentration oxygen
- assess cardiac and respiratory function
- check blood glucose levels using a finger prick test
- secure intravenous access in a large vein. [new 2011]

1.10.2 Lorazepam should be used as a first-line treatment in status epilepticus (see Appendix C of the full guideline).

1.15.1.2 Use intravenous lorazepam as a first-line treatment in hospital in adults and children with ongoing
<table>
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<tr>
<th>guideline)</th>
<th>generalised tonic-clonic seizures (status epilepticus). Use buccal midazolam if unable to secure immediate intravenous access. Use only a maximum of two doses of the first-line treatment (including pre-hospital treatment). <strong>[new 2011]</strong></th>
</tr>
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<tbody>
<tr>
<td><strong>1.11.4A</strong> In women of childbearing potential, the risk of the drugs (see 1.8.13A) causing harm to an unborn child should be discussed and an assessment made as to the risks and benefits of treatment with individual drugs. There are currently few data on which to base a definitive assessment of the risks to the unborn child associated with newer drugs. Specific caution is advised in the use of sodium valproate because of the risk of harm to the unborn child.</td>
<td><strong>1.16.1.4</strong> Discuss with women of childbearing potential the risk of AEDs causing malformations and neurodevelopmental delay to an unborn child. Assess the risks and benefits of treatment with individual drugs. There are limited data on risks to the unborn child associated with newer drugs. Risk of continued use of sodium valproate to the unborn child should specifically be discussed. <strong>[new 2011]</strong></td>
</tr>
<tr>
<td><strong>1.11.4C</strong> In girls of childbearing potential, including young girls who are likely to need treatment into their childbearing years, the risk of the drugs (see 1.8.13C) causing harm to an unborn child should be discussed with the child and/or her carer, and an assessment made as to the risks and benefits of treatment with individual drugs. There are currently few data</td>
<td><strong>1.16.1.5</strong> Discuss with girls of childbearing potential (including young girls who are likely to need treatment into their childbearing years) and their parents and/or carer the risk of AEDs causing malformations and neurodevelopmental delay to an unborn child. Assess the risks and benefits of treatment with individual</td>
</tr>
</tbody>
</table>

* Please see appendix E for licensing details.
on which to base a definitive
assessment of the risks to the unborn
child associated with newer drugs.
Specific caution is advised in the use
of sodium valproate because of the
risk of harm to the unborn child.

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<tr>
<td>drugs. There are limited data on risks to the unborn child associated with newer drugs. Risk of continued use of sodium valproate to the unborn child should specifically be discussed.</td>
<td></td>
</tr>
<tr>
<td>1.11.17 In all women with epilepsy, seizure freedom during pregnancy should be sought.</td>
<td>1.16.3.19 Aim for seizure freedom before conception and during pregnancy (particularly for women and girls with generalised tonic-clonic seizures) but consider the risk of adverse effects of AEDs and use the lowest effective dose of AED for each individual.</td>
</tr>
<tr>
<td>1.12.1 People with learning disabilities should receive the same support and care for their epilepsy as the general population. In addition, those with learning disabilities need the care of the learning disabilities team.</td>
<td>1.17.3.5 Do not discriminate against adults and children with learning difficulties and offer the same investigations and therapies as for the general population.</td>
</tr>
<tr>
<td>1.12.2 Learning disabilities are a common association with epilepsy. The management and treatment of the epilepsy should be undertaken by a specialist, working within a multidisciplinary team.</td>
<td>1.17.3.1 Enable adults and children who have learning disabilities, and their family and/or carers where appropriate, to take an active part in developing a personalised care plan for treating their epilepsy.</td>
</tr>
</tbody>
</table>
| 1.14.1 The recommendations on choice of treatment and the importance of regular monitoring of effectiveness and tolerability are the same for older people as for the general population. | 1.19.1 Do not discriminate against older people and offer the same investigations and therapies as for the general population. [new 2011]  
1.19.2 Pay particular attention to pharmacokinetic and pharmacodynamic issues with polypharmacy and comorbidity in older people with epilepsy. Consider using lower doses of AEDs and if using carbamazepine, offer modified-release carbamazepine preparations. [new 2011] |