

Epilepsy: the diagnosis and management of epilepsy in children and adults

NICE guideline

Second draft for consultation, March 2004

If you wish to comment on the recommendations, please make your
comments on the **full** version of the draft guideline.

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Key priorities for implementation

The following recommendations have been identified as key priorities for implementation.

1. All individuals with suspected recent onset seizures should be seen urgently by a specialist. This specialist should: establish the diagnosis, use investigations such as EEG and MRI appropriately, classify the epilepsy into seizure type and syndrome, and initiate drug therapy in collaboration with individuals.
2. All individuals with epilepsy should have a care plan agreed with individuals and/or family, primary and secondary care providers.
3. Drug therapy should be tailored to seizure type, epilepsy syndrome, co-medication, co-morbidity and individual lifestyle factors and preferences.
4. All individuals with epilepsy should have a regular structured review. In children this review should be carried out at a frequency not less than yearly by a specialist. In adults, this review should be carried out at a frequency not less than yearly by either a generalist or specialist, depending on how well the epilepsy is controlled and/or the presence of specific lifestyle issues. The review should include access to: written and visual information; counselling services; voluntary organizations; epilepsy nurse specialists; timely and appropriate investigations; referral to tertiary services including surgery.
5. Individuals with epilepsy and their carers should participate as partners in all decisions about their healthcare. All individuals with epilepsy should be fully informed about their condition, treatment options, prognosis and effects on lifestyle. All information should be tailored to the needs of the individual.
6. Women of childbearing potential should be fully informed about treatment choices and their options during pregnancy and the postnatal period to minimise risk to the child and mother.

7. If seizures are not controlled and/or there is diagnostic uncertainty or treatment failure, individuals should be referred to tertiary services for further assessment.

The following guidance is evidence based. The grading scheme used for the recommendations (A, B, C, D, NICE or good practice point [GPP]) is described in Appendix A; a summary of the evidence on which the guidance is based is provided in the full guideline (see Section 5).

1 Guidance

A – recommendation for adults C – recommendation for children

1.1 Principle of decision making

1.1.1 Healthcare professionals should adopt a consulting style that allows the individual with epilepsy and their carers to participate as partners in all decisions about their healthcare. **[D]**

1.2 Information

1.2.1 Individuals with epilepsy and their families and/or carers should be given, and have access to sources of, information about the following issues:

- epilepsy in general
- diagnosis and treatment options
- medication and side effects
- seizure type(s), triggers and seizure control
- first aid, safety and injury prevention
- psychological issues
- social security benefits and other social services
- insurance issues
- education and health care at school
- employment and independent living for adults
- prognosis
- sudden death in epilepsy (SUDEP)
- status epilepticus
- life style and social issues (including recreational drugs, alcohol, sexual activity and sleep deprivation)
- family planning and pregnancy
- access to voluntary organisations, and how to contact them. **[C]**

1.2.2 Information should be provided in a variety of formats, languages, and ways tailored to individual requirements. Consideration must be given to developmental age, gender, culture, and stage of life of the individual. **[GPP]**

1.2.3 Professionals should direct individuals to voluntary organisations and other sources of good information (on the world wide web if appropriate, www.jointepilepsycouncil.org.uk) if they have not found it themselves. **[GPP]**

1.2.4 Adequate time should be set aside to provide information and this should be re-visited on subsequent consultations. **[GPP]**

1.2.5 Checklists should be used to remind both individuals and professionals about information that should be discussed. **[GPP]**

1.2.6 Everyone providing care or treatment for individuals with epilepsy should be able to provide essential information, but for every individual person it should be clear who is the designated healthcare professional responsible for ensuring that the information needs of the individual and anyone who is identified as caring for individuals with epilepsy have been met at various times. **[GPP]**

1.2.7 Discussion about the possibility of having seizures and information on epilepsy should be provided before seizures occur to people at high risk of developing seizures, such as after severe brain injury, people with a learning disability or having a strong family history of epilepsy. **[GPP]**

1.2.8 In all individuals, a risk assessment should be made by an appropriate professional about when information should be given on the following (where appropriate):

- road safety
- domestic safety
- safety at school
- importance of disclosing epilepsy at work, if relevant; if further information or clarification is needed, voluntary organisations should be contacted.
- leisure activities
- SUDEP
- contraception
- recreational drugs, alcohol and other seizure triggers. **[GPP]**

1.2.9A Adults with epilepsy need information in advance of important decisions (for example, pregnancy, employment). **[C]**

Sudden death in epilepsy (SUDEP)

1.2.10 Information on SUDEP should be included in literature on epilepsy to show why preventing seizures is important, while tailored information on the individual's relative risk of SUDEP should also be part of the counselling checklist for people with epilepsy and their carers. **[C]**

1.2.11 The risk of SUDEP can be minimized by:

- optimising seizure control
- being aware of the potential consequences of nocturnal seizures. **[GPP]**

1.2.12 Tailored information and discussion between the individual with epilepsy, family (where appropriate) and professionals should take account of the small but definite risk of SUDEP. **[C]**

1.2.13 Where families and carers have been affected by SUDEP, healthcare professionals should contact families to offer their condolences, invite them to discuss the death, and offer referral to bereavement counselling and a SUDEP support group. **[C]**

1.3 Following a first seizure

1.3.1 All individuals with a recent onset suspected seizure should be seen urgently^a by a specialist. **[GPP]**

1.3.2 Individuals who have an unprovoked first seizure should be referred to a first seizures clinic for assessment. **[GPP]**

1.3.3 There should be protocols that ensure proper assessment in the emergency setting. **[D]**

1.3.4A [Awaiting the publication of the NICE technology appraisal on the use of newer drugs for epilepsy in adults (scheduled for March 2004)]

1.3.4C It is recommended that all children who have had a first non-febrile seizure should be seen as soon as possible by a specialist in the management of the epilepsies to ensure precise and early diagnosis and initiation of therapy as appropriate to their needs. **[A NICE]** Provisional recommendations based on the NICE technology appraisal of the use of newer anti-epilepsy drugs in children which has not yet been published.^b

1.3.5 Following a suspected seizure, there should be an initial screening. This should be done by an adult/paediatric physician with onwards referral to a specialist when epilepsy is suspected. **[GPP]**

1.3.6A The information that should be obtained from the individual and/or carer after a suspected seizure is contained in Appendix A of the full guideline. **[GPP]**

1.3.6C The information that should be obtained from the child and/or parent after a suspected seizure is contained in Appendix A of the full guideline. **[GPP]**

^a Using the NICE referral grading system as "**** is seen urgently", considered to be within 2 weeks.

^b When this document was prepared for consultation, a Final Appraisal Determination had been issued by the Institute.

1.3.7A 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. This information should be provided while the individual is awaiting a diagnosis and should also be provided to family and carers. **[GPP]**

1.3.7C Information should be provided to parents, carers and the child where appropriate, on what to do if a further seizure occurs. This information could include for example, first aid, safety issues, and who to contact. **[GPP]**

1.3.8 In an individual presenting with an attack a physical examination, including cardiac, neurological, mental state, and developmental assessment where appropriate, should be carried out. **[C]**

1.4 Diagnosis

1.4.1A The diagnosis of epilepsy in adults should be established by a specialist medical practitioner with training and expertise in epilepsy.^c **[C]**

1.4.1C The diagnosis of epilepsy in children should be established by a specialist.^d **[C]**

1.4.2C Children and their families should be given an opportunity to discuss the diagnosis with an appropriate health care professional. **[C]**

1.4.3 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. **[C]**

1.4.4 The diagnosis as to whether an epileptic seizure has or has not occurred should then be based on the combination of the description of the attack and different symptoms. The diagnosis should not be based on the presence or absence of single features. **[B]**

1.4.5 It is important to recognise that a definite diagnosis of epilepsy may not be possible. If the diagnosis cannot be clearly established, it is best to continue to investigate or refer to a tertiary centre rather than misdiagnose. Follow-up must always be arranged in such cases. **[GPP]**

1.4.6 Prospective recording of events, including video recording and written descriptions, can be helpful in reaching a diagnosis. **[GPP]**

^c For adults, defined throughout as a medical practitioner with training and expertise in epilepsy.

^d For children, defined throughout as a paediatrician with training and expertise in epilepsy.

1.5 Investigations

1.5.1 Information should be provided to individuals and carers on the reasons for tests, their results and meaning, the requirements of specific investigations, and the logistics of obtaining them. **[D]**

EEG

1.5.2 Individuals requiring an EEG should have the test performed within four weeks of it being requested.^e **[GPP]**

1.5.3A An EEG should be performed to support a diagnosis of epilepsy in adults in whom the clinical history suggests that the seizure is likely to be epileptic in origin. **[C]**

1.5.3C An EEG should be performed to support a diagnosis of epilepsy in children in whom the clinical history suggests that the seizure is likely to be epileptic in origin. An EEG should be performed after the second or subsequent epileptic seizure but may in certain circumstances, as evaluated by the specialist, be considered after a first epileptic seizure. **[C]**

1.5.4 An EEG should not be performed in the case of probable syncope because of the possibility of a false positive result. **[C]**

1.5.5 The EEG cannot be used to 'exclude' a diagnosis of epilepsy in an individual in whom the clinical presentation supports a diagnosis of a non-epileptic event. **[C]**

1.5.6 The EEG cannot be used in isolation to make a diagnosis of epilepsy. **[C]**

1.5.7 An EEG can be used to help determine seizure type and epilepsy syndrome prognosis in individuals suspected as having a diagnosis of epilepsy. This enables individuals to be given the correct prognosis. **[C]**

1.5.8 Unequivocal epileptiform activity shown on EEGs of individuals presenting with a first unprovoked seizure may be used to assess likelihood of increased risk of seizure recurrence. **[B]**

1.5.9 Specialist investigations should be available for individuals who present diagnostic difficulties. **[GPP]**

1.5.10 Serial 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 contributory. **[C]**

1.5.11 Serial standard EEGs should not be preferred to sleep or sleep deprivation EEGs. **[C]**

^e Using the NICE referral grading system as "*** is seen soon"

1.5.12 When the standard EEG has not contributed to diagnosis or classification a sleep EEG should be performed. (C) In children, this is best achieved through sleep deprivation or the use of melatonin. However, melatonin is currently unlicensed in the UK. **[GPP]**

1.5.13 Long-term video or ambulatory EEG has an important role in the assessment of individuals who present diagnostic difficulties following clinical assessment and standard EEG. **[C]**

1.5.14 Provocation by suggestion has a limited role in the evaluation of non-epileptic attack disorder, and may lead to false positive results in some individuals. **[C]**

1.5.15 Photic stimulation and hyperventilation should remain part of standard EEG assessment. The individual and carer should be made aware that such activation procedures may induce a seizure and they have a right to refuse if desired, as each seizure carries a risk to the individual. **[GPP]**

Neuroimaging

1.5.16 Neuroimaging should be used to identify structural abnormalities which cause certain epilepsies. **[C]**

1.5.17 MRI is the imaging investigation of choice in individuals with epilepsy. **[C]**

1.5.18 MRI is particularly important in those:

- who develop epilepsy before the age of two years and 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. **[C]**

1.5.19 Neuroimaging should not be routinely requested when a diagnosis of idiopathic generalised epilepsy has been made. **[C]**

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

1.5.21 In an acute situation, CT may be used to determine whether a seizure has been caused by an acute neurological lesion or illness. **[GPP]**

1.5.22 Individuals requiring MRI should have the test performed within four weeks of it being requested.^f **[GPP]**

Other tests

1.5.23 The use of serum prolactin to make a diagnosis of epilepsy cannot be recommended. **[C]**

^f Using the NICE referral grading system as “** is seen soon”

1.5.24A 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. **[GPP]**

1.5.24C In children, other investigations, including blood and urine biochemistry, should be undertaken at the discretion of the specialist to exclude a diagnosis other than epilepsy, and to determine an underlying cause of the epilepsy. However, the level of distress to the child and the carer should be taken into account when requesting blood tests. **[GPP]**

1.5.25A In adults a 12 lead ECG should be performed. **[GPP]**

1.5.25C In children a 12 lead ECG should be considered in cases of diagnostic uncertainty. **[GPP]**

1.5.26 In cases of diagnostic uncertainty, a referral to a cardiologist should be considered. **[GPP]**

1.6 Classification

1.6.1 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. **[D]**

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

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

1.7 Management

1.7.1 People with epilepsy should have an accessible point of contact with specialist services. **[GPP]**

1.7.2 All people with epilepsy should have a comprehensive care plan that is agreed with the individual, primary care providers and secondary care providers. This should include lifestyle issues as well as medical issues. **[GPP]**

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

Pharmacological treatment

1.7.4 Information that is provided about AEDs needs to be in the context of that provided by the manufacturer, for example, indications, side effects, license status and arrangements for continued supply. **[GPP]**

1.7.5 The AED treatment strategy should be individualised according to the seizure type, epilepsy syndrome, co-medication, co-morbidity and individual life-style factors (see Appendix B of the full guideline). **[A]**

1.7.6 The diagnosis of epilepsy needs to be critically evaluated if events continue despite an optimal dose of a first line AED. **[GPP]**

1.7.7 Different preparations may vary in bioavailability or have different pharmacokinetic profiles; careful consideration should be given to the potential for reduced effect or excessive side-effects before changing the formulation or brand of AEDs. **[D]**

1.7.8 Alternative monotherapy or add-on therapy: Awaiting the publication of the NICE technology appraisal on the use of newer drugs for epilepsy in adults (scheduled for March 2004)

1.7.9A Use of newer anti-epileptic drugs: awaiting the publication of the NICE technology appraisal on the use of newer drugs for epilepsy in adults (scheduled for March 2004)

1.7.9C The newer anti-epileptic drugs 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 treatment with the older anti-epileptic drugs such as carbamazepine or sodium valproate, or for whom the older anti-epileptic 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. **[A NICE]^g**

^g When this document was prepared for consultation, a Final Appraisal Determination had been issued by the Institute.

1.7.10C Vigabatrin is recommended as a first-line therapy for the management of infantile spasms. **[A NICE]**^h

1.7.11C It is recommended that children should be treated with a single anti-epileptic 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. **[A NICE]**ⁱ

1.7.12C It is recommended that combination therapy (adjunctive or 'add-on' therapy) should only be considered when attempts at monotherapy with anti-epileptic drugs 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 child, in terms of the balance between effectiveness in reducing seizure frequency and tolerability of side effects. **[A NICE]**^j

Initiation of pharmacological treatment

1.7.13 The informed decision to initiate AED therapy should be taken between the individual, parents and/or carers, if appropriate, and the specialist after a full discussion of the risks and benefits of treatment. This discussion should take into account details of the epilepsy syndrome, prognosis and individual lifestyle. **[GPP]**

1.7.14 It should be recognised that some individuals, patients and or carers, if appropriate, may choose not to take AEDs following a full discussion of the risks and benefits of treatment. **[GPP]**

^h When this document was prepared for consultation, a Final Appraisal Determination had been issued by the Institute.

ⁱ When this document was prepared for consultation, a Final Appraisal Determination had been issued by the Institute.

^j When this document was prepared for consultation, a Final Appraisal Determination had been issued by the Institute.

1.7.15A In adults, AED treatment should be initiated on the recommendation of a specialist. **[GPP]**

1.7.15C In children, AED treatment should be initiated by a specialist. **[GPP]**

1.7.16 AED therapy should be considered and discussed with individuals after a first unprovoked seizure if:

- the individual has a neurological deficit
- the EEG shows unequivocal epileptic activity
- the individual and/or carers consider the risk of having a further seizure unacceptable
- brain imaging shows a structural abnormality. **[B]**

1.7.17 Treatment with antiepileptic medication is generally recommended after a second epileptic seizure. **[A]**

1.7.18 AED treatment should only be started once the diagnosis of epilepsy is confirmed, except in exceptional circumstances which require discussion and agreement between the prescriber and the specialist. **[GPP]**

Continuation of pharmacological treatment

1.7.19 Continuing AED treatment should be supervised by the specialist and be part of the individual's agreed treatment plan, which includes consideration of specific drug choice, drug dosage, possible side effects, and action to take if seizures persist. **[GPP]**

1.7.20 The needs of the individual and carers should be taken into account when healthcare professionals take on the responsibility of continuing prescribing. **[GPP]**

1.7.21 Responsibility for prescribing can be taken in primary care if local circumstances and/or licensing allow. **[GPP]**

1.7.22 The prescriber must ensure that the individual is fully informed about treatment including action to be taken after a missed dose or after a gastro-intestinal upset. **[GPP]**

1.7.23 Adherence to treatment can be optimised with the following:

- education for individuals and carers in understanding of their condition and rationale of treatment
- reduction in the stigma associated with the condition
- simple medication regimens
- positive relationships with healthcare professionals, family and the individual with epilepsy. **[D]**

1.7.24A Regular blood test monitoring in adults is not recommended as routine, but should be done only if clinically indicated. **[C]**

1.7.24C Regular blood test monitoring in children is not recommended as routine, but should be done only if clinically indicated and recommended by the specialist because blood tests are distressing for children. **[GPP]**

1.7.25 Indications for monitoring of AED blood levels are:

- detecting 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, or pregnancy. **[D]**

1.7.26A Examples of blood tests include:

- before surgery: clotting studies in those on valproate
- FBC, 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. **[GPP]**

1.7.27 Asymptomatic minor abnormalities in test results are not necessarily an indication for changes in medication. **[GPP]**

Withdrawal of pharmacological treatment

1.7.28 The decision to continue or withdraw medication should be taken between the individual, parents and/or carers, if appropriate, and the specialist after a full discussion of the risks and benefits of withdrawal. At the end of the discussion individuals and carers, if appropriate, should understand the individual's risk of seizure recurrence on and off treatment. This discussion should take into account details of the epilepsy syndrome, prognosis and individual lifestyle. **[A]**

1.7.29 Withdrawal of AEDs must be managed by, or under the guidance of the specialist. **[GPP]**

1.7.30 The risks and benefits of continuing or withdrawing AED therapy should be discussed with individuals who have been seizure free for at least 2 years (see Appendix H of the full guideline). **[B adults, C children]**

1.7.31 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. **[D]**

1.7.32 Particular care should be taken when withdrawing benzodiazepines and barbiturates (may take up to 6 months or longer) due to the possibility of withdrawal symptoms other than seizure recurrence. **[GPP]**

1.7.33 There should be a fail-safe plan agreed with individuals, families and carers as appropriate whereby if seizures recur, the last dose reduction is reversed and medical advice sought. **[GPP]**

Referral for complex or refractory epilepsy

1.7.34 All individuals with epilepsy should have access via their specialist to a tertiary service when circumstances require. Approximately 10–15% of individuals who develop epilepsy are likely to require this tertiary service. **[GPP]**

1.7.35 Information should be provided to individuals and carers on the reasons for considering surgery. The benefits and risks of the surgical procedure under consideration should be fully explained. **[C]**

1.7.36 It is important that all individuals should be referred to tertiary services soon^k, due to the morbidity and mortality associated with uncontrolled epilepsy. Referral should be considered when one or more of the following criteria are present:

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

1.7.37C In children, the diagnosis and management of epilepsy within the first few years of life may be extremely challenging. For this reason children and infants with suspected epilepsy should be referred to tertiary services early, because of the profound developmental, behavioural and psychological effects which may be associated with continuing seizures. **[GPP]**

^kAs defined by NICE – soon** should be defined locally.

1.7.38 Behavioural or developmental regression or inability to identify the epilepsy syndrome in an individual, should result in immediate referral to tertiary services. **[GPP]**

1.7.39 Individuals with specific syndromes such as Sturge Weber, the hemispheric syndromes, Rasmussen's encephalitis and hypothalamic hamartoma, should be referred to a tertiary epilepsy service. **[GPP]**

1.7.40 Psychiatric co-morbidity and/or negative baseline investigations should not be a contraindication to referral to a tertiary centre. **[GPP]**

1.7.41 The specialist 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. **[GPP]**

1.7.42 The multidisciplinary team for the management of complex epilepsy should include psychology, psychiatry, social work, occupational therapy, counselling, neuroradiology, clinical nurse specialists, neurophysiology, neurology, neurosurgery and neuroanaesthesia, and have available to them MRI and video telemetry facilities. **[GPP]**

1.7.43 The neurosurgeon involved in the multidisciplinary team should have specialist experience and/or training in the area of epilepsy surgery and have access to the capability of carrying out invasive EEG recording. **[GPP]**

Psychological interventions

1.7.44A In adults where either the individual or the specialist assess seizure control as inadequate with optimal AED treatment, psychological interventions (relaxation, cognitive behaviour therapy, biofeedback) can be used in conjunction with AEDs and may be associated with improved quality of life in some individuals. **[A]**

1.7.44C Psychological interventions (relaxation, cognitive behaviour therapy) can be used in children with drug resistant focal epilepsy. (A)

1.7.45 Psychological interventions have not been proven to affect seizure frequency and are not an alternative to pharmacological treatment. **[A]**

Ketogenic diet

1.7.46A The ketogenic diet cannot be recommended for adults with epilepsy. **[C]**

1.7.46C The ketogenic diet may be considered as an adjunctive treatment in children with drug resistant epilepsy. **[C]**

Vagal nerve stimulation (VNS)

1.7.47A Vagal nerve stimulation (VNS) is a palliative procedure which may be considered in adults with drug resistant epilepsies who are not suitable for resective surgery. **[A]**

1.7.47C Vagal nerve stimulation (VNS) is a palliative procedure which may be considered in children with symptomatic or probably symptomatic drug resistant epilepsies who are not suitable for resective surgery. **[A]**

Neuropsychological assessment

1.7.48 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. **[D]**

1.8 Coping with epilepsy

1.8.1 People with epilepsy and their families should be empowered to manage their condition to a maximum possible extent. **[GPP]**

1.8.2A Adults should be receiving appropriate information and education about all aspects of epilepsy. This may be best achieved through structured self-management plans. **[A]**

1.8.2C In children, self management of epilepsy may be best achieved through active child-centred training models and interventions. **[A]**

1.8.3 Healthcare professionals should make individuals with epilepsy who wish to manage their condition more effectively aware of the Expert Patients Programme (<http://www.expertpatients.nhs.uk/>) and other programmes run by voluntary organisations. **[GPP]**

1.9 Prolonged or repeated seizures in the community

1.9.1 An individual who has prolonged convulsive (lasting 5 or more minutes) or serial seizures (3 or more seizures in an hour) in the community should receive urgent care and treatment. **[A]**

1.9.2 Rectal diazepam is safe and effective in first line treatment and is recommended in the majority of cases. **[A]**

1.9.3 In many individuals and circumstances buccal midazolam is more acceptable than rectal diazepam. It should be used according to an agreed protocol drawn up by the specialist and only used following training. **[GPP]**

1.9.4 Individuals, carers, and healthcare professionals should be aware that buccal midazolam is presently unlicensed, but preferred by individuals and easier to administer. **[GPP]**

1.9.5 Treatment may be administered by carers according to an individually agreed protocol drawn up by the specialist, or by trained clinical personnel. **[GPP]**

1.9.6 Care must be taken to secure the individual's airway and assess their respiratory and cardiac function. **[GPP]**

1.9.7 Depending on response and the individual's situation, admission to hospital should be considered 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. **[GPP]**

1.10 Treatment of status epilepticus

Convulsive status epilepticus

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 protocol in Appendix C of the full guideline):

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

1.10.2 The pharmacokinetics of lorazepam favour its use as a first-line treatment in status epilepticus (see Appendix C of the full guideline). **[D]**

Refractory convulsive status epilepticus

1.10.3 Treatment of refractory status epilepticus in secondary care should follow the suggested guidelines (See Appendix C of the full guideline). **[D]**

1.10.4A In adults, propofol or thiopentone should be used to control refractory status epilepticus with adequate monitoring, including blood levels of thiopentone, and support. **[C]**

1.10.4C In children, midazolam or thiopentone should be used to control refractory status epilepticus with adequate monitoring, including blood levels of thiopentone, and support. **[C]**

1.10.5 Regular medication should be continued at optimal doses and the reasons for status should be investigated. **[GPP]**

1.10.6 As the treatment pathway progresses the expertise of an anaesthetist/intensivist should be sought. **[GPP]**

1.10.7 If either the whole protocol or intensive care is required the tertiary centre should be consulted. **[GPP]**

1.10.8 In those who have recurrent convulsive status epilepticus an individual treatment pathway should be formulated. **[GPP]**

Non-convulsive status epilepticus

1.10.9 Non-convulsive status is uncommon and management is less urgent. A suggested protocol can be found in Appendix C of the full guideline. **[GPP]**

1.11 Women with epilepsy

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

1.11.2 Information about contraception, conception, pregnancy, or menopause should be given to girls and women in advance of sexual activity or pregnancy, or menopause, and the information should be tailored to their individual needs. This information should also be given as appropriate and as needed to people such as families and carers, who are closely involved with women with epilepsy. **[C]**

1.11.3 All health professionals who treat, care, or support women with epilepsy should be familiar with relevant information and the availability of counselling. **[GPP]**

1.11.4A Drug treatment: awaiting the publication of the NICE technology appraisal on the use of newer drugs for epilepsy in adults (scheduled for March 2004)

1.11.4C In girls of childbearing potential, including young girls who are likely to need treatment into their childbearing years, the risk of the drugs causing harm to an unborn child should be discussed with the child and/or their carer, 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. **[A NICE]¹**

1.11.5 All women on AEDs should be offered 5 mg per day of folic acid prior to any possibility of pregnancy. **[D]**

¹ When this document was prepared for consultation, a Final Appraisal Determination had been issued by the Institute.

Contraception

1.11.6A Awaiting the publication of the NICE technology appraisal on the use of newer drugs for epilepsy in adults (scheduled for March 2004)

1.11.6C 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 their carer, and an assessment made as to the risks and benefits of treatment with individual drugs. **[A NICE]^m**

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

1.11.8 If women on enzyme-inducing AEDs choose to take the combined oral contraceptive pill, a minimum initial dose of 50mcg of oestrogen is recommended. If breakthrough bleeding occurs, the dose of oestrogen should be increased to 75mcg or 100mcg per day, and 'tricycling' (taking three packs without a break) should be considered. **[D]**

1.11.9 The use of additional barrier methods should be discussed with women taking enzyme-inducing AEDs and oral contraception. **[GPP]**

Pregnancy

1.11.10 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 sections 1.2.10–1.2.12). **[C]**

1.11.11 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/). **[GPP]**

1.11.12 In all women with epilepsy, seizure freedom during pregnancy should be sought. **[GPP]**

1.11.13 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. **[D]**

1.11.14 Women should be re-assured that there is no evidence that simple partial, complex partial, absence and myoclonic seizures adversely affect the pregnancy or developing fetus unless they fall and sustain an injury. **[D]**

1.11.15 Women should be reassured that an increase in seizure frequency is generally unlikely in pregnancy or in the first few months after birth. **[B]**

^m When this document was prepared for consultation, a Final Appraisal Determination had been issued by the Institute.

1.11.16 Generally women can be reassured that the risk of a tonic-clonic seizure during the labour and the 24 hours after birth is only 1-4%. **[C]**

1.11.17 The clinician should discuss the relative benefits and risks of adjusting medication to enable the women to make an informed decision. Where appropriate, the woman's specialist should be consulted (see sections 1.7.27–1.7.33). **[GPP]**

1.11.18 Routine monitoring of drug levels in pregnancy is not recommended, but may be useful to plan or anticipate the extent of change of dose needed if seizures do increase. **[D]**

1.11.19 Most women with epilepsy should be informed that they are likely to have healthy pregnancies; however they should be informed that they have an increased risk of complications during the pregnancy and the labour. **[B]**

1.11.20 Care of pregnant women should be shared between the obstetrician and the specialist. **[GPP]**

1.11.21 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. **[GPP]**

1.11.22 During labour, although the risk of seizures is low, 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. **[GPP]**

1.11.23 All children born to mothers taking AEDs should be offered 1mg of vitamin K parenterally at delivery. **[C]**

1.11.24 Genetic counselling should be considered especially for those individuals with idiopathic epilepsy and a positive family history of epilepsy. **[D]**

1.11.25 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 unaffected is much higher than the probability that the child will have seizures. **[GPP]**

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

1.11.27 Joint epilepsy and obstetric clinics may be convenient for mothers and health care professionals but there is insufficient evidence to recommend their routine use. **[GPP]**

1.11.28 It is, however, important that there should be regular follow up, planning of delivery, liaison between the specialist/epilepsy team and the obstetrician/midwife. **[GPP]**

Breastfeeding

1.11.29 All women should be encouraged to breastfeed. Except in very rare circumstances, breastfeeding for most women taking AEDs is safe and should be encouraged. However, each mother needs to be supported in the choice of feeding method which best suits her and her family. **[GPP]**

1.11.30 Prescribers should consult Appendix 5 of the BNF when prescribing AEDs for women who are breastfeeding. **[GPP]**

After the birth

1.11.31 The safety of a new baby or young child should be considered by any mother, including women with epilepsy. 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. **[GPP]**

1.11.32 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). **[C]**

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

1.12 People with learning disabilities

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. **[GPP]**

1.12.2 Learning disabilities are a common association with childhood epilepsy. The management and treatment of the epilepsy should be undertaken by a specialist, working within a multi-disciplinary team. **[C]**

Diagnosis (see also Section 1.4)

1.12.3 The diagnosis of epilepsy may be difficult in this group of people so care should be taken to obtain a full clinical history. Confusion may arise between stereotypic or other behaviours and seizure activity. **[C]**

1.12.4 It is important to have an eye witness account supplemented by corroborative evidence (e.g. a video account), where possible. **[D]**

1.12.5 Clear, unbiased reporting is essential. Witnesses may need education to accurately describe their observations. **[GPP]**

Investigations (see also Section 1.5)

1.12.6 Those with learning disabilities may require particular care and attention to tolerate investigations. **[GPP]**

1.12.7 Facilities should be available for imaging under anaesthesia, if necessary. **[D]**

1.12.8C In the child presenting with epilepsy and learning disability, investigations directed at determining an underlying cause should be undertaken. **[GPP]**

1.12.9C All investigations should be performed in a child-centred environment. **[GPP]**

Management

1.12.10 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 antiepileptic drugs. **[D]**

1.12.11A Awaiting the publication of the NICE technology appraisal on the use of newer drugs for epilepsy in adults (scheduled for March 2004)

1.12.11C The recommendations on choice of treatment and the importance of regular monitoring of effectiveness and tolerability are the same for specific groups such as children with learning disabilities as for the general population of children with epilepsy. **[A NICE]ⁿ**

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

1.12.13 Healthcare professionals should be aware of the higher risks of mortality for people with learning disabilities and discuss these with parents and carers. **[GPP]**

1.12.14 All individuals with epilepsy and learning disabilities should have a risk assessment including:

- bathing and showering
- food preparation
- use of electrical equipment
- management of the acute seizure
- impact of epilepsy in social settings
- SUDEP
- independent living balancing the rights of the individual with the role of the carer. **[C]**

ⁿ When this document was prepared for consultation, a Final Appraisal Determination had been issued by the Institute.

1.13 Young people with epilepsy (see also Section 1.11)

1.13.1 The physical, psychological and social needs of young people with epilepsy should always be considered by health care professionals. Attention should be paid to their relationships with family, friends and at school. **[C]**

1.13.2 Healthcare professionals should adopt a consulting style that allows both professional and the young person with epilepsy to participate as partners in the consultation. **[GPP]**

1.13.3 Decisions about medication and lifestyle issues should draw on both the expertise of the healthcare professional as well as the experiences, beliefs and wishes of the young person with epilepsy as well as their family. **[GPP]**

1.13.4 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. **[GPP]**

1.13.5 Specialist teenage epilepsy clinics have a key role in the provision of multi-disciplinary care to the adolescent and distribution of information. **[D]**

1.13.6 Access to voluntary organisations, such as support groups and epilepsy charities, should be facilitated and a review of the diagnosis and management carried out before a smooth transition to adult services. **[D]**

1.13.7 The information given to young people should cover epilepsy in general and its diagnosis and treatment, the impact of seizures and adequacy of seizure control, treatment options including side effects and risks, and the risks of injury (see also section 1.2). **[D]**

1.13.8 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. **[D]**

1.13.9 The diagnosis and management of epilepsy should be reviewed during adolescence. **[D]**

1.14 Older people with epilepsy

1.14.1 Awaiting the publication of the NICE technology appraisal on the use of newer drugs for epilepsy in adults (scheduled for March 2004)

1.15 People from black and minority ethnic groups

1.15.1 Diagnosis is a challenging task in all circumstances. There may be special, or additional considerations in terms of appropriate communication and different cultural needs for people from black and minority ethnic groups. The need for interpretation should be considered alongside other means of ensuring that people's needs are appropriately met. **[D]**

1.15.2 The interpreter should have both cultural and medical knowledge. Family interpreters are generally not recommended as suitable, due to issues such as confidentiality, privacy, personal dignity and accuracy of translation.

[D]

1.15.3 Information, including that on 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. **[D]**

1.16 Review

1.16.1 Adults and children with epilepsy should have a regular structured review and be registered with a general medical practice. **[D]**

1.16.2A 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. **[D]**

1.16.2C Children should have a regular structured review with a paediatrician with expertise in epilepsy. **[D]**

1.16.3A For adults, the maximum interval between reviews should be one year but the frequency of review will be determined by the individual's epilepsy and the individual's wishes. **[D]**

1.16.3C For children, the maximum interval between reviews should be one year but the frequency of review will be determined by the individual's epilepsy and the individual's and family's wishes. The timing of the reviews should be agreed between the individual, family, and the specialist, but is likely to be between three and twelve months. **[GPP]**

1.16.4A [Awaiting the publication of the NICE technology appraisal on the use of newer drugs for epilepsy in adults (scheduled for March 2004)]

1.16.4C Treatment should be reviewed at regular intervals to ensure that children with epilepsy are not maintained for long periods on treatment that is ineffective or poorly tolerated and that concordance with prescribed medication is maintained. **[A NICE]^o**

1.16.5 Annual review should include an enquiry about side effects and concordance with treatment plan. **[GPP]**

^o When this document was prepared for consultation, a Final Appraisal Determination had been issued by the Institute.

1.16.6A In adults, if the individual or clinician view the epilepsy as inadequately controlled, the individual should have regular reviews and access to either secondary or tertiary care to ensure appropriate diagnosis, investigation and treatment. **[D]**

1.16.7A Adults with well controlled epilepsy may have specific medical or lifestyle issues (for example, pregnancy or drug cessation) which may need the advice of a specialist. **[D]**

1.16.8 At the review individuals should have access to: written and visual information; counselling services; information about voluntary organizations; epilepsy specialist nurses (ESNs); timely and appropriate investigations; referral to tertiary services including surgery where appropriate. **[D]**

1.16.9 Structured reviews of care may be best provided in the context of a specialist clinic. **[D]**

2 Notes on the scope of the guidance

All NICE guidelines are developed in accordance with a scope document that defines what the guideline will and will not cover. The scope of this guideline was established at the start of the development of this guideline, following a period of consultation; it is available from www.nice.org.uk/article.asp?a=29300

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, are 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.

3 Implementation in the NHS

3.1 In general

Local health communities should review their existing practice for epilepsy. The review should consider the resources required to implement the recommendations set out in Section 1, the people and processes involved and the timeline over which full implementation is envisaged. It is in the interests of patients that the implementation timeline is as rapid as possible.

Relevant local clinical guidelines, care pathways and protocols should be reviewed in the light of this guidance and revised accordingly.

This guideline should be used in conjunction with the National Service Frameworks for children and for long-term neurological conditions.

3.2 Audit

Suggested audit criteria are listed in Appendix D. These can be used as the basis for local clinical audit, at the discretion of those in practice.

4 Research recommendations

The following research recommendations have been identified for this NICE guideline, not as the most important research recommendations, but as those that are most representative of the full range of recommendations. The Guideline Development Group's full set of research recommendations is detailed in the full guideline produced by the National Collaborating Centre for Primary Care (see Section 5).

- Studies are needed to assess current rates of misdiagnosis in both adults and children with epilepsy.

- Economic evaluations are needed on the cost-effectiveness of investigations for the diagnosis of epilepsy in both adults and children. Economic evaluations that consider the incremental cost effectiveness of performing specific number of EEGs, or the cost effectiveness of video EEG as compared to EEG or MRI are needed to inform practice.
- Economic evaluations are needed into the cost effectiveness of training programmes in the area for health care professionals (general practitioners, nurses and specialists) involved in the diagnosis of epilepsy.
- Studies are needed to establish the utility, sensitivity and specificity of 24 hour ambulatory EEG, compared to standard and sleep-induced/-deprived EEG in the diagnosis of suspected epilepsy and epilepsy syndromes.
- Studies are needed to further investigate the prognosis of epilepsy in children, with a specific emphasis on the proportion of children who become intractable to drug therapy and become candidates for surgery.
- Studies are needed to establish the relative effectiveness of epilepsy clinics, in particular for special groups, when compared with usual care.
- The use of epilepsy specialist nurses in primary and secondary care and GPs with a special interest (GPwSI) in epilepsy should be evaluated in adequately powered RCTs that report all relevant clinical outcomes for individuals with epilepsy.
- Studies are needed to explore both the process and outcome of risk communication in the consultation between health care practitioners and the individual with epilepsy and their carers. This should include the perspectives of all relevant parties.
- A large RCT of longer-term clinical outcomes and cost-effectiveness of standard and new antiepileptic drugs (SANAD) has been sponsored by the NHS R&D Health Technology Appraisal Programme. The study will compare monotherapy with clinicians' first-choice standard drug with appropriate comparators from the newer AEDs.

5 Full guideline

The National Institute for Clinical Excellence commissioned the development of this guidance from the National Collaborating Centre for Primary Care. The Centre established a Guideline Development Group, which reviewed the evidence and developed the recommendations. The full guideline, *The diagnosis and management of the epilepsies in adults and children in primary and secondary care*, is published by the National Collaborating Centre for Primary Care; it is available on its website (TBA), the NICE website (www.nice.org.uk) and on the website of the National Electronic Library for Health (www.nelh.nhs.uk). **[Note: these details will apply to the published full guideline.]**

The members of the Guideline Development Group are listed in Appendix B. Information about the independent Guideline Review Panel is given in Appendix C.

The booklet *The Guideline Development Process – Information for the Public and the NHS* has more information about the Institute's guideline development process. It is available from the Institute's website and copies can also be ordered by telephoning 0870 1555 455 (quote reference N0038).

6 Related NICE guidance

Technology appraisal guidance in development – details will be added when the guidance has been published.

7 Review date

The process of reviewing the evidence is expected to begin 4 years after the date of issue of this guideline. Reviewing may begin earlier than 4 years if significant evidence that affects the guideline recommendations is identified sooner. The updated guideline will be available within 2 years of the start of the review process.

A version of this guideline for people with epilepsy, their families and carers is available from the NICE website (www.nice.org.uk) or from NHS Response Line (telephone 0870 1555 455 and quote reference number N0XXX for an English version and N0XXX for a version in English and Welsh).

Note: available for consultation during the second consultation on the NICE guideline.

Appendix A: Grading scheme

The grading scheme and hierarchy of evidence used in this guideline (see Table) are adapted from Eccles and Mason (2001).

Recommendation grade	Evidence
A	Directly based on category I evidence
B	Directly based on: <ul style="list-style-type: none"> • category II evidence, or • extrapolated recommendation from category I evidence
C	Directly based on: <ul style="list-style-type: none"> • category III evidence, or • extrapolated recommendation from category I or II evidence
D	Directly based on: <ul style="list-style-type: none"> • category IV evidence, or • extrapolated recommendation from category I, II, or III evidence
A NICE	Recommendation taken from NICE guideline or Technology Appraisal
GPP	Good practice point based on the clinical experience of the GDG

Evidence category	Source
I:	Evidence from: <ul style="list-style-type: none">• meta-analysis of randomised controlled trials, or• at least one randomised controlled trial
II:	Evidence from: <ul style="list-style-type: none">• at least one controlled study without randomisation, or• at least one other type of quasi-experimental study
III:	Evidence from non-experimental descriptive studies, such as comparative studies, correlation studies and case-control studies
IV:	Evidence from expert committee reports or opinions and/or clinical experience of respected authorities

Adapted from Eccles M, Mason J (2001) How to develop cost-conscious guidelines. *Health Technology Assessment* 5: 8

Appendix B: The Guideline Development Group

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Appendix C: The Guideline Review Panel

The Guideline Review Panel is an independent panel that oversees the development of the guideline and takes responsibility for monitoring its quality. The Panel includes experts on guideline methodology, health professionals and people with experience of the issues affecting patients and carers. The members of the Guideline Review Panel were as follows.

To be added

Appendix D: Technical detail on the criteria for audit

Key priority for implementation	Criterion: data items needed	Exceptions: interpreting the data	Definitions and other comments
<p>All individuals with suspected recent onset seizures should be seen urgently by a specialist. This specialist should: establish the diagnosis, use investigations such as EEG and MRI appropriately, classify the epilepsy into seizure type and syndrome and initiate drug therapy in collaboration with individuals.</p>	<p>The records show that any individuals with suspected onset seizures were seen by a specialist within two weeks</p>	<p>The rate is likely to be higher in localities where epilepsy services are already well developed.</p>	
<p>All individuals with epilepsy should have a care plan agreed with individuals and/or family, primary and secondary care providers.</p>	<p>The records show that all individuals with a diagnosis of epilepsy have an agreed care plan.</p>	<p>No exceptions</p>	<p>In more sophisticated audit, additional criteria on the content of the care plan could be added.</p>

DRAFT FOR SECOND CONSULTATION

Key priority for implementation	Criterion: data items needed	Exceptions: interpreting the data	Definitions and other comments
<p>All individuals with epilepsy should have a regular structured review. In children this review should be carried out at a frequency not less than yearly by a specialist. In adults, this review should be carried out at a frequency not less than yearly by either a generalist or specialist, depending on how well the epilepsy is controlled and/or the presence of specific lifestyle issues. The review should include access to: written and visual information; counselling services; voluntary organisations; epilepsy nurse specialists; timely and appropriate investigations; referral to tertiary services including surgery.</p>	<p>The records show that all individuals with epilepsy have had a review in the previous 12 months</p> <p>The records show that seizure frequency has been documented in the past 12 months for all individuals with a diagnosis of epilepsy</p>	<p>No exceptions.</p> <p>Some individuals may have their care reviewed more frequently than 12 months.</p> <p>No exceptions</p>	<p>In more sophisticated audit, additional criteria on the content of the review could be added.</p>

Appendix E: Outline care algorithm

