Complete Summary

GUIDELINE TITLE

The diagnosis and management of the epilepsies in adults and children in primary and secondary care.

BIBLIOGRAPHIC SOURCE(S)

National Collaborating Centre for Primary Care. The diagnosis and management of the epilepsies in adults and children in primary and secondary care. London (UK): Royal College of General Practitioners; 2004 Oct. 525 p. [324 references]

GUIDELINE STATUS

This is the current release of the guideline.

** REGULATORY ALERT **

FDA WARNING/REGULATORY ALERT

Note from the National Guideline Clearinghouse: This guideline references a drug(s) for which important revised regulatory and/or warning information has been released.

- December 12, 2007, Carbamazepine: The U.S. Food and Drug Administration (FDA) has provided recommendations for screening that should be performed on specific patient populations before starting treatment with carbamazepine.

COMPLETE SUMMARY CONTENT

SCOPE

DISEASE/CONDITION(S)

Epilepsy including:

- Focal/partial/localisation related epilepsies
- Idiopathic generalised epilepsies
- Status epilepticus

GUIDELINE CATEGORY

Diagnosis
Evaluation
Management
Treatment

CLINICAL SPECIALTY

Family Practice
Internal Medicine
Medical Genetics
Neurology
Obstetrics and Gynecology
Pediatrics

INTENDED USERS

Advanced Practice Nurses
Nurses
Patients
Pharmacists
Physician Assistants
Physicians

GUIDELINE OBJECTIVE(S)

To offer evidence-based and best practice advice on the diagnosis, treatment, and management of the epilepsies in children and adults in primary and secondary care

TARGET POPULATION

Adults and children, over 28 days old, who have epilepsy and are seen in primary or secondary care settings, including pregnant women, women/girls of child-bearing age, and people with learning disabilities

Exclusions

The following populations are *not* included*:*

- Neonates (infants aged 28 days or under)
- People with febrile convulsions

INTERVENTIONS AND PRACTICES CONSIDERED

Evaluation/Diagnosis

1. Specialist assessment
2. Full clinical history with eye witness account supported by corroborative evidence
3. Physical examination (including cardiac, neurological/mental status, and development assessment)
4. Referral, when appropriate
5. Investigations, including:
    - Electroencephalogram (EEG)
        - Provocation techniques
    - Neuroimaging (magnetic resonance imaging [MRI] and computed tomography [CT])
    - Other tests
        - Adults: serum prolactin, plasma electrolytes, glucose, calcium
        - Children: blood and urine biochemistry
        - 12 lead electrocardiogram (ECG)
    - Neuropsychological assessment
6. Classification using multi-axial diagnostic scheme

Treatment/Management

Overall Approach

1. Patient/parent/family/carer education
2. Referral to specialist/support services as needed
3. Comprehensive Care Plan

Pharmacological Treatment

1. Anti-epileptic drugs (AEDs) (monotherapy/combination)
    - Adults: gabapentin, lamotrigine, levetiracetam, oxcarbazepine, tiagabine, topiramate, and vigabatrin
    - Children: gabapentin, lamotrigine, oxcarbazepine, tiagabine, topiramate, and vigabatrin
2. Continuation of treatment
    - Blood test monitoring, as needed
3. Withdrawal of treatment
    - Managed AED withdrawal
4. Referral for complex or refractory epilepsy

Psychological Treatment

1. Relaxation, cognitive behaviour therapy, biofeedback

Other Treatments

1. Ketogenic diet (Not recommended in adults; considered as adjunctive treatment in children)
2. Vagus nerve stimulation (VNS)
3. Rectal diazepam or buccal midazolam* for prolonged or rectal seizures
4. Lorazepam for sustained epilepticus
5. Refractory status epilepticus
    - Adults: propofol and thiopental
    - Children: midazolam or thiopental
    - Individual treatment pathways

Special Populations

Women

1. Specialised patient education regarding contraception, conception, pregnancy, caring for children, breastfeeding, and menopause
2. Folic acid for women on AEDs
3. Referral to genetic counseling as appropriate
4. Vitamin K parenterally for newborns at delivery

People with Learning Disabilities

1. Full clinical history with eye witness account supported by corroborative evidence
2. Special investigations (e.g. imaging under anesthesia), as needed
3. Risk assessment

Young People with Epilepsy

1. Consulting style of medical management
2. Multidisciplinary services
3. Patient education and referral to support services

Older People with Epilepsy

1. Interventions same as for general population

People from Black and Minority Ethnic Groups

1. Additional communication and cultural information such as interpreters and translations of information about employment rights and driving

Review

1. Structured review, dependent on patient
2. Provide access to written and visual information, counseling, information about voluntary organizations, epilepsy specialist nurses, investigations, and referral, when appropriate

* Note: Buccal midazolam is currently unlicensed for the treatment of prolonged or repeated seizures.

MAJOR OUTCOMES CONSIDERED

- Recurrence of epileptic seizures
- Quality of life
- Morbidity and mortality

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Literature Search Strategy

The aim of the literature review was to seek to identify all available, relevant published evidence in relation to the key clinical questions generated by the Guideline Development Group (GDG). The prioritised key clinical questions (KCQs) were turned into evidence-based questions (EBQs) by the project lead and systematic reviewer. Literature searches were conducted using generic search filters and modified filters designed to best address the specific question being investigated. Searches included both medical subject headings (MeSH terms) and free-text terms. Details of all literature searches are available from the National Collaborating Centre for Primary Care (NCC-PC), University of Leicester.

The information librarian developed a search strategy for each question with the assistance of the systematic reviewer and the project lead. Searches were re-run at the end of the guideline development process, thus including evidence published up to the end of December 2003.

Depending on the clinical area, some or all of the following databases were searched: Cochrane Library (up to Issue 3, 2003) was searched to identify any relevant systematic reviews, and for reports of randomised controlled trials, MEDLINE (for the period January 1966 to November 2003, on the OVID interface), EMBASE (for the period January 1980 to November 2003, on the OVID interface), the Cumulative Index of Nursing and Allied Health Literature (for the period January 1982 to November 2003, on the Dialog DataStar interface), PsycINFO (for the period 1887 to September 2003, on the OVID and the Dialog DataStar interfaces), the Health Management Information Consortium database (HMIC), the British Nursing Index (BNI), and the Allied and Complementary Medicine Database (AMED). Searches for nonsystematic reviews of the literature were limited to 1997 to November 2003. This was a pragmatic decision that draws on the search strategies used by the North Of England Evidence Based Guideline Development Project. No systematic attempt was made to search "grey literature" (such as conference proceedings, abstracts, unpublished reports or trials, etc.).

Existing systematic reviews and meta-analyses relating to epilepsy were identified. Recent (last 6 years) high quality reviews of the epilepsy literature were also identified. New searches, including identification of relevant randomised

controlled trials (RCTs), were conducted in areas of importance to the guideline development process, for which existing systematic reviews were unable to provide valid or up to date answers. The search strategy was dictated by the exact EBQ the GDG wished to answer. Expert knowledge of group members was also drawn upon to corroborate the search strategy.

The National Research Register (NRR), National Guidelines Clearinghouse (NGC), New Zealand Guidelines Group (NZGG), and the Guidelines International Network (GIN) were searched to identify any existing relevant guidelines produced by other organisations. The reference lists in these guidelines were checked against the methodology team's search results to identify any missing evidence.

The titles and abstracts of records retrieved by the searches were scanned for relevance to the GDG's clinical questions. Any potentially relevant publications were obtained in full text. These were assessed against the inclusion criteria and the reference lists were scanned for any articles not previously identified. Further references were also suggested by the GDG. Evidence submitted by stakeholder organisations that was relevant to the GDG's KCQs, and was of at least the same level of evidence as that identified by the literature searches, was also included.

Initial Review

The searches were first sifted by the information librarian and systematic reviewer to exclude papers that did not relate to the scope of the guideline. The abstracts of the remaining papers were scrutinised for relevance to the EBQ under consideration. Initially both the systematic reviewer and project lead reviewed the abstracts independently. This proved impractical as the guideline progressed and the task was delegated to the systematic reviewer. The project lead was asked to review the abstracts in cases of uncertainty.

The papers chosen for inclusion were obtained and assessed for their methodological rigour against a number of criteria that determine the validity of the results. These criteria differed according to study type and were based on the checklists developed by the Scottish Intercollegiate Guidelines Network (SIGN). Critical appraisal was carried out by the systematic reviewer. To minimise bias in the assessment a sample of papers was independently appraised by the project lead. Further appraisal was provided by the GDG members at the relevant GDG meeting.

NUMBER OF SOURCE DOCUMENTS

Not stated

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Weighting According to a Rating Scheme (Scheme Given)

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Levels of Evidence

Ia - Systematic review or meta-analysis of randomised controlled trials

Ib - At least one randomised controlled trial

IIa - At least one well-designed controlled study without randomization

IIb - At least one well-designed quasi-experimental study, such as a cohort study

III - Well-designed non-experimental descriptive studies, case-control studies, and case series

IV - Expert committee reports, opinions and/or clinical experience of respected authorities

NICE - National Institute for Clinical Excellence (NICE) guidelines or Health Technology Appraisal programme

METHODS USED TO ANALYZE THE EVIDENCE

Review of Published Meta-Analyses
Systematic Review with Evidence Tables

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

The data were extracted to a standard template on an evidence table. The findings were summarised by the systematic reviewer into a series of evidence statements and an accompanying narrative review. The project lead independently assessed the accuracy of the derived evidence statements. None of the evidence based questions (EBQs) required the preparation of a quantitative synthesis (meta-analysis) by the project team.

The evidence statements were graded by the systematic reviewer according to the established hierarchy of evidence table presented in the above section titled "Rating Scheme for the Strength of the Evidence." This system reflects the susceptibility to bias inherence in particular study designs. The project lead independently assessed the accuracy of the grading.

The type of EBQ dictates the highest level of evidence that may be sought. For questions relating to therapy/treatment, the highest possible level of evidence is a systematic review or meta-analysis of randomized controlled trials (RCTs) (evidence level Ia) or an individual RCT (evidence level Ib). For questions relating to prognosis, the highest possible level of evidence is a cohort study (evidence level IIb). For diagnostic tests, the highest possible level of evidence is a test evaluation study using a quasi-experimental design that uses a blind comparison of the test with a validated reference standard applied to a sample of individuals who are representative of the population to whom the test would apply (evidence level IIb). For questions relating to information needs and support, the highest possible level of evidence is a descriptive study using either questionnaire survey or qualitative methods (III).

For each clinical question, the highest level of evidence was selected. If a systematic review, meta-analysis, or RCT existed in relation to an EBQ, studies of a weaker design were ignored.

Summary results and data are presented in the text of the original guideline document. More detailed results and data are presented in the evidence tables (Appendix F of the original guideline document).

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

The Guideline Development Group (GDG) met at six weekly intervals for 16 months to review the evidence identified by the methodology team, to comment on its quality and completeness, and to develop recommendations for clinical practice based on the available evidence. In order to generate separate recommendations for adults and children the GDG was divided into adult and child subgroups. Each subgroup met to discuss the evidence reviews and to make preliminary recommendations. The final recommendations were agreed by the full GDG.

For each key clinical question (KCQ), the recommendations were derived from the evidence statements presented to the GDG. The link between the evidence statement and recommendation was made explicit. The GDG were able to reach their agreed recommendations through a process of informal consensus.

Each recommendation was graded according to the level of evidence upon which it was based using the established grading of recommendations table presented in the section below labeled "Rating Scheme for the Strength of the Recommendations." For questions relating to therapy/treatment, the best possible level of evidence (a systematic review or meta-analysis or an individual randomized controlled trial [RCT]) would equate to a grade A recommendation. For questions relating to prognosis and diagnostic tests, the best possible level of evidence (a cohort study) would equate to a grade B recommendation. For questions relating to information needs and support, the best possible level of evidence (descriptive study) would equate to a grade C recommendation. It is important that the grading in such areas is not treated as inferior to those of therapy as it represents the highest level of relevant evidence.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Grades of Recommendation

A - Based directly on level I evidence

B - Based directly on level II evidence or extrapolated from level I evidence

C - Based directly on level III evidence or extrapolated from level I or level II evidence

D - Based directly on level IV evidence or extrapolated from level I, level II, or level III evidence

A (NICE) - Recommendation taken from National Institute for Clinical Excellence (NICE) guideline or Technology Appraisal

GPP - Good practice points based on the clinical experience of the Guideline Development Group (GDG)

COST ANALYSIS

The Cost of Epilepsy Misdiagnosis

The guideline authors examined the economic burden of misdiagnosis in epilepsy from the Health Sector point of view. The results presented must be treated with caution since they relied on various assumptions. Despite this, they believe the results are important and highlight the problem from an economic perspective. Even when the lower bands (and probably underestimated) of the estimations are considered the value of the resources wasted due to misdiagnosis is significant. Indirect costs (costs of lost productivity) were not estimated for reasons already mentioned. However, they may be large considering that one study estimated the average indirect costs per person with epilepsy to be 3,770 pounds sterling due to unemployment and in another study 23/46 misdiagnosed were unemployed, or under threat of job loss.

Other important costs and consequences of misdiagnosis which are not considered in this study (mainly for lack of reliable data) are the cost of side effects caused by incorrect treatment on misdiagnosed persons, and the forgone benefits in terms of health, quality of life, and productivity for receiving the correct treatment. Also, they did not consider the direct costs for the patients and their families (for example, transport costs to the health center hospital). And the costs of legal settlements for both misdiagnosed persons and the National Health Service (NHS) (for example, during 2002/3 the families of children misdiagnosed in Leicester and Coroners Inquests).

To summarise, the guideline authors found that the opportunity costs of misdiagnosis are considerably high. This is especially true if the developers account for the fact that a large amount of lost resources could be used to give the correct treatment to misdiagnosed persons and to improve the quality of the treatment received by patients with epilepsy.

See Appendix G of the original guideline document for detailed information on the cost analysis.

METHOD OF GUIDELINE VALIDATION

External Peer Review
Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

The guideline has been developed in accordance with the Institute's guideline development process. This has included allowing registered stakeholders the opportunity to comment on the scope of the guideline, the first draft of the full and short form guideline, and the final draft of the guideline. In addition, the first draft was reviewed by nominated individuals with an interest in epilepsy and an independent Guideline Review Panel (GRP) established by the Institute.

The comments made by the stakeholders, peer reviewers and the GRP were collated and presented anonymously for consideration by the Guideline Development Group (GDG). All comments were considered systematically by the GDG and the project team recorded the agreed responses.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

Levels of evidence (Ia-IV) and grades of recommendations (A-D, A [NICE], and GPP) are defined at the end of the Major Recommendations field.

Principle of Decision Making

D - 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.

Coping with Epilepsy

GPP - People with epilepsy and their families and/or carers should be empowered to manage their condition as well as possible.

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

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

GPP - Healthcare professionals should highlight the Expert Patients Programme (www.expertpatients.nhs.uk) to individuals with epilepsy who wish to manage their condition more effectively.

Information

C - 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
- Life style, 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

GPP - The time at which this information should be given will depend on the certainty of the diagnosis and the need for confirmatory investigations.

GPP - 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.

GPP - 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).

GPP - Adequate time should be set aside in the consultation to provide information, which should be revisited on subsequent consultations.

GPP - Checklists should be used to remind both individuals and healthcare professionals about information that should be discussed during consultations.

GPP - Everyone providing care or treatment for individuals with epilepsy should be able to provide essential information.

GPP - 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.

GPP - 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.

C (adults)/**GPP** (children) - People with epilepsy should be given appropriate information before they make important decisions (for example, regarding pregnancy or employment).

Sudden Death in Epilepsy (SUDEP)

C - 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.

GPP - The risk of SUDEP can be minimized by:

- Optimising seizure control
- Being aware of the potential consequences of nocturnal seizures

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

C - 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.

Following a First Seizure

GPP - 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* when an epileptic seizure is suspected or there is diagnostic doubt.

*For adults, a specialist is defined throughout at 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.

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

GPP (adults) - The information that should be obtained from the individual and/or family or carer after a suspected seizure is contained in Appendix A of the original guideline document.

GPP (children) - The information that should be obtained from the child and/or parent or carer after a suspected seizure is contained in Appendix A of the original guideline document

A [NICE] (adults) - It is recommended that all people having a first 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] (children) - It is recommended that all children who have had a first nonfebrile 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.

*The Guideline Development Group considered that with a recent onset suspected seizure, referrals should be urgent, meaning that patients should be seen within 2 weeks.

GPP - At the initial assessment for a recent onset seizure, the specialist should have access to appropriate investigations.

C - 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.

GPP - 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 family and/or carers.

Diagnosis

C (adults) - The diagnosis of epilepsy in adults should be established by a specialist medical practitioner with training and expertise in epilepsy.

C (children) - The diagnosis of epilepsy in children should be established by a specialist paediatrician with training and expertise in epilepsy.

GPP (adults)/**C** (children) - Individuals and their families and/or carers should be given an opportunity to discuss the diagnosis with an appropriate healthcare professional.

C - 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.

B - 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.

GPP - It may not be possible to make a definite diagnosis of epilepsy. If the diagnosis cannot be clearly established, further investigations and/or referral to a tertiary centre (see section on Referral below) should be considered. Follow-up should always be arranged.

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

GPP - Prospective recording of events, including video recording and written descriptions, can be very helpful in reaching a diagnosis.

Investigations

D - 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.

GPP (children) - All investigations should be performed in a child centred environment.

Electroencephalogram (EEG)

GPP - Individuals requiring an EEG should have the test performed soon (within 4 weeks) after it has been requested.

C (adults) - 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.

C (children) - 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.

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

C - 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.

C - The EEG should not be used in isolation to make a diagnosis of epilepsy.

C - 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.

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

GPP - For individuals in whom epilepsy is suspected, but who present diagnostic difficulties, specialist investigations should be available.

C - 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.

C - Repeated standard EEGs should not be used in preference to sleep or sleep-deprived EEGs.

C - When a standard EEG has not contributed to diagnosis or classification, a sleep EEG should be performed.

GPP - In children, a sleep EEG is best achieved through sleep deprivation or the use of melatonin. (Note: Melatonin is not currently licensed in the United Kingdom.)

C - Long-term video or ambulatory EEG may used in the assessment of individuals who present diagnostic difficulties after clinical assessment and standard EEG.

C - 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.

GPP - 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.

Neuroimaging

C - Neuroimaging should be used to identify structural abnormalities that cause certain epilepsies.

C - Magnetic resonance imaging (MRI) should be the imaging investigation of choice in individuals with epilepsy.

C - 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

GPP - Individuals requiring MRI should have the test performed soon (within 4 weeks).

C - Neuroimaging should not be routinely requested when a diagnosis of idiopathic generalised epilepsy has been made.

C - Computed tomography (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.

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

Other Tests

C - Measurement of serum prolactin is not recommended for the diagnosis of epilepsy.

GPP (adults) - In adults, appropriate blood tests (for example, plasma electrolytes, glucose, calcium) to identify potential causes and/or to identify any significant comorbidity should be considered.

GPP (children) - 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.

GPP (adults) - A 12 lead electrocardiogram (ECG) should be performed in adults with suspected epilepsy.

GPP (children) - In children a 12 lead electrocardiogram should be considered in cases of diagnostic uncertainty

GPP - In cases of diagnostic uncertainty, a referral to a cardiologist should be considered.

Neuropsychological Assessment

D - 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 - 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

Classification

D - 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.

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

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

Management

GPP - People with epilepsy should have an accessible point of contact with specialist services.

GPP - 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.

D - Epilepsy specialist nurses (ESNs) should be an integral part of the network of care of individuals with epilepsy. The key roles of the epilepsy specialist nurses 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.

GPP - 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.

Pharmacological Treatment

Appendix B of the original guideline document provides details on prescribing for different seizure types and epilepsy syndromes. Significant side effects are also described.

GPP - 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 license status.

A - The AED treatment strategy should be individualised according to the seizure type, epilepsy syndrome, comedication and comorbidity, the individual's lifestyle, and the preferences of the individual and their family and/or carers as appropriate (see Appendix B in the original guideline document).

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

D - 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.

A [NICE] - 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.

GPP - 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.

GPP - 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.

A [NICE] - 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.

A [NICE] (adults) - 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

A [NICE] (children) - 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 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

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

Initiation of Pharmacological Treatment

GPP - 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.

GPP (adults) - AED therapy should be initiated in adults on the recommendation of a specialist.

GPP (children) - AED therapy in children should be initiated by a specialist.

GPP - The decision to initiate AED therapy should be taken between the individual, their family 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 individual's epilepsy syndrome, prognosis and lifestyle.

A - Treatment with AED therapy is generally recommended after a second epileptic seizure.

B - AED therapy should be considered and discussed with individuals and their family and/or carers as appropriate after a first unprovoked seizure if:

- The individual has a neurological deficit
- The EEG shows unequivocal epileptic activity
- The individual and/or their family and/or carers consider the risk of having a further seizure unacceptable
- Brain imaging shows a structural abnormality

GPP - 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.

Continuation of Pharmacological Treatment

GPP - 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.

GPP - 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.

GPP - If management is straightforward, continuing AED therapy can be prescribed in primary care if local circumstances and/or licensing allow.

GPP - 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.

D - 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
- Using simple medication regimens
- Positive relationships between healthcare professionals, the individual with epilepsy and their family and/or carers

C (adults) - Regular blood test monitoring in adults is not recommended as routine, and should be done only if clinically indicated.

GPP (children) - Regular blood test monitoring in children is not recommended as routine, and should be done only if clinically indicated and recommended by the specialist.

D - 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

GPP - Examples of blood tests 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 to 5 years for adults taking enzyme-inducing drugs

GPP - Asymptomatic minor abnormalities in test results are not necessarily an indication for changes in medication.

Withdrawal of Pharmacological Treatment

A - 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.

GPP - Withdrawal of AEDs must be managed by, or be under the guidance of, the specialist.

A - 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 in the original

guideline document for tables for the prognosis for remission of seizures in adults).

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

GPP - 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.

GPP - 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.

Referral for Complex or Refractory Epilepsy

GPP - All individuals with epilepsy should have access via their specialist to a tertiary service when circumstances require.

C - 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 consideration should be fully explained before the individual's informed consent is obtained.

If seizures are not controlled and/or there is diagnostic uncertainty or treatment failure, individuals should be referred to tertiary services soon (within 4 weeks) for further assessment. Referral should be considered when one or more of the following criteria are present:

D - The epilepsy is not controlled with medication within 2 years

GPP - Management is unsuccessful after two drugs

GPP - The individual is aged under 2 years

GPP - An individual experiences, or is at risk of, unacceptable side effects from medication

GPP - There is a unilateral structural lesion

GPP - There is psychological and/or psychiatric comorbidity

GPP - There is diagnostic doubt as to the nature of the seizures and/or seizure syndrome

D (children) - 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.

GPP - Behavioural or developmental regression or inability to identify the epilepsy syndrome in an individual should result in immediate referral to tertiary services.

GPP - 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.

GPP - Psychiatric comorbidity and/or negative baseline investigations should not be a contraindication for referral to a tertiary centre.

GPP - 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.

GPP - 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.

GPP - 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.

Psychological Interventions

A (adults) - 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.

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

A - 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.

Ketogenic Diet

C (adults) - The ketogenic diet should not be recommended for adults with epilepsy.

C (children) - The ketogenic diet may be considered as an adjunctive treatment in children with drug-resistant epilepsy.

Vagus Nerve Stimulation (VNS)

A (adults) - 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.

A (children) - 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.

Prolonged or Repeated Seizures in the Community

A - 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.

A - Rectal diazepam is safe and effective in first-line treatment of prolonged seizures and is recommended in the majority of cases.

GPP - 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.

*__Note__: Buccal midazolam is currently unlicensed for the treatment of prolonged or repeated seizures.

GPP - Healthcare professionals should inform individuals, and their families and/or carers, that buccal midazolam is currently unlicensed.

GPP - 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.

GPP - Care must be taken to secure the individual's airway and assess his or her respiratory and cardiac function.

GPP - 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

Treatment of Status Epilepticus

Convulsive Status Epilepticus

GPP - 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 C of the original guideline document):

- Secure airway
- Give oxygen
- Assess cardiac and respiratory function
- Secure intravenous (IV) access in a large vein

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

Refractory Convulsive Status Epilepticus

D - Treatment of refractory status epilepticus in secondary care should follow the suggested guidelines (see Appendix C of the original guideline document).

C (adults) - In adults, propofol or thiopental should be used to control refractory status epilepticus. Adequate monitoring, including blood levels of thiopental, and critical life systems support is required (see Appendix C of the original guideline document).

C (children) - In children, midazolam or thiopental should be used to control refractory status epilepticus. Adequate monitoring, including blood levels of thiopental, and critical life systems support is required (see Appendix C of the original guideline document).

GPP - Regular medication should be continued at optimal doses and the reasons for status epilepticus should be investigated.

GPP - As the treatment pathway progresses, the expertise of an anaesthetist/intensivist should be sought.

GPP - If either the whole protocol or intensive care is required the tertiary centre should be consulted.

GPP - An individual treatment pathway should be formulated for people who have recurrent convulsive status epilepticus.

Non-convulsive Status Epilepticus

GPP - Non-convulsive status epilepticus is uncommon and management is less urgent. A suggested guideline can be found in Appendix C of the original guideline document.

Women with Epilepsy

C - 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.

C - 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 girls and women with epilepsy. These may include an individual's family and/or carers.

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

A [NICE] (adults) - In women of childbearing potential, the risk of the drugs (see section on AEDs in the original guideline document) 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.

A [NICE] (children) - In girls of childbearing potential, including young girls who are likely to need treatment into their childbearing years, the risk of the drugs (see section on AEDs in the original guideline document) 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 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.

GPP - Prescribers should 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.

D - All women on AEDs should be offered 5 mg per day of folic acid before any possibility of pregnancy.

A [NICE] (adult) - 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.

A [NICE] (children) - 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.

GPP - In women of childbearing potential, the risks and benefits of different contraceptive methods, including hormone-releasing intra-uterine devices (IUDs), should be discussed.

D - 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.

D - The progesterone-only pill is not recommended as reliable contraception in women taking enzyme-inducing AEDs.

D - 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).

D - The progesterone implant is not recommended in women taking enzyme-inducing AEDs.

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

D - 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.

Pregnancy

C - 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 on withdrawal in the original guideline document).

GPP - All pregnant women with epilepsy should be encouraged to notify their pregnancy, or allow their clinician to notify the pregnancy, to the United Kingdom (UK) Epilepsy and Pregnancy Register (www.epilepsyandpregnancy.co.uk).

GPP - In all women with epilepsy, seizure freedom during pregnancy should be sought.

GPP - 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.

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

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

C - 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 to 4%).

D - 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.

B - 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.

GPP - Care of pregnant women should be shared between the obstetrician and the specialist.

GPP - 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 to 20 weeks' gestation by an appropriately trained ultrasonographer, but earlier scanning may allow major malformations to be detected sooner.

GPP - 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.

C - All children born to mothers taking enzyme-induced AEDs should be given 1 mg of vitamin K parenterally at delivery.

D - Genetic counselling should be considered if one partner has epilepsy, particularly if the partner has idiopathic epilepsy and a positive family history of epilepsy.

GPP - 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.

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

GPP - Joint epilepsy and obstetric clinics may be convenient for mothers and healthcare professionals but there is insufficient evidence to recommend their routine use.

GPP - 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.

Breastfeeding

GPP - 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 best suits her and her family.

GPP - 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 should be based on the risks and benefits of breastfeeding against the potential risks of the drug affecting the child.

After the Birth

GPP - 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.

C - 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 - Parents should be reassured that the risk of injury to the infant caused by maternal seizure is low.

People with Learning Disabilities

GPP - 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.

C - 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.

Diagnosis

C - 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.

D - It is important to have an eye witness account supplemented by corroborative evidence (for example, a video account), where possible.

GPP - Clear, unbiased reporting is essential. Witnesses may need education to describe their observations accurately.

Investigations

GPP - Those with learning disabilities may require particular care and attention to tolerate investigations.

D - Facilities should be available for imaging under anaesthesia, if necessary.

C (children) - In the child presenting with epilepsy and learning disability, investigations directed at determining an underlying cause should be undertaken.

Management

D - 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.

A [NICE] - 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.

B - Every therapeutic option should be explored in individuals with epilepsy in the presence or absence of learning disabilities.

GPP - 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.

C - 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

Young People with Epilepsy

C - 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.

GPP - Healthcare professionals should adopt a consulting style that allows the young person with epilepsy to participate as a partner in the consultation.

GPP - 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.

GPP - 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.

D - 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.

D - 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.

D - 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.

D - The diagnosis and management of epilepsy should be reviewed during adolescence.

Older People with Epilepsy

A [NICE] - 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.

People from Black and Minority Ethnic Groups

D - 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.

D - 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.

D - 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.

Review

D - Adults and children with epilepsy should have a regular structured review and be registered with a general medical practice.

D (adults) - Adults should have a regular structured review with their general practitioner (GP), but depending on the individual's wishes, circumstances, and epilepsy, the review may be carried out by the specialist.

D (children) - Children should have a regular structured review with a specialist.

D (adults) - 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.

GPP (children) - 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.

D (adults) - 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.

D (adults) - 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.

D - If the structured review is to be conducted by the specialist, this may be best provided in the context of a specialist clinic.

A [NICE] - 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.

GPP - Annual review should include an enquiry about side effects and a discussion of the treatment plan to ensure concordance and adherence to medication

D - 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, and referral to tertiary services including surgery, where appropriate.

Definitions:

Levels of Evidence

Ia - Systematic review or meta-analysis of randomized controlled trials

Ib - At least one randomized controlled trial

IIa - At least one well-designed controlled study without randomization

IIb - At least one well-designed quasi-experimental study, such as a cohort study

III - Well-designed non-experimental descriptive studies, case-control studies, and case series

IV - Expert committee reports, opinions and/or clinical experience of respected authorities

NICE - NICE guidelines or Health Technology Appraisal programme

Grades of Recommendations

A - Based directly on level I evidence

B - Based directly on level II evidence or extrapolated from level I evidence

C - Based directly on level III evidence or extrapolated from level I or level II evidence

D - Based directly on level IV evidence or extrapolated from level I, level II, or level III evidence

A (NICE) - Recommendation taken from NICE guideline or Technology Appraisal

GPP - Good practice points based on the clinical experience of the GDG

CLINICAL ALGORITHM(S)

Algorithms are provided in the original guideline document for the outline of care for adults and for children.

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of supporting evidence is provided for each recommendation (see 'Major Recommendations' field).

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

- The correct classification of seizure type and epilepsy syndrome
- Appropriate investigations, appropriate treatment, and information about the likely prognosis of the seizure type and/or syndrome
- Reduced mortality and morbidity
- Improved quality of life

POTENTIAL HARMS

Diagnosis

Individuals misdiagnosed with epilepsy may experience social and financial deprivation as a result of having the wrong diagnostic label and from side-effects of antiepileptic medication. In addition, there may be a risk of unnecessary teratogenicity as a result of Anti-epileptic drug (AED) therapy in women incorrectly diagnosed as having epilepsy. In a small number of cases, individuals may die prematurely because the correct diagnosis was not made, and a serious condition was neither diagnosed nor treated. Individuals who have symptoms due

to epileptic seizures but who are wrongly diagnosed as having psychiatric or associated disorders are disadvantaged from being labeled with an incorrect diagnosis and by the effects of continuing seizure activity because AEDs are not used. It is therefore crucial that specialists involved in diagnosing epilepsy take great care to establish the correct diagnosis.

Side Effects of Drug Treatments

- Refer to Table 4 in Appendix B for side effects of drug treatment for adults.
- Refer to Table 5 in Appendix B for side effects of drug treatment for children.

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

The guideline documentation and recommendations are subject to various limitations. The National Institute for Clinical Excellence (NICE), the commissioner of this work, is primarily concerned with the National Health Service in England and Wales and is not able to make recommendations for practice outside the National Health Service (NHS). It is important to stress that social services, educational services and the voluntary sector have an important role to play in the care of people with epilepsy and this guideline is highly relevant to these agencies.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

Local health communities should review their existing practice for epilepsy. The review should consider the resources required to implement the recommendations set out in the original guideline document and the "Major Recommendations" section of this summary, the people and processes involved, and the timeline over which full implementation is envisaged. It is in the interests of people with epilepsy 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, older people, and for long-term neurological conditions.

Suggested audit criteria are listed in Section 6 of the original guideline document. These can be used as the basis for local clinical audit, at the discretion of those in practice.

The following have been identified as key priorities for implementation

Diagnosis

- All individuals with a recent onset suspected seizure should be seen urgently[a] by a specialist[b]. This is to ensure precise and early diagnosis and initiation of therapy as appropriate to their needs.
- The seizure type(s) and epilepsy syndrome, aetiology, and comorbidity should be determined.

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.
- 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.
- The anti-epileptic drug (AED) treatment strategy should be individualised according to the seizure type, epilepsy syndrome, comedication and comorbidity, the individual's lifestyle, and the preferences of the individual, their family and/or carers as appropriate.

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

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.

[a]The Guideline Development Group considered that "urgently" meant being seen within 2 weeks.

[b] 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.

[c] The Guideline Development Group considered that "soon" meant being seen within 4 weeks.

IMPLEMENTATION TOOLS

Audit Criteria/Indicators
Clinical Algorithm
Patient Resources
Quick Reference Guides/Physician Guides

For information about availability, see the "Availability of Companion Documents" and "Patient Resources" fields below.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

Getting Better
Living with Illness

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

National Collaborating Centre for Primary Care. The diagnosis and management of the epilepsies in adults and children in primary and secondary care. London (UK): Royal College of General Practitioners; 2004 Oct. 525 p. [324 references]

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

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GUIDELINE DEVELOPER(S)

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GUIDELINE COMMITTEE

Guideline Development Group

COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE

Committee Members: Ms Kathy Bairstow, Patient Representative, Leeds; Ms Bernie Concannon, Clinical Nurse Specialist Paediatric Epilepsy, Birmingham Children's Hospital; Mr Ian Costello, Chief Pharmacist, Centre for Paediatric Research, School of Pharmacy, London; Dr Helen Cross, Senior Lecturer & Honorary Consultant in Paediatric Neurology, Institute of Child Health and Great Ormond Street Hospital for Children, London; Professor John Duncan, Professor of Neurology, The National Hospital for Neurology and Neurosurgery, London; Dr Amanda Freeman, Consultant Paediatrician, St Mary's Hospital, Portsmouth; Ms Sally Gomersall, Patient Representative, Newark; Ms Jane Hanna, Patient Representative, Wantage; Mr William Harkness, Consultant Neurological Surgeon, Great Ormond Street Hospital for Children, London; Dr Peter Humphrey, Consultant Neurologist, The Walton Centre for Neurology & Neurosurgery, Liverpool; Dr Tanzeem Raza, Consultant Physician, Royal Bournemouth Hospital; Mr Peter Rogan, Patient Representative, Ormskirk; Dr Henry Smithson, Guideline Development Group Lead General Practitioner, York

FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

All Guideline Development Group (GDG) members made a formal "Declaration of Interests" at the start of the guideline development and provided updates throughout the development process.

GUIDELINE STATUS

This is the current release of the guideline.

GUIDELINE AVAILABILITY

Electronic copies: Available in Portable Document Format [PDF] format from the National Institute for Clinical Excellence (NICE) Web site.

AVAILABILITY OF COMPANION DOCUMENTS

The following are available:

- The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. NICE guideline. 2004 Oct. 73 p. Available in Portable Document Format (PDF) from the National Institute for Clinical Excellence (NICE) Web site.
- The epilepsies: diagnosis and management of the epilepsies in adults in primary and secondary care. Quick reference guide. 2004 Oct. 18 p. Available in Portable Document Format (PDF) from the National Institute for Clinical Excellence (NICE) Web site.
- The epilepsies: diagnosis and management of the epilepsies in children and young people in primary and secondary care. Quick reference guide. 2004 Oct. 18 p. Available in Portable Document Format (PDF) from the National Institute for Clinical Excellence (NICE) Web site.

Print copies: Available from the National Health Service (NHS) Response Line 0870 1555 455. ref: N0739 and N0740. 11 Strand, London, WC2N 5HR.

Additionally, Audit Criteria can be found in Section 6 of the original guideline document.

PATIENT RESOURCES

The following is available:

- The diagnosis and care of children and adults with epilepsy. Understanding NICE guidance information for people with epilepsy, their families and carers, and the public. London: National Institute for Clinical Excellence. 2004 Oct. 68 p. Available in Portable Document Format (PDF) from the National Institute for Clinical Excellence (NICE) Web site.

Print copies: Available from the National Health Service (NHS) Response Line 0870 1555 455. ref: N0741. 11 Strand, London, WC2N 5HR.

Please note: This patient information is intended to provide health professionals with information to share with their patients to help them better understand their health and their diagnosed disorders. By providing access to this patient information, it is not the intention of NGC to provide specific medical advice for particular patients. Rather we urge patients and their representatives to review this material and then to consult with a licensed health professional for evaluation of treatment options suitable for them as well as for diagnosis and answers to their personal medical questions. This patient information has been derived and prepared from a guideline for health care professionals included on NGC by the authors or publishers of that original guideline. The patient information is not reviewed by NGC to establish whether or not it accurately reflects the original guideline's content.

NGC STATUS

This NGC summary was completed by ECRI on February 7, 2005. The information was verified by the guideline developer on March 23, 2005. This summary was updated by ECRI on April 21, 2005 following the release of a public health advisory from the U.S. Food and Drug Administration (FDA) regarding Trileptal (oxcarbazepine). This summary was updated by ECRI on November 16, 2006, following the FDA advisory on Lamictal (lamotrigine). This summary was updated by ECRI Institute on January 10, 2008, following the U.S. Food and Drug Administration advisory on Carbamazepine.

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