



**National Institute for  
Clinical Excellence**

MidCity Place  
71 High Holborn  
London  
WC1V 6NA

Tel: 020 7067 5800  
Fax: 020 7067 5801  
[nice@nice.nhs.uk](mailto:nice@nice.nhs.uk)

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

**PRESS RELEASE**

**NICE guideline to improve care of children and adults with epilepsy**

The National Institute for Clinical Excellence (NICE) and the National Collaborating Centre for Primary Care (NCC PC) are today issuing a clinical practice guideline on the diagnosis and management of epilepsy in children and adults. The guideline aims to ensure that people with epilepsy, wherever they live in England and Wales, can access treatments and interventions that are based on the best available evidence.

Epilepsy, which is a neurological disorder characterised by unprovoked recurring seizures, is the most common serious neurological condition in the UK with an estimated 400,000 people in England and Wales affected by it. Epilepsy is not a uniform condition, but comprises many different seizure types and epilepsy syndromes.

Priorities highlighted in the guideline include:

- All individuals with a recent onset suspected seizure should be seen urgently by a specialist to ensure precise and early diagnosis and initiation of therapy.
- Drug therapy should be tailored to seizure type, epilepsy syndrome, co-medication, co-morbidity and individual lifestyle factors and preferences.
- All individuals with epilepsy should have a comprehensive care plan that is agreed between the individuals, their family and/or carers and primary and secondary care providers.

- All individuals with epilepsy should have a regular structured review at least yearly.
- Individuals with epilepsy should be referred to a tertiary service as soon as possible if their seizures are not controlled and/or there is uncertainty about their diagnosis or treatment failure.
- Individuals with epilepsy and their carers should participate as partners in all decisions about their healthcare.
- 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.

**Andrea Sutcliffe, Planning and Resources Director and Executive Lead for the guideline said:** “The guideline, which complements recent guidance from NICE on the use of newer antiepileptic drugs, has the potential to significantly improve the care that people with epilepsy receive. It puts people with epilepsy, their family and carers firmly at the centre of care. In doing so the guideline covers issues of real concern to people with epilepsy such as accurate and timely diagnosis, appropriate communication and the need for regular reviews of medication.”

**Dr Henry Smithson, Chair of the Guideline Development Group and Spokesperson on Epilepsy for the Royal College of General Practitioners (RCGP) said:** “In the past, epilepsy care has been the province of the specialist but with this guidance all health professionals will be better placed to offer information and support to patients and monitor their condition. In particular, the guidelines will be useful for general practitioners, physicians and paediatricians in their work with epilepsy sufferers and their families, leading to a more comprehensive and structured level of care.”

**Professor John Duncan, Professor of Neurology, The National Hospital for Neurology and Neurosurgery, London, Medical Director of the National**

**Society for Epilepsy and member of the Guideline Development Group** said:

“The NICE epilepsy guidelines set out comprehensive standards for the care of those with epilepsy. Taken with the organisational standards indicated in the recent GP contract and the National Primary and Care Trust development programme, they represent a major step forward in improving healthcare provision. Of particular importance are the needs to establish a correct diagnosis and, if treatment is unsuccessful, to keep the diagnosis under critical review and to consider referral for a further specialist opinion; timely and accurate information provision, and the integration of medical and social care.”

**Dr Helen Cross, Reader and Honorary Consultant in Paediatric Neurology, Institute of Child Health and Great Ormond Street Hospital for Children and member of the Guideline Development Group** said:

“The term 'epilepsy' encompasses many, not a single disorder. It requires a structured care pathway to ensure optimal management of all individuals. Although medical aspects are important, wider issues also need to be addressed, not least in children. This guideline is comprehensive in both its scope and coverage, and will contribute toward the development of an optimal standard of epilepsy care across the NHS.”

**Bernie Concannon, clinical nurse specialist, paediatric epilepsy, and member of the Guideline Development Group** said: “The NICE guidelines will enable health professionals and people with epilepsy to work together to ensure their epilepsy is managed according to the most up-to-date knowledge and best practice and that all will receive equal expert care.”

Epilepsy is associated with an increase in the risk of premature death. Of the 1000 deaths as a result of epilepsy each year, some 500 are sudden and unexpected. A 2002 UK-wide audit of Sudden Unexplained Death in Epilepsy (SUDEP), led by Epilepsy Bereaved and funded by NICE, found that 59% of child deaths and 39% of adult deaths could be potentially or probably avoidable. The development of this guideline was informed by the results of the SUDEP audit. **Jane Hanna, patient representative and member of the Guideline Development Group** commented: “The NICE guideline clearly sets out national good practice in the management of epilepsy. From the perspective of the 1000 families bereaved through epilepsy every

year the guideline addresses significant concerns highlighted in the SUDEP audit of epilepsy deaths. We hope that these guidelines will be put into practice at a local level so that people with epilepsy have a choice to be seizure-free and unnecessary deaths are avoided".

Ends

### **Notes to Editors:**

#### **Further quotes:**

**Sharon Harvey, General Secretary of the Joint Epilepsy Council:** "The Joint Epilepsy Council welcomes the NICE Guideline on Epilepsy, which we believe makes good sense. The challenge for the NHS will be implementing and monitoring the guideline to achieve the standards set, and this will require imagination, investment and intensive effort."

**Sally Gomersall, National Society for Epilepsy and member of the Guideline Development Group:** "The NICE guideline provides a clear road map for improved epilepsy services and emphasises the importance of regular, structured reviews of treatment and information needs involving the preferences of the individual with epilepsy. The road begins at diagnosis with the right to a care plan, and follows through to annual reviews, referral to specialists and onwards to epilepsy centres if necessary. The Guidelines have the potential to make a real difference to individuals with epilepsy."

**Dr Tim Stokes, Deputy Director, National Collaborating Centre for Primary Care and Senior Lecturer in General Practice, University of Leicester and Project Lead, Guideline Development Group:** "Epilepsy is the most common chronic disabling neurological condition in the UK and this guideline is of great importance to adults and children with epilepsy, their family and/or carers, and all health care professionals. A key feature of the guideline is that it is patient-centred and has had a strong input from patient representatives as well as from a wide range of health care professionals. The guideline offers a rigorous and comprehensive review of the available research evidence and makes many important recommendations for diagnosis and management. It is hoped that many of these recommendations will be accorded priority by health care commissioners."

**Simon Wigglesworth, Deputy Chief Executive, Epilepsy Action:** "Epilepsy Action is delighted to have been able to support NICE in the development of this guideline which we believe provides excellent standards for the care and treatment of the 400,000 people in England and Wales with epilepsy. We are particularly pleased that the partnership approach to the management of the condition is stressed throughout and that the information and support needs of people with epilepsy are emphasised."

#### **About NICE**

1. NICE is part of the NHS. It is the independent organisation responsible for providing national guidance on treatments and care for those using the NHS in England and Wales. Its guidance is for healthcare professionals and patients and their carers to help them make decisions about treatment and healthcare. For further information about NICE you can visit [www.nice.org.uk](http://www.nice.org.uk).

2. NICE produces guidance in three areas of health:
  - the use of new and existing medicines and treatments within the NHS in England and Wales – technology appraisals
  - the appropriate treatment and care of patients with specific diseases and conditions within the NHS in England and Wales – clinical guidelines
  - whether interventional procedures used for diagnosis or treatment are safe enough and work well enough for routine use – interventional procedures.

NICE also funds three enquiries that undertake research into the way patients are treated to identify ways of improving the quality of care (the investigations are known as confidential enquiries).

3. NICE guidance and recommendations are prepared by independent groups that include professionals working in the NHS and people who are familiar with the issues affecting patients and carers.

### **About the National Collaborating Centre for Primary Care (NCC-PC)**

4. NICE has established a number of National Collaborating Centres (NCCs) to harness the expertise of the Medical Royal Colleges, professional bodies and patient/carer organisations when developing clinical guidelines. Each NCC is a professionally led group with the experience and resources to develop guidance for the NHS on behalf of NICE.
5. The National Collaborating Centre for Primary Care is based at the Royal College of General Practitioners. Its guidelines are developed in collaboration with the Clinical Governance Research and Development Unit, Department of Health Sciences, University of Leicester.

### **About clinical guidelines**

6. Clinical guidelines are recommendations on the appropriate treatment and care of patients with specific diseases and conditions within the NHS in England and Wales. They sit alongside, but do not replace, the knowledge and skills of experienced health professionals.
7. Our clinical guidelines are developed by independent groups that include healthcare professionals working in the NHS, patients and people who are familiar with the issues affecting patients and carers. Professional and patient/carer groups whose members are likely to be affected by the guideline are able to submit information and comment on the recommendations before they are finalised.

### **About the clinical guideline on epilepsy**

8. The NICE guideline is available from [www.nice.org.uk/CG020NICEguideline](http://www.nice.org.uk/CG020NICEguideline). The full version detailing the evidence base behind the recommendations is produced by the National Collaborating Centre for Primary Care and is available on the NICE website. A version for the public is available from [www.nice.org.uk/CG020publicinfo](http://www.nice.org.uk/CG020publicinfo). Quick reference guides for healthcare professionals are also available from the NICE website
9. The guideline makes recommendations about the diagnosis, treatment and management of epilepsy in children, adolescents, adults and older people, including the use of pharmacological interventions, the management of epilepsy during pregnancy and in women of child-bearing age, the management of epilepsy in people

with learning disabilities, the use of non-pharmacological interventions, for example, the use of vagal nerve stimulation and surgery and psychological therapies

10. The guideline asks local health communities to review their existing management of the treatment of epilepsy against this guideline. The review should consider the resources required to implement the recommendations set out in the guideline, 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.
11. Further information about the 2002 UK-wide audit of Sudden Unexplained Death in Epilepsy (SUDEP), led by Epilepsy Bereaved and funded by NICE, can be found on the NICE website at: <http://www.nice.org.uk/page.aspx?o=32146>.