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Guidelines

Epilepsies in children, young people, and adults: summary of updated NICE guidance

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Box start

What you need to know

- Epilepsy is a common condition that associates with substantial risk of morbidity and mortality owing to, for example, sudden unexpected death in epilepsy
- Working together, primary, secondary, and tertiary care can offer holistic care to people with epilepsy to improve seizure control, impact positively on comorbidities that people with epilepsy may experience, and reduce mortality risk
- A diagnosis of epilepsy should be made by a specialist experienced in the management of epilepsies
- Specific consideration should be given to the appropriate anti-seizure medication for women and girls who are able to have children
- New diagnostic and management options mean that all people with uncontrolled seizures should be referred to a specialist epilepsy centre that has access to epilepsy surgery and other non-pharmacological treatments

Box end

Epilepsy is one of the most common and serious neurological disorders worldwide, affecting about 50 million people, and more than 600 000 people in the UK.[1] Epilepsy is a symptom of different underlying causes. Many different types of epilepsy and epilepsy syndromes exist, varying in terms of presentation, management, and prognosis. Epilepsy represents far more than seizures alone, and is associated with complex cognitive, developmental, psychological, and psychosocial comorbidities.[2] Seizures also have

significant risks, including injuries and premature mortality.[3] Epilepsy consequently has high socioeconomic costs. The holistic care of people with epilepsy could be improved through a standardised approach underpinned by a comprehensive guideline.

The National Institute for Health and Care Excellence (NICE) initially published guidance on the management of people with epilepsy in 2004, with a limited update (to pharmacological treatment) in 2012.[4] Since then, important advances have occurred in the diagnosis, treatment, and holistic management of people with epilepsy, highlighting the need for an update to the guideline.

Although specialist teams commonly manage epilepsy, primary care and non-specialists play a vital role in the identification, referral, early management, and provision of information and support to people with epilepsy, their families, or carers. This article summarises the most recent recommendations from the NICE guideline on epilepsies in children, young people, and adults,[5] with an emphasis on aspects most relevant for primary and secondary care. Evidence levels for the recommendations are given in italics in square brackets.

Recommendations

NICE recommendations are based on systematic reviews of best available evidence and explicit consideration of cost effectiveness. When minimal evidence is available, recommendations are based on the guideline development group’s experience and opinion of what constitutes good practice.

Diagnosis and assessment

People with epilepsy receive a diagnosis after two unprovoked seizures, or after a single seizure when assessment suggests a high risk of further events. A first seizure may significantly affect a person’s life. Diagnosing a paroxysmal event as a seizure is complex. People presenting with a suspected first seizure should, therefore, be referred urgently (for an appointment within two weeks) to ensure that a specialist (an adult or paediatric neurologist who undertakes continuing professional development in the investigation, diagnosis, and management of epilepsy) is involved early in diagnosis. The likelihood of having a further seizure differs between individuals, and quantifying the risk of a second seizure is challenging. The updated guideline contains recommendations aimed at minimising seizures and risks associated with them; avoiding potential provoking factors for seizures, including specific factors to consider when assessing the likelihood of a second seizure occurring; and for conducting initial investigations. It also includes updated recommendations about

information and support to offer patients after a first seizure, and provides comprehensive advice on activities of daily living for people with epilepsy (box 1).

Box start

Box 1 Topics to discuss with people with epilepsy and their families and carers

Activities of daily living

- Safety issues, including activities to be adapted or avoided; for example, showering rather than having baths, cooking safely, caring for babies and young children safely, and avoiding working at heights
- Safety issues for children and young people, including supervised swimming and water sports, and not climbing above their height without supervision
- Potential impact on lifestyle and social life and any experiences of social exclusion
- Driving, including Driver and Vehicle Licensing Agency regulations[6]
- Employment and education, including concerns and rights related to employment and education

Carers

- Physical and emotional demands of caring for and supporting a person with epilepsy
- Information and support for carers, including assessing carers' needs (see also NICE's guideline on supporting adult carers[7]

Cognition

- Concerns about the impact of epilepsy and anti-seizure medication on cognitive function, including memory, attention, concentration, educational attainment, and performance in the workplace

Medication

- Adherence to anti-seizure medication and how to improve this (see also NICE's guidelines on medicines adherence[8] and medicines optimisation[9])
- Experiences of side effects from medication, and coping strategies
- Explaining changes to medication

Mental health

- Emotional health and psychological wellbeing, for example, experience of depression, anxiety, or low mood (see also NICE's guidelines on depression in adults with a chronic physical health problem,[10] depression in children and young people,[11] and mental health problems in people with learning disabilities[12])
- Neurobehavioural disorders commonly associated with epilepsy, including autism and attention deficit/hyperactivity disorder
- ·Stigmatisation of epilepsy

Reproductive health and pregnancy

- Support and information on contraception and pregnancy for women and their partners to enable them to make informed decisions
- Support for changes in medications and the potential interactions with contraception
- Teratogenicity of medications
- Pre-conception planning, including the use of folic acid and reducing risk related to epilepsy during pregnancy
- Planning the birth
- Postnatal care and breastfeeding.

See also the section on anti-seizure medications for women and girls in the full guideline and follow the Medicines and Healthcare products Regulatory Agency (MHRA) safety advice on antiepileptic drugs in pregnancy[13]

Sudden unexpected death in epilepsy (SUDEP)

- Concerns of people with epilepsy and their families and carers about SUDEP
- Information about SUDEP, including risk factors for SUDEP and how to reduce the risks
- Availability of SUDEP counselling

Box end

Assessing the risk of a second seizure

- When a child, young person, or adult presents with a first seizure, carry out an individualised assessment of their risk of a second seizure.
- In adults, assessment should include checking for the following modifiable factors that may increase the risk of a second seizure:
  - An underlying mental health problem (such as depression, anxiety, psychosis, and alcohol or substance misuse)
  - Vascular risk factors (for example, diabetes, hypertension, atrial fibrillation)
  - Sepsis.
- Be aware that children presenting with a first afebrile seizure (seizure without a fever) are at an increased risk of further afebrile seizures, especially within six to 12 months, compared with children with a febrile seizure (seizure with a fever).
- Be aware that children presenting with complicated febrile seizures (febrile seizures that last longer than 10 minutes or febrile seizures associated with other features, such as weakness, on one side of the body) may be at higher risk of epilepsy, especially if other predisposing risk factors for epilepsy are present.
- Using a person centred approach, discuss with the person, and their family and carers if appropriate, their individualised risks for further seizures. This should include any mental, physical, and social factors identified as possible risk factors and how these may be modified.

  [All recommendations are based on low to very low quality evidence and the experience and opinion of the guideline committee]

Initial investigations

Neuroimaging

- Offer a magnetic resonance imaging (MRI) scan to children, young people, and adults diagnosed with epilepsy, unless they have idiopathic generalised epilepsy or self-limited epilepsy with centrotemporal spikes. The MRI should be carried out:
  - Within six weeks of the MRI referral and
  - Following regionally agreed epilepsy MRI protocols.
- If MRI is contraindicated, consider a computed tomography scan for children, young people, and adults with epilepsy.

  [All recommendations are based on very low quality evidence and the experience and opinion of the guideline committee]

Electroencephalogram (EEG)

- If the person's history and examination suggest an epileptic seizure, and a diagnosis of epilepsy is suspected, consider a routine EEG carried out while awake to support diagnosis and provide information about seizure type and epilepsy syndrome.
- Do not use EEG to exclude a diagnosis of epilepsy.
- If an EEG is requested after a first seizure, perform it as soon as possible (ideally within 72 hours of the seizure).

[All recommendations are based on moderate to very low quality evidence and the experience and opinion of the guideline committee]

Principles of treatment, safety, monitoring, and withdrawal

Anti-seizure medications are the mainstay of treatment in epilepsy. Epilepsy is a treatable condition and around 70% of people with epilepsy will become free of seizures with appropriate medication. Before starting medication, discuss with the patient an individualised strategy, considering the epilepsy type, personal preferences, and the individual's circumstances. The updated guideline stresses the importance of taking the fewest medicines possible to optimise seizure control. The guideline also includes new recommendations on safety considerations, with a focus on information, support, and individualised treatment plans. Specific recommendations for the support and monitoring of women and girls or women planning a pregnancy or who are pregnant are provided.

When to start anti-seizure medication

- Start treatment with an anti-seizure medication once the diagnosis of epilepsy is confirmed.
- Consider starting treatment after a first unprovoked seizure if any of the following apply:
  - An examination identifies signs of neurological deficit
  - The EEG shows unequivocal epileptic activity
  - After a discussion of the risk of further seizures, the person or their family or carers consider the risk unacceptable
  - Brain imaging shows a structural abnormality.

[All recommendations are based on the experience and opinion of the guideline committee]

Anti-seizure medications for women and girls

- Refer women and girls with epilepsy who are planning pregnancy or are pregnant to an epilepsy specialist team for a review of their anti-seizure medication options.
- Give women and girls with epilepsy information and support that is tailored to their age-specific and developmental needs. Review regularly information provided about:
  - Contraception
  - Folic acid supplementation
  - Conception
  - Pregnancy
  - Breastfeeding
  - Caring for children

- Menopause.

• Discuss with women and girls with epilepsy who are able to have children (including young girls who are likely to need treatment when they are able to have children), and their families or carers if appropriate, the risks to an unborn child of taking anti-seizure medications during pregnancy, such as congenital malformations, neurodevelopmental impairments, and fetal growth restriction.

• Assess the risks and benefits of treatment with individual anti-seizure medications when prescribing anti-seizure medications for women and girls who are able to have children, now or in the future. Take into account the latest data on the risks to the unborn child and be aware of important uncertainties about the risks, particularly with newer drugs. Follow the MHRA safety advice on anti-epileptic drugs in pregnancy.[13]

• Specifically, discuss the risks to the unborn child of using sodium valproate during pregnancy, including the increased risk with higher doses and polytherapy. Follow the MHRA safety advice on valproate use by women and girls.[14]

[All recommendations are based on the experience and opinion of the guideline committee]

Monitoring and review

• Arrange regular (at least annual) monitoring reviews for adults with epilepsy and any of the following:

- A learning disability
- Drug-resistant epilepsy
- A high risk of SUDEP (see the below 'Reducing the risk of epilepsy related death including sudden unexpected death in epilepsy')
- A serious comorbidity, such as a complex psychosocial, cognitive, or mental health problems
- Adults who are taking anti-seizure medications associated with long term side effects or drug interactions
- Adults who are able to get pregnant and are taking valproate or any other high-risk teratogenic anti-seizure medication (see also the MHRA safety advice on antiepileptic drugs in pregnancy[13]).

[Based on moderate to very low quality evidence and the experience and opinion of the guideline committee]

• Discuss monitoring reviews with children and young people with epilepsy and their families and carers, and agree a frequency for regular reviews that is:

- Individually tailored to the child or young person's needs, preferences, and the nature of their epilepsy, and
- At least every 12 months.

[Based on the experience and opinion of the guideline committee]

Discontinuing anti-seizure medication

Discontinuing anti-seizure medication is a nuanced decision that should be made based on the individual's preferences and individualised risk of seizure recurrence. The updated guideline retains the recommendation to conduct an individualised assessment by a specialist if there are doubts or concerns of the risk of seizure recurrence in those who have been two

years without seizures, and focuses on specific factors to take into consideration when agreeing on a plan for discontinuing anti-seizure medication.

Management of focal seizures with or without evolution to bilateral tonic-clonic seizures

Focal seizures originate in one part of the brain and may evolve during the clinical course of the seizure to involve a wider area of the brain resulting in tonic-clonic seizures—these are referred to as focal to bilateral tonic-clonic seizures (previously called secondarily generalised tonic-clonic seizures). New evidence was identified to provide guidance on the management of focal seizures with or without evolution to bilateral tonic-clonic seizures (box 2).

Box start

Box 2 Monotherapy for focal seizures with or without evolution to bilateral tonic-clonic seizures

• Consider lamotrigine or levetiracetam as first line monotherapy for people with focal seizures. If the first choice is unsuccessful, consider the other of these options.

In April 2022, these were off-label uses of lamotrigine in children under 13 and levetiracetam in children and young people under 16. See NICE's information on prescribing medicines.[15]

• If first line monotherapies are unsuccessful in people with focal seizures, consider one of the following second line monotherapy options:

- Carbamazepine
- Oxcarbazepine
- Zonisamide.

If the first choice is unsuccessful, consider the other second line monotherapy options.

In April 2022, these were off-label uses of oxcarbazepine in children under 6 and zonisamide in children. See NICE's information on prescribing medicines.[15]

• If second line monotherapies tried are unsuccessful in people with focal seizures, consider lacosamide as third line monotherapy.

In April 2022, this was an off-label use of lacosamide in children under 4. See NICE's information on prescribing medicines.[15]

[All recommendations are based on high to moderate quality evidence]

Box end

Management of generalised tonic-clonic seizures

Generalised tonic-clonic seizures are common amongst many different epilepsy types. These are defined as seizures that rapidly engage both sides of the brain from onset.

New evidence was identified to provide guidance on the management of generalised tonic-clonic seizures (box 3).

Box start

Box 3 Monotherapy for generalised tonic-clonic seizures

• Offer sodium valproate as first line monotherapy for generalised tonic-clonic seizures in:

- Boys and men

- Girls under 10 and who are unlikely to need treatment when they are old enough to have children
- Women who are unable to have children.

• Offer lamotrigine or levetiracetam as first line monotherapy for generalised tonic-clonic seizures in women and girls able to have children (including young girls who are likely to need treatment when they are old enough to have children). If the first choice is unsuccessful, offer the other of these options.

In April 2022, these were off-label uses of lamotrigine in children under 13 and levetiracetam in adults and children. See NICE's information on prescribing medicines.[15]

• If first line monotherapy with sodium valproate is unsuccessful for generalised tonic-clonic seizures, offer lamotrigine or levetiracetam as second line monotherapy treatment. If the first choice is unsuccessful, try the other of these options.

In April 2022, these were off-label uses of lamotrigine in children under 13 and levetiracetam in adults and children. See NICE's information on prescribing medicines.[15]

• Do not offer sodium valproate monotherapy for generalised tonic-clonic seizures in women and girls able to have children (including young girls who are likely to need treatment when they are old enough to have children) unless:

- Other treatment options are unsuccessful
- The risks and benefits have been fully discussed, including the risks to an unborn child
- The likelihood of pregnancy has been taken into account and a pregnancy prevention programme put in place, if appropriate.

Follow the MHRA safety advice on valproate use by women and girls.[14]
[All recommendations are based on moderate quality evidence]

Box end

Referral to tertiary epilepsy services

Whilst diagnosis should be made by specialist physicians with expertise in epilepsy and management may remain local thereafter, specific circumstances warrant referral to tertiary epilepsy services. The updated guideline strengthens previous recommendations for referral to specialist services for further advice, investigations, and management. The updated guideline includes new criteria for immediate referral, however most recommendations are in line with the previous guideline.

Reducing the risk of epilepsy-related death, including sudden unexpected death in epilepsy

Epilepsy associates with mortality from a range of causes, one of which is SUDEP. The lifetime risk of SUDEP is estimated to be between 7% and 12%. The updated guideline provides recommendations on when to discuss epilepsy related mortality, how to reduce this risk, and the co-occurring conditions that may increase it.

• Potentially modifiable risk factors for SUDEP include:
- Non-adherence to medication
- Alcohol and drug misuse
- Having focal to bilateral tonic-clonic seizures or generalised tonic-clonic seizures

- Having uncontrolled seizures
- Living alone
- Sleeping alone without supervision.

• The risk of epilepsy related death is increased in people with:
- Previous brain injury
- Previous central nervous system function
- Metastatic cancer
- Previous stroke
- Abnormal neurological examination findings.

[All recommendations are based on low to very low quality evidence and the experience and opinion of the guideline committee]

• Discuss the possibility of introducing or increasing night time supervision, for example, a parent or carer may wish to use a night monitor for people with epilepsy who have seizures during sleep and have been assessed to be at higher risk of epilepsy related death.

• Support people with epilepsy to take their medications as prescribed to reduce seizures. Explain that uncontrolled seizures increase the risk of epilepsy related death, particularly for people with generalised tonic-clonic seizures or focal to bilateral tonic-clonic seizures. Follow the recommendations in NICE's guideline on medicines adherence.[8]

[All recommendations are based on the experience and opinion of the guideline committee]

Epilepsy specialist nurses

Epilepsy specialist nurses are embedded in practice and play a key role in assisting other healthcare providers in primary, secondary, and tertiary care settings, as well as educational and social care settings. The updated guideline puts marked emphasis on this and used the evidence to determine the common features of clinically and cost-effective epilepsy specialist nurse interventions.

• Ensure that all children, young people, and adults with epilepsy have access to an epilepsy specialist nurse who:
- Has a central role in providing information, education, and support
- Supports both epilepsy specialists and healthcare professionals in primary and secondary care, and in educational, respite, and social care settings
- Is a point of contact for, and facilitates access to, other community and multi-agency services.

• Offer people with epilepsy an information and care planning session with an epilepsy specialist nurse that includes emotional wellbeing and self-management strategies promoting inclusion and participation.

• For people with epilepsy who continue to have seizures, offer epilepsy specialist nurse sessions:
- At least twice a year and
- After emergency department visits.

• Consider epilepsy specialist nurse-led group sessions for education and information giving in young people and adults with epilepsy.

[Based on low quality evidence and the experience and opinion of the guideline committee]

Implementation

Challenges to implementing this guidance are the availability of services within local areas—including the availability of specialist nurses to support other healthcare professionals in primary, secondary, and tertiary care—and time constraints within appointments in primary care, specialist care, and in the community.

Box start

Future research

The guideline committee prioritised the following questions for further research:

- What immunomodulation strategies are effective in people with defined autoimmune epilepsy syndromes?
- What anti-seizure therapies (alternative or add-on) are effective in the treatment of complex epilepsy syndromes (Dravet syndrome, Lennox-Gastaut syndrome, infantile spams syndrome, and Doose syndrome) when first line therapy is unsuccessful or not tolerated?
- Development of a risk prediction tool to detect all-cause mortality, including sudden unexpected death in epilepsy in people with epilepsy or those who have had a single seizure, and an external validation of a risk prediction tool to detect the probability of epilepsy related death.
- What is the effectiveness of vagus nerve stimulation in treating epilepsy (including people with learning disabilities as a subgroup)?
- What is the cost effectiveness of providing tailored psychological treatments for people with epilepsy?
- What is the clinical and cost effectiveness of therapeutic drug monitoring in girls, young women, and women with epilepsy?

Box end

Box start

Guidelines into practice

- What is your local pathway for referring women and girls with epilepsy who are planning a pregnancy or are pregnant to a specialist team?
- Do you consider the association of epilepsy with mortality and the potentially modifiable risk factors for sudden unexpected death in epilepsy (SUDEP) in all people with epilepsy?

Box end

Box start

What is not included in this summary

See the full guideline[5] for recommendations on referral after a first seizure; referral after remission; information and support after a first seizure; specialist assessment and diagnosis; neuroimaging; genetic testing; antibody testing; information and support; referral to tertiary epilepsy services; treatment with anti-seizure medications; safety considerations; support and monitoring for women planning a pregnancy or who are pregnant; management of absence seizures; management of myoclonic seizures; management of tonic or atonic seizures; management of idiopathic generalised epilepsies; treating childhood onset epilepsies; treating status epilepticus, repeated or cluster seizures, and prolonged seizures; non-pharmacological

treatments; psychological, neurobehavioural, cognitive, and developmental comorbidities in epilepsy; and service provision and transition.
Box end

Box start
Further information on the guidance
This guidance was developed by the National Guideline Alliance and National Guideline Centre in accordance with NICE guideline methodology (www.nice.org.uk/media/default/about/what-we-do/our-programmes/developing-nice-guidelines-the-manual.pdf). Two guideline committees (GCs) were established respectively at the National Guideline Alliance and National Guideline Centre, which incorporated healthcare and allied healthcare professionals (the two GCs comprised one consultant neurologist, one consultant paediatric neurologist, two general practitioners, two paediatric nurses, two paediatricians, one paediatric clinical psychologist, two learning disability psychiatrists, two neurologists, two adult pharmacists, one child pharmacist, two epilepsy nurse specialists, two paediatric neurologists, one clinical psychologist, one clinical fellow, one neuroradiologist, one consultant neuropsychiatrist, one paediatric educational psychologist, one neurological surgeon, one neurophysiologist, one emergency medicine physician, one paediatric surgeon) and three lay members.
The guideline is available at https://www.nice.org.uk/guidance/ng217
The GC identified relevant review questions and collected and appraised clinical and cost effectiveness evidence. Quality ratings of the evidence were based on GRADE methodology (www.gradeworkinggroup.org). These relate to the quality of the available evidence for assessed outcomes or themes rather than the quality of the study. The GC agreed recommendations for clinical practice based on the available evidence or, when evidence was not found, based on their experience and opinion using informal consensus methods. Original economic modelling was undertaken in priority areas not sufficiently addressed by the published cost effectiveness literature.
The scope and the draft of the guideline went through a rigorous reviewing process, in which stakeholder organisations were invited to comment; the GC took all comments into consideration when producing the final version of the guideline.
NICE will conduct regular reviews after publication of the guidance, to determine whether the evidence base has progressed significantly enough to alter the current guideline recommendations and require an update.
Box end

Box start
How patients were involved in the creation of this article
Committee members involved in this guideline update included people with epilepsy, carers and members with lived experience of epilepsy, and use of relevant services, all of whom contributed to the formulation of the recommendations summarised here.
Box end

The members of the guideline committee from the National Guideline Alliance (NGA) were (shown alphabetically according to last name): Rachel Batchelor, Christine Cole, Helen Cross (topic adviser), Anita Devlin, Benjamin Dorward, Mo Eyeoyibo, Diane Flower, Richard Grunewald, Jonathan Higham, Sarah Hughes, Harriet Joy, Elizabeth Kay (chair), Angie Pullen, Ashifa Trivedi.

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The guideline authors' full statements can be viewed at https://www.nice.org.uk/guidance/ng217/documents/register-of-interests-3

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