NICE National Institute for Health and Care Excellence

NICE Pathways

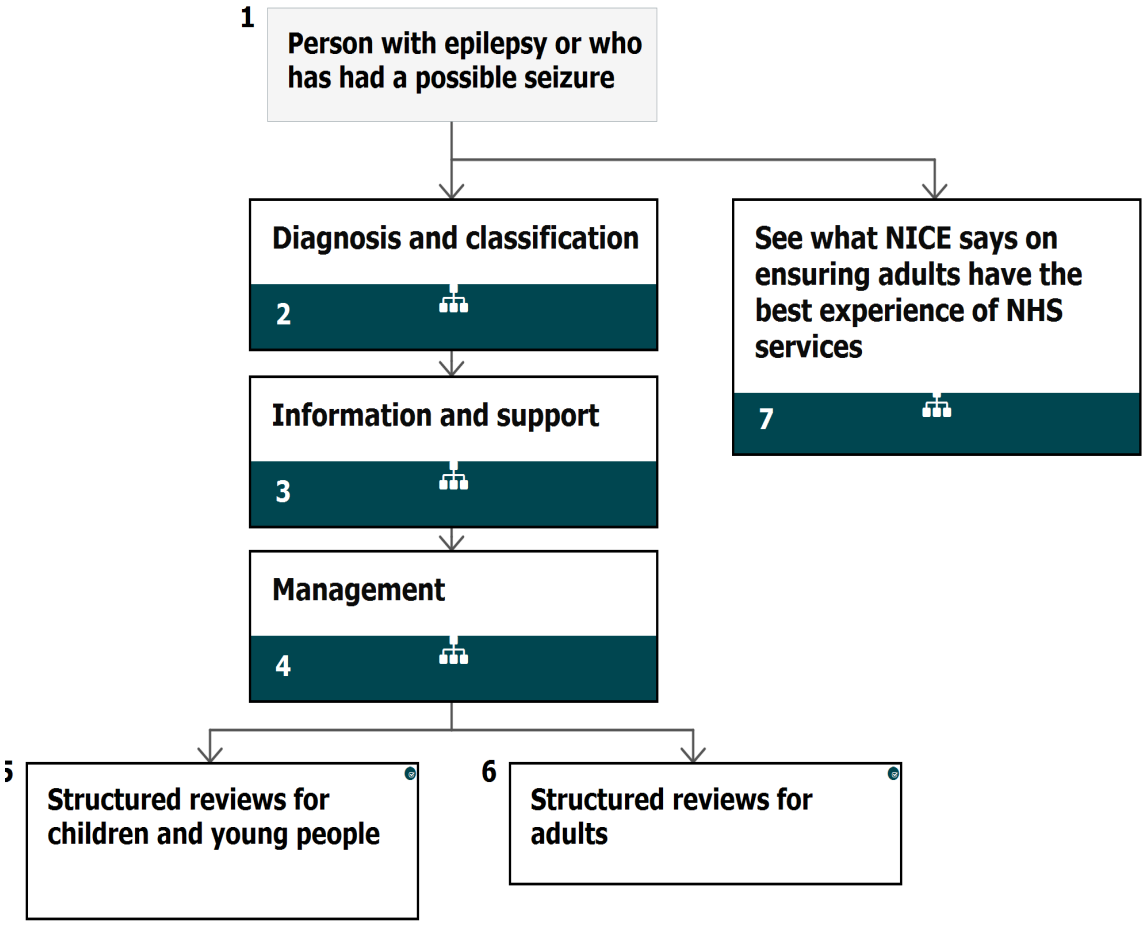
Epilepsy overview

NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

http://pathways.nice.org.uk/pathways/epilepsy
NICE Pathway last updated: 24 April 2018

This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.



1 Person with epilepsy or who has had a possible seizure

No additional information

2 Diagnosis and classification

See Epilepsy / Diagnosing and classifying epilepsy

3 Information and support

See Epilepsy / Information and support for people with epilepsy and their family or carers

4 Management

See Epilepsy / Managing epilepsy

5 Structured reviews for children and young people

Children, young people and adults with epilepsy should have a regular structured review and be registered with a general medical practice.

Children and young people should have a regular structured review with a specialist.

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

Frequency of the review

Treatment should be reviewed at regular intervals to ensure that children, young people and adults with epilepsy are not maintained for long periods on treatment that is ineffective or poorly tolerated and that concordance with prescribed medication is maintained.

For children and young people, the maximum interval between reviews should be 1 year, but the frequency of reviews should be determined by the child or young person's epilepsy and their wishes and those of the family and/or carers. The interval between reviews should be agreed between the child or young person, their family and/or carers as appropriate, and the specialist,

but is likely to be between 3 and 12 months.

At the review

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

For more information on adherence to medication, see what NICE says on medicines optimisation.

At the review, children, young people and adults should have access to: written and visual information; counselling services; information about voluntary organisations; epilepsy specialist nurses; timely and appropriate investigations; referral to tertiary services including surgery, where appropriate. See also information for young people and when to refer to a tertiary epilepsy service.

For special considerations when conducting a review in young people before they transfer to adult care, see young people.

Review of diagnosis and management during adolescence

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

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

8. Review (children and young people)

6 Structured reviews for adults

Children, young people and adults with epilepsy should have a regular structured review and be registered with a general medical practice.

Adults should have a regular structured review with their GP, but depending on the person's wishes, circumstances and epilepsy, the review may be carried out by the specialist.

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 person or

clinician view the epilepsy as inadequately controlled.

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.

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

Frequency of the review

Treatment should be reviewed at regular intervals to ensure that children, young people and adults with epilepsy are not maintained for long periods on treatment that is ineffective or poorly tolerated and that concordance with prescribed medication is maintained.

For adults, the maximum interval between reviews should be 1 year but the frequency of review will be determined by the person's epilepsy and their wishes.

At the review

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

For more information on adherence to medication, see what NICE says on medicines optimisation.

At the review, children, young people and adults should have access to: written and visual information; counselling services; information about voluntary organisations; epilepsy specialist nurses; timely and appropriate investigations; referral to tertiary services including surgery, where appropriate. See also information for young people and when to refer to a tertiary epilepsy service.

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

8. Re-access to specialist care (adults)

7 See what NICE says on ensuring adults have the best experience of NHS services

See Patient experience in adult NHS services

Glossary

Absence seizures

seizures characterised by behavioural arrest associated with generalised spike wave activity on EEG

Adherence

the extent to which a person's behaviour matches the prescriber's recommendations; adherence emphasises the need for agreement and that the patient is free to decide whether or not to adhere to the doctor's recommendation

Adjunctive treatment

where a medication is added to a first-line anti-epileptic drug for combination therapy

AED

anti-epileptic drug: medication taken daily to prevent the recurrence of epileptic seizures

AEDs

anti-epileptic drugs: medication taken daily to prevent the recurrence of epileptic seizures

Atonic seizures

generalised seizures characterised by sudden onset of loss of muscle tone

Benign epilepsy with centrotemporal spikes

an epilepsy syndrome of childhood (5–14 years) characterised by focal motor and/or secondarily generalised seizures, the majority from sleep, in an otherwise normal individual, with centrotemporal spikes seen on EEG

Concordance

a term that was initially applied to the consultation process in which doctor and patient agree therapeutic decisions that incorporate their respective views, but now includes supporting patients in medicine-taking as well as communication when prescribing (concordance reflects

social values but does not address medicine-taking and may not lead to improved adherence)

Continuous spike and wave during slow sleep

an epilepsy syndrome with childhood onset, characterised by a plateau and regression of cognitive abilities associated with dramatic increase in spike wave activity in slow wave sleep (> 85% of slow sleep); there may be few seizures at presentation

Convulsive status epilepticus

a convulsive seizure that continues for longer than 5 minutes, or convulsive seizures that occur one after the other with no recovery between; this is an emergency and requires immediate medical attention

Dravet syndrome

previously known as severe myoclonic epilepsy of infancy: an epilepsy syndrome with onset in infancy, characterised by initial prolonged, typically lateralised, febrile seizures, subsequent development of multiple seizure types including myoclonic, absence, focal and generalised tonic–clonic seizures, with developmental plateau or regression

ECG

electrocardiogram (a test that records the heart's electrical activity)

EEG

electroencephalogram (an investigation that involves recording the electrical activity of the brain)

Epileptic seizure

a transient occurrence of signs and/or symptoms, the result of a primary change to the electrical activity (abnormally excessive or synchronous) in the brain

Epileptic seizures

transient occurrences of signs and/or symptoms, the result of primary changes to the electrical activity (abnormally excessive or synchronous) in the brain

Epilepsy syndrome

a distinctive disorder identifiable on the basis of a typical age of onset, seizure types, specific EEG characteristics, and often other features; identification of epilepsy syndrome has implications for treatment, management and prognosis

Focal seizures

seizures that originate within networks limited to one hemisphere, discretely localised or more widely distributed

Generalised seizures

seizures that originate in, and rapidly engage, bilaterally distributed networks (can include cortical and subcortical structures but do not necessarily include the entire cortex)

GTC seizures

a seizure of sudden onset involving generalised stiffening and subsequent rhythmic jerking of the limbs, the result of rapid widespread engagement of bilateral cortical and subcortical networks in the brain

Ictal phenomenology

description or history of ictal events (seizures)

Idiopathic

a syndrome that is only epilepsy, with no underlying structural brain lesion or other neurological signs or symptoms; presumed to be genetic in aetiology and usually age dependent

IGE

idiopathic generalised epilepsy (a well-defined group of disorders characterised by typical absences, myoclonic and generalised tonic–clonic seizures, alone or in varying combinations in otherwise normal individuals)

Infantile spasms

a specific seizure type presenting in the first year of life, most commonly between 3 and 9

months; spasms are brief axial movements lasting 0.2–2 seconds, most commonly flexor in nature, involving flexion of the trunk with extension of the upper and lower limbs (sometimes referred to as 'salaam seizures')

IUDs

intrauterine devices

JME

juvenile myoclonic epilepsy; an epilepsy syndrome with an age of onset of 5–20+ years (peak 10–16 years) characterised by myoclonic seizures that most commonly occur soon after waking

Landau–Kleffner syndrome

a very rare epilepsy syndrome with an age of onset of 3–6 years characterised by loss of language (after a period of normal language development) associated with an epilepsy of centrotemporal origin, more specifically bitemporal spikes on EEG with enhancement in sleep or continuous spike and wave during slow sleep

Late-onset childhood occipital epilepsy (Gastaut type)

epilepsy that starts in mid-childhood to adolescence with frequent brief seizures characterised by initial visual hallucinations, ictal blindness, vomiting and post-ictal headache; EEG typically shows interictal occipital spikes attenuated by eye opening

Lennox–Gastaut syndrome

an epilepsy syndrome with an age of onset of 3–10 years characterised by multiple seizure types (including atonic, tonic, tonic–clonic and atypical absence seizures), cognitive impairment and specific EEG features of diffuse slow spike and wave (< 2 Hz) as well as paroxysmal fast activity (10 Hz or more) in sleep

Myoclonic-astatic epilepsy

an epilepsy syndrome with an age of onset of 18–60 months, characterised by different seizure types with myoclonic and myoclonic-astatic seizures seen in all, causing children to fall; the EEG shows generalised spike/polyspike and wave activity at 2–6 Hz (also known as Doose syndrome)

Myoclonic seizures

sudden brief (<100 ms) and almost shock-like involuntary single or multiple jerks due to abnormal excessive or synchronous neuronal activity and associated with polyspikes on EEG

Neurological deficit

deficiency or impairment of the nervous system

Non-convulsive status epilepticus

a change in mental status or behaviour from baseline, associated with continuous seizure activity on EEG, which is also seen to be a change from baseline

Non-epileptic attack disorder

a disorder characterised by episodes of change in behaviour or movement, not caused by a primary change in electrical activity of the brain; movements are varied, and the attacks can be difficult to differentiate from epileptic seizures

Panayiotopoulos syndrome

epilepsy syndrome presenting in early childhood (mean 4–7 years) with rare, prolonged seizures; characterised by autonomic features including vomiting, pallor and sweating followed by tonic eye deviation, impairment of consciousness with possible evolution into secondary generalisation; prognosis is excellent and treatment often unnecessary

Polypharmacy

multiple different drugs used in a patient's treatment, which could include anti-epileptic drugs

Polytherapy

two or more medications used in combination therapy

Provocation

methods used to provoke seizures, such as hyperventilation, photic stimulation, sleep deprivation and withdrawal of medication

Specialist

for children and young people: a paediatrician with training and expertise in epilepsy; for adults: a medical practitioner with training and expertise in epilepsy

SUDEP

sudden unexpected death in epilepsy: sudden, unexplained, witnessed or unwitnessed, non-traumatic and non-drowning death in people with epilepsy, with or without evidence for a seizure, and excluding documented status epilepticus, in which post-mortem examination does not reveal a toxicological or anatomic cause for death

Syncope

a brief lapse in consciousness caused by transient reduction in blood flow to the brain

Tertiary epilepsy specialist

an adult neurologist who devotes the majority of their working time to epilepsy, works in a multidisciplinary tertiary referral centre with appropriate diagnostic and therapeutic resources, and is subject to regular peer review

Tertiary paediatric epilepsy specialist

a paediatric neurologist who devotes the majority of their working time to epilepsy, works in a multidisciplinary tertiary referral centre with appropriate diagnostic and therapeutic resources, and is subject to regular peer review

Tonic

tonic seizures are epileptic seizures characterised by abrupt generalised muscle stiffening possibly causing a fall; the seizure usually lasts less than a minute and recovery is rapid

Tonic–clonic

an epileptic seizure characterised by initial generalised muscle stiffening, followed by rhythmical jerking of the limbs, usually lasting a few minutes; the person may bite their tongue, be incontinent, feel confused or sleepy afterwards, and take a while to recover fully

Sources

Epilepsies: diagnosis and management (2012 updated 2018) NICE guideline CG137

Your responsibility

Guidelines

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Technology appraisals

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and

their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Medical technologies guidance, diagnostics guidance and interventional procedures guidance

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this interactive flowchart should be interpreted in a way that would be inconsistent with compliance with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.