

The epilepsies

Support for education and learning: clinical case scenarios – Adults with epilepsy

February 2012

These clinical case scenarios accompany the clinical guideline: 'The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care' (available at www.nice.org.uk/guidance/CG137).

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Introduction

NICE clinical case scenarios

Clinical case scenarios are an educational resource that can be used for individual or group learning. Each question should be considered by the individual or group before referring to the answers.

These five clinical case scenarios have been put together to improve your knowledge of the epilepsies and its application in practice. They illustrate how the recommendations from 'The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care', (NICE clinical guideline 137 <http://guidance.nice.org.uk/CG137>) can be applied to the care of adults presenting within primary care.

The clinical case scenarios are available in two formats: this PDF, which can be used for individual learning, and a slide set that can be used for groups. Slides from the clinical case scenario slide set can be added to the standard NICE slide set (<http://guidance.nice.org.uk/CG137/SlideSet/ppt/English>) produced for this guideline.

You will need to refer to the NICE clinical guideline to help you decide what steps you would need to follow to diagnose and manage each case, so make sure that users have access to a copy (either online at www.nice.org.uk/guidance/CG137 or as a printout). You may also want to refer to the epilepsy NICE pathway (<http://pathways.nice.org.uk/pathways/epilepsy>) and the specialist library page on NHS Evidence (<https://www.evidence.nhs.uk/topic/epilepsies?q=epilepsy>).

Each case scenario includes details of the adult's initial presentation. The clinical decisions about diagnosis and management are then examined using a question and answer approach. Relevant recommendations from the NICE guideline are quoted in the text (after the answer), with corresponding recommendation numbers.

The epilepsies

Epilepsy is a common neurological disorder characterised by recurring seizures. Different types of epilepsy have different causes. Accurate estimates of incidence and prevalence are difficult to achieve because identifying people who may have epilepsy is difficult. Epilepsy has been estimated to affect between 362,000 and 415,000 people in England. In addition, there will be further individuals, estimated to be 5–30%, so amounting to up to another 124,500 people, who have been diagnosed with epilepsy, but in whom the diagnosis is incorrect. Incidence is estimated to be 50 per 100,000 per year and the prevalence of active epilepsy in the UK is estimated to be 5–10 cases per 1000. Two-thirds of people with active epilepsy have their epilepsy controlled satisfactorily with anti-epileptic drugs (AEDs). Other approaches may include surgery. Optimal management improves health outcomes and can also help to minimise other, often detrimental, impacts on social, educational and employment activity. 'The epilepsies' (NICE clinical guideline 20) stated that the annual estimated cost of established epilepsies was £2 billion (direct and indirect costs).

Clinical case scenarios for adults

Case scenario 1: Aisha

Presentation

Aisha is a 24-year-old female who attends your surgery after an episode of odd behaviour. Her mum, who has come with her, witnessed an episode last week when Aisha suddenly stood up from the table, started making an 'mm, mm, mm' sound, and wandered around before collapsing to the ground, looking stiff followed by a few jerks. She regained consciousness after about a minute, but had bitten her tongue. She was confused for a further hour or so and she can't recall the event. She had a similar episode about 6 months ago at work, where a colleague commented on her looking bewildered, walking around the office and muttering to herself. At the time, Aisha put this down to stress.

1.1 Question

What information do you try to obtain?

1.1 Answer

You should take a detailed history from Aisha and her mother and explore Aisha's 'odd behaviour' with them both as her mother witnessed it. This should help determine whether an epileptic seizure is likely to have occurred.

Consideration of a diagnosis should not be based on the presence or absence of single features.

You should also carry out a physical examination that includes assessment of the skin and examination of the cardiovascular system.

The detailed history highlights that Aisha is using the combined hormonal contraceptive pill, but is on no other medication. She rarely drinks alcohol and doesn't use recreational drugs. She does drive a car.

On examination, Aisha does not have any abnormal neurological signs.

Relevant recommendations

A detailed history should be taken from the child, young person or adult and an eyewitness to the attack, where possible, to determine whether or not an epileptic seizure is likely to have occurred. **[1.5.4]**

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. **[1.5.5]**

In a child, young person or adult presenting with an attack, a physical examination should be carried out. This should address their cardiac, neurological and mental status, and should include a developmental assessment where appropriate. **[1.4.8]**

1.2 Question

You think Aisha has had a focal seizure followed by a secondarily generalised seizure. What do you do at this stage, and what should you consider?

1.2 Answer

You should refer Aisha urgently to a first seizure/urgent assessment neurology clinic, and explain that her mother should also attend the appointment because she was an eye witness to the attack. Aisha should be seen soon, and within 2 weeks. You should advise Aisha that she must not drive, and go through the regulations in the [DVLA 'At a glance' guide](#) regarding driving after episodes of loss of consciousness and seizures with her. You must inform Aisha of her legal responsibility to notify the DVLA about her change in health. You should also give her information on supervised bathing and showers because of the risk of drowning in the event of another seizure.

You should explain to Aisha that she may have to undergo further tests and be started on treatment when she is seen by the specialist. You should ask her to make a further appointment with you if she has another attack before she is seen in the clinic.

You should also provide information on how to recognise a seizure, first aid and the importance of reporting further attacks.

Your consulting style should be such that it enables Aisha to participate as a partner in all decisions about her care.

Relevant recommendations

It is recommended that all adults having a first seizure should be seen as soon as possible ⁷ by a specialist in the management of the epilepsies to ensure precise and early diagnosis and initiation of therapy as appropriate to their needs. **[1.4.5]**

Essential information on how to recognise a seizure, first aid, and the importance of reporting further attacks should be provided to a child, young person or adult who has experienced a possible first seizure, and their family/carer/parent as appropriate. This information should be provided while the child, young person or adult is awaiting a diagnosis and should also be provided to their family and/or carers. **[1.4.9]**

Healthcare professionals should adopt a consulting style that enables the child, young person or adult 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. **[1.1.1]**

7 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.

At the specialist clinic, Aisha is seen by a consultant neurologist who obtains further history of unpleasant brief sensations of déjà vu, and ‘flipping over’ of her tummy. The specialist also finds no abnormal signs. She makes a clinical diagnosis of temporal lobe epilepsy (with simple focal, complex focal and secondarily generalised seizures).

1.3 Question

What tests should be arranged to support this diagnosis? Also, what information should be provided?

1.3 Answer

Routine blood tests, an electrocardiogram (ECG), an electroencephalogram (EEG) and a magnetic resonance imaging (MRI) brain scan should be arranged initially. Aisha should be given information about why these tests need to be performed and what they will entail.

It is important to check that a person is likely to tolerate an MRI if one is to be performed (that is, check whether Aisha has claustrophobia).

It is also important to check whether Aisha is on any herbal medication and, if so, what she is taking. This needs to be established because some herbal medications can interact with AEDs.

Relevant recommendations

Information should be provided to children, young people and adults 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. **[1.6.1]**

Children, young people and adults requiring an EEG should have the test performed soon after it has been requested. **[1.6.3]**

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. **[1.6.4]**

An EEG should be performed only to support a diagnosis of epilepsy in children and young people. 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. **[1.6.5]**

The EEG should not be used in isolation to make a diagnosis of epilepsy. **[1.6.8]**

Neuroimaging should be used to identify structural abnormalities that cause certain epilepsies. **[1.6.19]**

MRI should be the imaging investigation of choice in children, young people and adults with epilepsy. **[1.6.20]**

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. **[1.6.21]**

In adults, appropriate blood tests (for example, plasma electrolytes, glucose, calcium) to identify potential causes and/or to identify any significant co-morbidity should be considered. **[1.6.27]**

A 12-lead ECG should be performed in adults with suspected epilepsy. **[1.6.29]**

Next steps for management

1.4 Question

What treatment should be offered to Aisha at this stage, and what other issues should be discussed?

1.4 Answer

Lamotrigine should be offered as a first-line treatment.

Carbamazepine and lamotrigine are both first-line treatments in focal epilepsy. However, Aisha is using a combined hormonal contraceptive pill. This may be affected by enzyme-inducing drugs such as carbamazepine, so this should not be used first line if Aisha does not want to change her current contraceptive. Lamotrigine levels may be reduced by oestrogen-based contraceptive methods, so this should be taken into account if Aisha changes her contraception in the future.

Because Aisha is being started on a potentially teratogenic drug, the risks of teratogenicity and neurodevelopmental abnormalities associated with her anti-epileptic treatment should be discussed at this stage, and again in the future if she is planning pregnancy.

Treatment with high-dose folic acid should be offered to Aisha (to reduce the risk of neural tube defects early in pregnancy).

Aisha should be taken through the DVLA regulations. These state that because she has been diagnosed with epilepsy she cannot drive until she has been free of seizures for 1 year.

Written instructions about her treatment should be given. Patient information leaflets on different aspects of epilepsy diagnosis, management and lifestyle issues associated with epilepsy should be provided. The discussion on anti-epileptic medication should include the different medications that are available, the evidence base for using these medications, and their common and potentially unwanted side effects (for example, skin rash with lamotrigine, and the need to seek urgent medical advice if this occurs). Likely outcome or prognosis should also be discussed, and Aisha and her mother should be referred to an epilepsy nurse who can provide information and guidance on lifestyle and other non-medical issues. Enough time should be given to the consultation to allow for full discussion.

Aisha should be given the contact details of a named individual to contact if further information is needed.

Relevant recommendations

Offer carbamazepine or lamotrigine as first-line treatment to children, young people and adults with newly diagnosed focal seizures. **[1.9.3.1]**

Discuss with women and girls who are taking lamotrigine that the simultaneous use of any oestrogen-based contraceptive can result in a significant reduction of lamotrigine levels and lead to loss of seizure control. When a woman or girl starts or stops taking these contraceptives, the dose of lamotrigine may need to be adjusted. **[1.15.2.9]**

All women and girls on AEDs should be offered 5 mg per day of folic acid before any possibility of pregnancy. **[1.15.1.6]**

Epilepsy specialist nurses (ESNs) should be an integral part of the network of care of children, young people and adults with epilepsy. The key roles of the ESNs 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 child, young person or adult, families, carers and, in the case of children, others involved in the child's education, welfare and well-being. **[1.8.3]**

Children, young people and adults 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
- lifestyle, 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. **[1.3.1]**

- Information should be provided in formats, languages and ways that are suited to the child, young person or adult's requirements. Consideration should be given to developmental age, gender, culture and stage of life of the person. **[1.3.3]**
- If children, young people and adults, and their 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). **[1.3.4]**
- Adequate time should be set aside in the consultation to provide information, which should be revisited on subsequent consultations. **[1.3.5]**
- The child, young person or adult 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 child, young person or adult and/or their family and/or carers are met. **[1.3.8]**

At Aisha's 3-month review, she tells the specialist that she is tolerating her treatment well. Her déjà vu and epigastric rising stopped as soon as she reached the maintenance dose of treatment, and she has not had any more episodes of wandering or collapse.

Her blood tests and ECG are normal; her EEG shows left anterior and mid-temporal spike waves, consistent with a left temporal focus; her MRI brain scan shows reduction in left hippocampal volume, but no hippocampal sclerosis.

The specialist suggests that because the findings are in keeping with focal (temporal lobe) epilepsy, and Aisha's seizures are well controlled on her current dose, her treatment should not be changed at this stage.

Nine months later, Aisha attends your surgery to find out about travel vaccinations. She mentions to the nurse that she has stopped all her treatment because she is planning to have a baby after her wedding in 2 months' time.

1.5 Question

The nurse asks you to discuss this with Aisha. What should you do?

1.5 Answer

You should discuss Aisha's worries with her and using the information she was given when she saw the specialist, explain to her the risks and benefits of taking anti-epileptic treatment during pregnancy. You should specifically discuss the risk of uncontrolled seizures and sudden unexpected death in epilepsy (SUDEP) with her, because she has stopped her treatment. She has experienced a few episodes of déjà vu since stopping treatment, but does not consider this enough to restart her treatment.

You should encourage Aisha to notify her pregnancy to the UK Epilepsy and Pregnancy Register.

Relevant recommendations

Women and girls with epilepsy need accurate information during pregnancy, and the possibility of status epilepticus and SUDEP should be discussed with all women and girls who plan to stop AED therapy (see section 1.9.18 of the guideline). **[1.15.3.1]**

All pregnant women and girls with epilepsy should be encouraged to notify their pregnancy, or allow their clinician to notify the pregnancy, to the UK Epilepsy and Pregnancy Register (www.epilepsyandpregnancy.co.uk). **[1.15.3.2]**

The clinician should discuss with the woman and girl the relative benefits and risks of adjusting medication to enable her to make an informed decision. Where appropriate, the woman or girl's specialist should be consulted. **[1.15.3.3]**

Women and girls should be reassured that there is no evidence that focal, absence and myoclonic seizures affect the pregnancy or developing fetus adversely unless they fall and sustain an injury. **[1.15.3.5]**

1.5 Question

Aisha is still unsure about restarting her treatment. What should you do?

1.5 Answer

You should make Aisha an urgent appointment with the local specialist epilepsy service.

Aisha sees a specialist nurse a week later, having experienced a complex focal seizure three days before her appointment. With further counselling, she decides to gradually restart her lamotrigine, aiming to achieve her previous maintenance dose, because she had noticed that her seizures had stopped at this dose previously. She had not stopped taking her folic acid.

Relevant recommendations

Aim for seizure freedom before conception and during pregnancy (particularly for women and girls with generalised tonic–clonic seizures) but consider the risk of adverse effects of AEDs and use the lowest effective dose of each AED, avoiding polytherapy if possible. **[1.15.3.18]**

Case scenario 2: Kieran

Presentation

Kieran is a 19-year-old male who has been referred to a first seizure/urgent assessment neurology clinic from A&E after a single episode of collapse with jerking. He is unable to give you much of a history; he was at his girlfriend's house, sitting and chatting on the sofa, and the next thing he remembers is feeling disorientated on the floor.

2.1 Question

What do you do next, and what information should you obtain?

2.1 Answer

You telephone Kieran's girlfriend, who gives a clear description of a brief single generalised tonic-clonic seizure. You ask her if she has noticed any other blank spells, signs of collapse, jerks or odd behaviours. She tells you that sometimes, in the mornings, she has noticed that Kieran makes strange quick jerks of his upper limbs. Kieran is aware of these episodes, in that he feels like he switches on and off briefly, like flicking a light switch. He thinks he has had them for years, since he was about 15, but has never been concerned by them.

You should carry out a physical examination and provide information on how to recognise a seizure, first aid, and the importance of reporting further attacks. The examination should include assessment of the cardiovascular system and an examination of the skin.

You should establish Kieran's past medical and family history, and should ask about alcohol consumption, drug use and sleep deprivation.

Relevant recommendations

Children, young people and adults 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.

[1.4.1]

It is recommended that all adults 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. **[1.4.5]**

In a child, young person or adult presenting with an attack, a physical examination should be carried out. This should address their cardiac, neurological and mental status, and should include a developmental assessment where appropriate. **[1.4.8]**

Essential information on how to recognise a seizure, first aid, and the importance of reporting further attacks should be provided to a child, young

person or adult who has experienced a possible first seizure, and their family/carer/parent as appropriate. This information should be provided while the child, young person or adult is awaiting a diagnosis and should also be provided to their family and/or carers. [1.4.9]

Kieran has no past medical or family history of note. He had not drunk any alcohol that evening, but he was very tired because he had been up late completing an essay for the past two nights. He does not drive, but you explain the driving regulations to him briefly, and discuss safety issues.

Kieran's general and neurological examinations were normal, and he had a normal routine blood screen (urea and electrolytes, calcium and glucose) when he attended A&E.

You make a clinical diagnosis of juvenile myoclonic epilepsy (JME)

2.2 Question

What tests should you arrange to support this diagnosis?

2.2 Answer

Routine blood tests, ECG and EEG initially.

Relevant recommendations

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. **[1.6.4]**

The EEG should not be used in isolation to make a diagnosis of epilepsy. **[1.6.8]**

In adults, appropriate blood tests (for example, plasma electrolytes, glucose, calcium) to identify potential causes and/or to identify any significant co-morbidity should be considered. **[1.6.27]**

A 12-lead ECG should be performed in adults with suspected epilepsy. **[1.6.29]**

2.3 Question

Kieran asks if he needs a brain scan. How do you answer him?

2.3 Answer

You discuss with Kieran the fact that his type of epilepsy is not usually associated with MRI abnormalities, and you agree not to arrange scanning at this stage. You will review this if his EEG shows abnormalities that are not consistent with a diagnosis of JME, if he does not respond to treatment, or if he develops new symptoms or signs.

You stress the importance of avoiding sleep deprivation, excess alcohol and recreational drugs.

Relevant recommendations

Neuroimaging should not be routinely requested when a diagnosis of idiopathic generalised epilepsy has been made. **[1.6.23]**

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. **[1.6.21]**

2.4 Question

What treatment should you offer Kieran and what information should you provide?

2.4 Answer

Because Kieran is a male, otherwise well, and on no treatment, you agree that he should try sodium valproate first line, explaining the rationale for treatment and the common side effects of this drug.

Kieran should be prescribed a consistent supply of a particular manufacturer's sodium valproate preparation because different preparations of some AEDs may vary in bioavailability or pharmacokinetic profiles, and care needs to be taken to avoid reduced effect or excessive side effects. You should explain to him what to do if side effects occur. You should also discuss with him the potential need for a prescriber to advise a patient on how a change in brand may affect them.

You should provide Kieran and his mother and girlfriend with information about JME and epilepsy in general. High-quality information from voluntary organisations should be provided including details about how to access these organisations.

Relevant recommendations

Offer sodium valproate as first-line treatment to children, young people and adults with newly diagnosed JME, unless it is unsuitable. Be aware of teratogenic risks of sodium valproate (see recommendation 1.9.1.10 of the NICE guideline). **[1.9.13.1]**

Consistent supply to the patient of a particular manufacturer's AED preparation is recommended, unless the prescriber, in consultation with the patient, considers that this is not a concern. Different preparations of some AEDs may vary in bioavailability or pharmacokinetic profiles and care needs to be taken to avoid reduced effect or excessive side effects. Consult the summary of product characteristics (SPC) and 'British national formulary' (BNF; available at <http://bnf.org.uk>) on the bioavailability and pharmacokinetic profiles of individual AEDs, but note that these do not give information on comparing bioavailability of different generic preparations. **[1.9.1.4]**

The AED treatment strategy should be individualised according to the seizure

type, epilepsy syndrome, co-medication and co-morbidity, the child, young person or adult's lifestyle, and the preferences of the person and their family and/or carers as appropriate (see appendix E of the NICE guideline). **[1.9.1.2]**

Children, young people and adults 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
- lifestyle, 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. **[1.3.1]**

2.5 Question

At Kieran's six-month review, he tells you he is unhappy with his treatment. His seizures are reasonably well controlled, with just a few morning jerks each month (particularly if he has been up late the night before), but he has put on weight (about 6 kg) and is very unhappy. His girlfriend's cousin has epilepsy, which is well controlled with carbamazepine, and he would like to try this drug.

What do you do next?

2.5 Answer

You discuss the balance between seizure control and side effects with Kieran, and establish that he finds the weight gain an unacceptable side effect of the sodium valproate and wishes to change his treatment.

You explain that carbamazepine is not the best drug to treat the type of epilepsy that he has because it could make his jerks worse. You discuss the treatment options open to him: continuing on sodium valproate, or trying lamotrigine, topiramate or levetiracetam.

Relevant recommendations

Consider lamotrigine^{*}, levetiracetam^{*} or topiramate^{*} if sodium valproate is unsuitable or not tolerated. Be aware that topiramate has a less favourable side-effect profile than lamotrigine, levetiracetam and sodium valproate, and that lamotrigine may exacerbate myoclonic seizures. **[1.9.13.2]**

^{*} At the time of publication (January 2012), this drug did not have UK marketing authorisation for this indication and/or population (see appendix E of the guideline for details). Informed consent should be obtained and documented.

You agree to a management plan of gradual withdrawal of sodium valproate and introduction of levetiracetam, and give Kieran written instructions on how to do this. Levetiracetam should be introduced and well tolerated before sodium valproate is tapered.

Kieran returns to the clinic after three months; he has lost some weight, and is tolerating the levetiracetam well. He has not had any further generalised tonic-clonic seizures, and he and his girlfriend only notice his myoclonic seizures after a night out.

You discuss factors that may aggravate his seizures, such as missing doses of levetiracetam, alcohol consumption and sleep deprivation. You agree to leave his treatment unchanged and plan to review him in six months' time.

Case scenario 3: Molly

Presentation

Molly is 18 years old. She has made an appointment because her friends have noticed that she has 'funny turns' and persuaded her to seek advice.

Past medical history

Molly has a history of two febrile convulsions at the age of 18 months and 22 months. She drinks 20 units of alcohol a week, usually on Friday and Saturday nights. She drives a car.

She has had stereotyped feelings of déjà vu associated with a rising feeling in her abdomen for 4–5 years, but has previously ignored them. Her friends have witnessed three episodes when she has looked blank, fiddled with her hands, and opened and closed her mouth repetitively. Molly is unaware of her friends during these episodes and afterwards has no memory of the events.

On examination

There is no abnormality on examination. You are considering a diagnosis of epilepsy.

3.1 Question

What type of epilepsy is this likely to be?

3.1 Answer

Focal epilepsy (temporal lobe).

3.2 Question

What should you do next?

3.2 Answer

You should ask about other markers of seizures, particularly seizures from sleep (enuresis, waking with a bitten tongue or myalgia) because these may affect management (generalised convulsive seizures from sleep carry a higher risk of injury and SUDEP than focal dyscognitive seizures in wakefulness).

You should inform Molly of your diagnosis, advise her not to drive and to moderate her alcohol intake, and you should give her advice about personal safety. You should ensure that the consultation is long enough for the diagnosis to be discussed fully.

You should refer her to a specialist in epilepsy and ask her to take with her to the consultation someone who witnessed one of her episodes.

You should inform her about the investigations she should expect, to determine a diagnosis. People with suspected epilepsy should have an ECG. Those with focal epilepsy should have imaging with MRI to detect a structural cause. An EEG may be done to confirm the type of epilepsy, but it may not show any abnormality.

Relevant recommendations

The diagnosis of epilepsy in adults should be established by a specialist medical practitioner with training and expertise in epilepsy. **[1.5.1]**

Children, young people and adults and their families and/or carers should be given an opportunity to discuss the diagnosis with an appropriate healthcare professional. **[1.5.3]**

A detailed history should be taken from the child, young person or adult and an eyewitness to the attack, where possible, to determine whether or not an epileptic seizure is likely to have occurred. **[1.5.4]**

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. **[1.6.4]**

Photic stimulation and hyperventilation should remain part of standard EEG

assessment. The child, young person or adult and family and/or carer should be made aware that such activation procedures may induce a seizure and they have a right to refuse. **[1.6.18]**

Neuroimaging should be used to identify structural abnormalities that cause certain epilepsies. **[1.6.19]**

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. **[1.6.21]**

Molly's MRI brain scan is normal; the EEG shows focal changes over the left anterior temporal region.

3.3 Question

Should Molly start treatment with anti-epileptic medication?

3.3 Answer

This is a personal choice. Molly needs to be advised about the risks of seizures, the impact of continuing seizures on her lifestyle (for example, driving and employment), the serious adverse events associated with seizures (injury and, very rarely, SUDEP) and the efficacy of anti-epileptic medication.

Relevant recommendations

Healthcare professionals should adopt a consulting style that enables the child, young person or adult 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. **[1.1.1]**

Children, young people and adults 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

- lifestyle, 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. **[1.3.1]**

The decision to initiate AED therapy should be taken between the child, young person or adult, their family and/or carers (as appropriate) and the specialist after a full discussion of the risks and benefits of treatment. This discussion should take into account details of the person's epilepsy syndrome, prognosis and lifestyle. **[1.9.2.4]**

3.4 Question

If she chooses to take medication, what medication would be first choice for Molly?

3.4 Answer

Choice of anti-epileptic medication is guided by the type of epilepsy and the personal circumstances of the individual.

First-line medication for focal epilepsy is carbamazepine or lamotrigine. If these are not suitable, alternatives include oxcarbazepine, valproate or levetiracetam.

Relevant recommendations

Offer carbamazepine or lamotrigine as first-line treatment to children, young people and adults with newly diagnosed focal seizures. **[1.9.3.1]**

Levetiracetam is not cost effective at June 2011 unit costs*. Offer levetiracetam, oxcarbazepine or sodium valproate (provided the acquisition cost of levetiracetam falls to at least 50% of June 2011 value documented in the National Health Service Drug Tariff for England and Wales) if carbamazepine and lamotrigine are unsuitable or not tolerated. If the first AED tried is ineffective, offer an alternative from these five AEDs. Be aware of the teratogenic risks of sodium valproate (see recommendation 1.9.1.10). **[1.9.3.2]**

* Estimated cost of a 1500 mg daily dose was £2.74 at June 2011. Cost taken from the National Health Service Drug Tariff for England and Wales, available at www.ppa.org.uk/ppa/edt_intro.htm

3.5 Question

What factors might influence choice of medication?

3.5 Answer

Molly is a young female of childbearing potential. She is likely to remain on anti-epileptic medication for several years and one with a low teratogenic risk should be chosen. This excludes valproate, which has the highest risk of teratogenicity.

Drug interactions are important in choice of anti-epileptic medication. In young women, choice of contraception can influence choice of anti-epileptic medication. Molly is keen to take an oral contraceptive. Molly should also be offered 5 mg per day of folic acid.

Relevant recommendations

The AED treatment strategy should be individualised according to the seizure type, epilepsy syndrome, co-medication and co-morbidity, the child, young person or adult's lifestyle, and the preferences of the person and their family and/or carers as appropriate (see appendix E of the NICE guideline). **[1.9.1.2]**

Discuss with women and girls of childbearing potential (including young girls who are likely to need treatment into their childbearing years), and their parents and/or carers if appropriate, the risk of AEDs causing malformations and possible neurodevelopmental impairments in an unborn child. Assess the risks and benefits of treatment with individual drugs. There are limited data on risks to the unborn child associated with newer drugs. Specifically discuss the risk of continued use of sodium valproate to the unborn child, being aware that higher doses of sodium valproate (more than 800 mg/day) and polytherapy, particularly with sodium valproate, are associated with greater risk. **[1.15.1.4]**

All women and girls on AEDs should be offered 5 mg per day of folic acid before any possibility of pregnancy. **[1.15.1.6]**

3.6 Question

What first-line anti-epileptic medication for focal epilepsy does not interact with oral contraceptives?

3.6 Answer

Levetiracetam does not interact with oral contraceptives.

Valproate does not interact with oral contraceptives but would not be chosen because of the risk of teratogenicity.

Carbamazepine and oxcarbazepine induce hepatic enzymes, are not compatible with the progestogen-only pill and reduce the efficacy of the combined oral contraceptive pill.

Oestrogens, even in intravaginal contraceptives, lower the blood level of lamotrigine by an unpredictable amount.

Progestogens do not affect lamotrigine levels.

3.7 Question

What other methods of contraception might be compatible with enzyme-inducing anti-epileptic medication?

3.7 Answer

Depot injection of medroxyprogesterone, Mirena IUD.

Related recommendations

- 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. **[1.15.2.1]**
- 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. **[1.15.2.2]**
- In women and girls of childbearing potential, the risks and benefits of different contraceptive methods, including hormone-releasing IUDs, should be discussed. **[1.15.2.3]**

Case scenario 4: David

Presentation

David is 46 years old and was admitted to hospital after he collapsed at work because of a posterior fossa intracranial haemorrhage with intraventricular extension. He had surgery to remove a haematoma, and after surgery he had aspiration pneumonia due to dysphagia. He needed a percutaneous endoscopic gastrostomy (PEG) tube insertion 1 week later for further care.

On transfer to a rehabilitation unit, David had hospital-acquired pneumonia and was treated with intravenous co-amoxiclav. Sputum grew pseudomonas after culturing and he was treated with intravenous gentamycin. Because his breathing was compromised, a tracheostomy was performed to maintain his ventilation. Removal of the tracheostomy tube took place 4 weeks later and he was able to manage his own secretions.

Because of his ongoing ill health, David had routine blood tests while being treated for pneumonia. Results of these highlighted that he had abnormal liver function; however, liver ultrasound showed no abnormalities and they now appear settled after antibiotic therapy.

David was diagnosed with hypertension after the stroke, and he may have been suffering with hypertension for some time before it occurred. His blood pressure is now controlled with ramipril.

He had episodes where his facial muscles showed features of twitching and he turned his head. Twitching was also observed in the mouth when he was asked to open his jaw. The episodes did not affect his level of consciousness and lasted for 2–5 minutes.

4.1 Question

What are the next steps and investigations required to find out the reason for David's episodes of twitching?

4.1 Answer

David should be seen by an epilepsy specialist as soon as possible, and within two weeks, after his first episode of twitching. A physical examination should be carried out and information about how to recognise seizures, first aid and the importance of reporting further attacks should be provided. The physical examination should include assessment of the cardiovascular system and an examination of the skin.

A detailed history should be taken along with an eye witness account of the episode of twitching if available.

An EEG should be requested and carried out soon after. David should be given information about this EEG, why it has been requested and what it will involve.

Relevant recommendations

It is recommended that all adults 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. **[1.4.5]**

In a child, young person or adult presenting with an attack, a physical examination should be carried out. This should address their cardiac, neurological and mental status, and should include a developmental assessment where appropriate. **[1.4.8]**

Essential information on how to recognise a seizure, first aid, and the importance of reporting further attacks should be provided to a child, young person or adult who has experienced a possible first seizure, and their family/carer/parent as appropriate. This information should be provided while the child, young person or adult is awaiting a diagnosis and should also be provided to their family and/or carers. **[1.4.9]**

A detailed history should be taken from the child, young person or adult and an eyewitness to the attack, where possible, to determine whether or not an epileptic seizure is likely to have occurred. **[1.5.4]**

Information should be provided to children, young people and adults 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. **[1.6.1]**

Children, young people and adults requiring an EEG should have the test performed soon after it has been requested¹. **[1.6.3]**

* 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.

¹ The Guideline Development Group considered that 'soon' meant being seen within 4 weeks.

The EEG highlights that there is an excess of theta and delta slow-wave activity in the background, and more prominent over the left hemisphere. There are additional bursts of widespread slow-wave activity. David had continuous repetitive right lower facial twitches but no definite EEG correlates other than movement artefact are observed. There are no epileptiform discharges. The posterior dominant rhythm is mildly slow at 7 Hz. The abnormalities seen may indicate mild diffuse cerebral dysfunction mainly of the left hemisphere. No EEG correlates are observed with the facial twitches; however, focal seizures do not always have a surface correlate.

A diagnosis of focal seizures is made.

4.2 Question

What treatment should you offer David for the focal seizures?

4.2 Answer

Because the diagnosis of epilepsy is confirmed, treatment with AED therapy is recommended and the decision to initiate this should be made between David and the specialist after a full discussion about the risks and benefits.

Lamotrigine should be prescribed.

Relevant recommendations

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 child, young person or adult and their family and/or carers as appropriate. **[1.9.2.1]**

The decision to initiate AED therapy should be taken between the child, young person or adult, their family and/or carers (as appropriate) and the specialist after a full discussion of the risks and benefits of treatment. This discussion should take into account details of the person's epilepsy syndrome, prognosis and lifestyle. **[1.9.2.4]**

Offer carbamazepine or lamotrigine as first-line treatment to children, young people and adults with newly diagnosed focal seizures. **[1.9.3.1]**

4.3 Question

If lamotrigine is ineffective, what adjunctive treatment should be offered to David?

4.3 Answer

David should be offered and started on carbamazepine.

Relevant recommendations

Offer carbamazepine, clobazam², gabapentin¹³, lamotrigine, levetiracetam, oxcarbazepine, sodium valproate or topiramate as adjunctive treatment to children, young people and adults with focal seizures if first-line treatments (see recommendations 1.9.3.1 and 1.9.3.2) are ineffective or not tolerated. Be aware of teratogenic risks of sodium valproate (see recommendation 1.9.1.10).

[1.9.3.4]

² At the time of publication (January 2012), this drug did not have UK marketing authorisation for this indication and/or population (see appendix E of the NICE guideline for details). Informed consent should be obtained and documented.

Treatment of David's epileptic seizures resulted in improvement in his swallow and this was confirmed after videofluoroscopy. Videofluoroscopy showed rhythmic contractions of the soft palate, larynx and muscles of the left side of the neck. It also highlighted right-sided vocal cord palsy with reasonable closure of glottis.

Repeat videofluoroscopy after 3 months showed reduced palatal tremors.

Improved swallow resulted in the removal of the PEG tube.

Case scenario 5: Sally

Past medical history

Sally developed epilepsy after a prolonged febrile convulsion damaged her brain at the age of 15 months. She was admitted to hospital and treated according to local protocols.

Later in life, she underachieved both at school and in the workplace. As a child she was under the care of a paediatrician. Because her seizures were not controlled, the paediatrician prescribed a change in drugs that resulted in an increase in seizures while Sally was studying for her GCSEs. After this and until she was a young adult, she was seen by a psychiatrist.

The branch manager of the bank where Sally first worked found her epilepsy a problem. He pressurised her to stop the seizures occurring at work. The more pressure, the more seizures Sally had. She became trapped in such a vicious circle that there was nothing she could do but resign.

She eventually found another job, but the extra travelling left her very tired and this in turn increased the seizures. One afternoon, waiting for a train home, she wandered off the station platform and onto the line during a complex partial seizure.

Later, when Sally became pregnant she asked her GP about the possible risks to her unborn child. She was told that the epilepsy medication would already have damaged her baby. Both Sally and her husband worried throughout the pregnancy about the baby.

5.1 Question

What information and assessments should healthcare professionals have given to Sally as a young person to prevent her concerns when she became pregnant?

5.1 Answer

Sally should have been given accurate information and counselling about contraception, conception, pregnancy, caring for children and breastfeeding so that she could make an informed decision.

The risks of AEDs causing malformations and possible neurodevelopmental impairments in an unborn child should have been discussed. Sally should have been offered 5 mg per day of folic acid before any possibility of pregnancy.

Sally should have been offered an early ultrasound test.

Relevant recommendations

In order to enable informed decisions and choice, and to reduce misunderstandings, women and girls 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. **[1.15.1.1]**

Discuss with women and girls of childbearing potential (including young girls who are likely to need treatment into their childbearing years), and their parents and/or carers if appropriate, the risk of AEDs causing malformations and possible neurodevelopmental impairments in an unborn child. Assess the risks and benefits of treatment with individual drugs. There are limited data on risks to the unborn child associated with newer drugs. Specifically discuss the risk of continued use of sodium valproate to the unborn child, being aware that higher doses of sodium valproate (more than 800 mg/day) and polytherapy, particularly with sodium valproate, are associated with greater risk. **[1.15.1.4]**

All women and girls on AEDs should be offered 5 mg per day of folic acid before any possibility of pregnancy. **[1.15.1.6]**

5.2 Question

What information should have been given to Sally during pregnancy?

5.2 Answer

The possibility of status epilepticus and SUDEP should have been explained if Sally had planned to stop AED therapy. She should have also been encouraged to notify her pregnancy to the UK Epilepsy and Pregnancy Register.

Sally should have been reassured that an increase in seizure frequency is generally unlikely in pregnancy or in the first few months after birth.

Sally should have been informed that although she was likely to have a healthy pregnancy, her risk of complications was higher than for those without epilepsy.

Relevant recommendations

Women and girls with epilepsy need accurate information during pregnancy, and the possibility of status epilepticus and SUDEP should be discussed with all women and girls who plan to stop AED therapy (see section [1.9.18](#) of the NICE guideline). **[1.15.3.1]**

All pregnant women and girls with epilepsy should be encouraged to notify their pregnancy, or allow their clinician to notify the pregnancy, to the UK Epilepsy and Pregnancy Register (www.epilepsyandpregnancy.co.uk). **[1.15.3.2]**

Women and girls should be reassured that an increase in seizure frequency is generally unlikely in pregnancy or in the first few months after birth. **[1.15.3.6]**

Women and girls 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 and girls without epilepsy. **[1.15.3.8]**

Sally's healthy baby boy was born after a long labour. However, after the delivery Sally had a convulsive seizure. When she came round after the seizure, she didn't realise she had a son.

Night-time feeds meant that Sally started to become exhausted. The more tired she became, the more frequent her seizures. The more seizures she had, the more anxious and depressed she became. At this time her treatment for her

epilepsy was under a consultant neurologist who had prescribed vigabatrin post-natally.

Sally believed that if she told a healthcare professional she was not coping, Social Services would deem her an unfit mother and take her baby away. Sally weighed 6 stone, couldn't eat or sleep and suffered with anxiety, lack of confidence and depression.

She constantly pestered her neurologist for referral to an epilepsy specialist neurologist but it was not until after the birth of her second child that this was done.

5.3 Question

How have services let Sally down and what should have happened?

5.3 Answer

Sally should have had access to a tertiary service through her specialist earlier on in her care. If seizures are not controlled within 2 years, referral to tertiary services for further assessment should occur.

Relevant recommendations

All children, young people and adults with epilepsy should have access via their specialist to a tertiary service when circumstances require. [1.10.1]

If seizures are not controlled and/or there is diagnostic uncertainty or treatment failure, children, young people and adults should be referred to tertiary services soon for further assessment. Referral should be considered when one or more of the following criteria are present:

- the epilepsy is not controlled with medication within 2 years
- management is unsuccessful after two drugs
- the child is aged under 2 years
- a child, young person or adult experiences, or is at risk of, unacceptable side effects from medication
- there is a unilateral structural lesion
- there is psychological and/or psychiatric co-morbidity
- there is diagnostic doubt as to the nature of the seizures and/or seizure syndrome. [1.10.2]

On referral Sally saw an epilepsy specialist neurologist who indicated that she was unlikely to reach her 40th birthday unless he could find a way to stop her seizures. Strangely, she left him feeling confident and calm: she was relieved that someone finally understood her epilepsy.

Sally had many different tests to find out if curable epilepsy surgery would be safe and effective for her. Just nine months after meeting the epilepsy specialist neurologist, she was offered brain surgery.

Fifteen years later Sally's life has been truly transformed. Being able to drive a car has enabled her to be independent for the first time in her life.

Relevant recommendations

The tertiary service should include a multidisciplinary team, experienced in the assessment of children, young people and adults with complex epilepsy, and have adequate access to investigations and treatment by both medical and surgical means. **[1.10.7]**

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. **[1.10.8]**

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. **[1.10.9]**

Other implementation tools

NICE has developed tools to help organisations implement the clinical guideline on the epilepsies (listed below). These are available on the NICE website (www.nice.org.uk/guidance/CG137).

- Costing statement – details of the likely costs and savings when the cost impact of the guideline is not considered to be significant.
- Audit support – for monitoring local practice.
- Pharmacological treatment tables – tables from appendix E of the NICE guideline separated for ease of use and printing.
- Slide set – educational slide set which highlights the key recommendations.
- Online educational tool – developed in conjunction with BMJ Learning, the interactive module uses interactive case histories to improve users' knowledge of the guidance. The tools are free to use and open to all. You will need to provide your email address and a password to register with BMJ Learning.

A practical guide to implementation, 'How to put NICE guidance into practice: a guide to implementation for organisations', is also available (www.nice.org.uk/usingguidance/implementationtools).

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