

# The diagnosis and management of epilepsy in children, young people and adults

Information for the public

Published: 1 January 2012

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

## About this information

NICE clinical guidelines advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive. The information applies to people using the NHS in England and Wales.

In April 2018, we updated the advice in the guideline with warnings about [sodium valproate](#). Sodium valproate must not be used in pregnancy, and only used in girls and women when there is no alternative and a pregnancy prevention plan is in place. This is because of the risk of malformations and developmental abnormalities in the baby.

This information explains the advice about the diagnosis and management of epilepsy in children, young people and adults that is set out in NICE clinical guideline 137.

This is a partial update of advice on epilepsy that NICE produced in 2004. The advice on medicines used to treat epilepsy has been updated, some advice has been strengthened, and other guidance will be reviewed in due course.

## *Does this information apply to me?*

Yes, if you have epilepsy, or you are the parent or carer of a child or young person with epilepsy.

The advice in the NICE guideline covers the diagnosis, treatment and management of epilepsy. It does not cover surgical interventions in detail.

It also does not specifically look at the treatment of newborn babies or the diagnosis or management of seizures caused by fever (febrile seizures). It does not cover complementary ('alternative') therapies, such as acupuncture or herbal medicine, or lifestyle issues.

For the remainder of this information, the term:

- 'child' will be used to describe a child aged from 1 month to 11 years old
- 'young person' will be used to describe those between the ages of 12 and 17
- 'adult' will be used to describe those who are 18 or over
- 'older people' will be used to describe those who are 65 or over based on the evidence that was reviewed.

## Your care

In the NHS, patients and healthcare professionals have rights and responsibilities as set out in the NHS Constitution ([www.dh.gov.uk/en/DH\\_132961](http://www.dh.gov.uk/en/DH_132961)). All NICE guidance is written to reflect these. You have the right to be involved in discussions and make informed decisions about your treatment and care with your healthcare team. Your choices are important and healthcare professionals should support these wherever possible. You should be treated with dignity and respect.

To help you make decisions, healthcare professionals should explain epilepsy and the possible treatments for it. They should cover possible benefits and risks related to your personal circumstances. All decisions about tests, treatments and care should be made jointly by you, and your family or carers as appropriate, and your healthcare professional. Your needs, wishes and concerns should be discussed and taken into account, and information should be provided to help you understand your circumstances and the choices you have. (See '[After your diagnosis](#)' for more details about information that should be provided.)

The relevant information should be suitable for you and reflect your age and level of understanding, and any religious, ethnic, or cultural needs you have. It should also take into account whether you have any physical or learning disability, sight or hearing problem or language

difficulties. You should have access to an interpreter or advocate (someone who helps you put your views across) if needed.

Your family and carers should be given their own information and support. If you agree, they should also have the chance to be involved in decisions about your care.

You should be able to discuss or review your care as your treatment progresses, or your circumstances change. This may include changing your mind about your treatment or care. If you have made an 'advance decision' (known as a 'living will' in the past) in which you have already given instructions about any treatments that you do not wish to have, your healthcare professionals have a legal obligation to take this into account.

All treatment and care should be given with your informed consent. If, during the course of your illness, you are not able to make decisions about your care, your healthcare professionals have a duty to talk to your family or carers unless you have specifically asked them not to. Healthcare professionals should follow the Department of Health's advice on consent ([www.dh.gov.uk/en/DH\\_103643](http://www.dh.gov.uk/en/DH_103643)) and the code of practice for the Mental Capacity Act. Information about the Act and consent issues is available from [www.nhs.uk/CarersDirect/moneyandlegal/legal](http://www.nhs.uk/CarersDirect/moneyandlegal/legal). In Wales healthcare professionals should follow advice on consent from the Welsh Government ([www.wales.nhs.uk/consent](http://www.wales.nhs.uk/consent)).

In an emergency, healthcare professionals may give treatment immediately, without obtaining your informed consent, when it is in your best interests.

Care of young people who are moving from services for children to adult services should be planned according to guidance from the Department of Health ('Transition: getting it right for young people' available from [www.dh.gov.uk/en/DH\\_4132145](http://www.dh.gov.uk/en/DH_4132145)).

If you are under 16, your parents or carers will need to agree to your treatment, unless it is clear that you fully understand the treatment and can give your own consent.

In an emergency, if the person with parental responsibility cannot be contacted, healthcare professionals may give treatment immediately when it is in the child's best interests.

## What is epilepsy?

Epilepsy is a condition that affects the brain. There are billions of nerve cells (neurons) in the brain, which are linked together to form chains. All of the functions of the brain are controlled by these

neuron chains, and so movement, speech, thoughts, sensations and feelings all depend on the signals being passed in a regulated and orderly way. The activity of the neuron chains is coordinated by electrical and chemical signals.

People with epilepsy have recurrent bursts of abnormal electrical activity in the brain. This change in brain activity leads to an epileptic seizure. An epileptic seizure can take a number of different forms – it can cause changes in a person's body movements, awareness, behaviour, emotions or senses (such as taste, smell, vision or hearing). Usually a seizure lasts for only a few seconds or minutes and then the brain activity returns to normal.

Having one seizure does not necessarily mean that someone has epilepsy – people can have a 'one-off' seizure.

'Epilepsy' is not a single condition: in the NICE guideline, the term 'the epilepsies' is used to show that not just one but many brain conditions can result in recurrent epileptic seizures. Some epilepsies start in childhood, some start in young people or in adults, while others start in older people; some last for only a short time and others last for a lifetime; some have little impact on a person's life and others can have a major effect on a person's ability to function and live their daily life.

## Types of seizure

There are many different types of epileptic seizure, but they are divided into two main groups (focal or generalised) depending on the source of the seizure within the brain.

### *Focal seizures*

Focal (or partial) seizures are seizures that start in one part of the brain. These seizures may take many different forms depending on the part of the brain that is affected. They may involve a change of movement or behaviour; a person may remain aware of their surroundings during a seizure, or they may lose awareness.

### *Generalised seizures*

Generalised seizures are more distributed and affect both sides of the brain at once. There are different types of generalised seizure, the most recognised of which is the 'tonic-clonic seizure' (where the person goes stiff and then has jerking movements). During a generalised seizure, the person may lose consciousness, fall or have muscle spasms.

## *Secondarily generalised seizures*

Sometimes a focal seizure spreads from one side of the brain to the other – when this happens this is known as secondary generalisation.

## *Seizures and possible causes*

Some people with epilepsy have only one type of seizure, and others have more than one type. The type of seizures a person has may change over time. In this information, the term 'seizure' could mean 'seizures' for people who have more than one type of seizure.

With increasing advances in technology, it is possible to give a cause of the epileptic seizures in a growing number of cases (for example, damage to the brain during a difficult birth, or a head injury). However, sometimes there is no known cause.

## **Treating epilepsy**

Some treatments may not be suitable for you, depending on your exact circumstances. If you have questions about specific treatments and options, please talk to a member of your healthcare team.

There are effective treatments that can prevent seizures happening. The type of treatment needed and how effective it is depends on the type of epilepsy, so it is important to accurately diagnose the type of seizure and the 'epilepsy syndrome'. Each epilepsy syndrome is defined by a particular combination of symptoms and signs, which includes the type of seizure, the age of the person when seizures start, and the results from examinations and tests. For more information see '[Treatment and care](#)'

## **After a first seizure**

If it is suspected that you have had a seizure, you should be assessed by a healthcare professional. This is likely to be a doctor at the hospital emergency department or it could be your GP. If they think that you may have had an epileptic seizure, you should be offered an urgent appointment with a specialist. An urgent appointment should take place within 2 weeks.

## **Specialists**

For an adult, the specialist should be a doctor with training and expertise in diagnosing and treating epilepsy.

For a child or young person, the specialist should be a doctor who treats and cares for children (a paediatrician) and who has also had special training in diagnosing and treating epilepsy.

While you are waiting for your appointment with the specialist, you and your family or carer should be given information about how to recognise a seizure and what to do if you have another one. This should include advice about first aid. You should be advised to contact a healthcare professional if you do have another seizure before you have been seen by a specialist.

## Seeing a specialist

When you see the specialist they should ask you, and anyone who was with you at the time, what happened when you had the seizure. Your description of what happened, and any information from witnesses, is really important, and will help the specialist to decide whether or not you may have had an epileptic seizure.

The specialist should also carry out a physical examination. This should include checks on your heart and brain. In children, the specialist may also check their development. They may also ask you to see professionals with training in other areas, such as a cardiologist (a doctor who specialises in heart problems), a psychiatrist or a clinical psychologist.

The specialist will use the information about what happened when you had the seizure and any other symptoms you have to determine whether you may have epilepsy. However, epilepsy can be difficult to diagnose, so the specialist may want to carry out some tests (see '[Tests](#)') or refer you to a specialist centre (see '[Referral to a specialist centre](#)') to confirm the diagnosis. Even if the specialist thinks it is unlikely that you have epilepsy, you should be offered another appointment to see how you are.

The specialist may also ask you or your family or carer to write down what happens before, during and after your seizure, and to keep a diary of when the seizures happen and what you were doing at the time. They may ask if it's possible to make a video recording of a seizure, so that they can watch it to help them find out what is causing your seizures.

## Tests

If the specialist thinks that you should have some tests they should discuss with you why you need them, what exactly will happen and what they are looking for. If the tests are for a child, they should be done in a child-friendly environment. Examples of some tests you may be offered are given below.

Once you have had the tests, the results should be explained fully to you.

## An EEG

EEG is short for 'electroencephalogram' and is also known as a brainwave test. It is a painless test that records the brain's electrical activity. You may be offered an EEG if the specialist thinks you have epilepsy because it may help to show whether your seizures are starting in the brain (meaning they are epileptic). However, you should not be offered this test if it is thought that you fainted or had a blackout rather than an epileptic seizure, because the EEG may give inaccurate results.

If you are offered an EEG, you should have the test within 4 weeks of the specialist requesting it.

Before you have an EEG the specialist should explain that flashing lights may be used to try to trigger abnormal electrical activity in your brain. It is possible that this could cause you to have a seizure, but only if you are sensitive to light, which is quite rare. If you decide you would prefer not to have the test you should be supported in this.

EEG results on their own are not accurate enough to show whether you have epilepsy or not – the specialist should use them along with your symptoms to help make a diagnosis. They may also help the specialist decide what type of seizure and epilepsy syndrome you have.

If after having an EEG it is still not clear whether you have epilepsy, or the type of epilepsy you have remains uncertain, you may be offered a repeat EEG. This should normally be done when you are either very tired or asleep (also called a sleep-deprived or sleep EEG) because it makes it easier to see any abnormal brain activity.

When a child or young person is going to have a sleep EEG, their parent or carer may be asked to change their child's normal sleep patterns so that they become extra tired. Or a substance called melatonin may be used to make them sleepy.

If a diagnosis still can't be made, you may be offered an 'ambulatory EEG' or an EEG combined with video recording. An ambulatory EEG uses small electrodes to measure your brain activity over several hours, days or weeks while you continue with your daily life. In a video EEG, you will be monitored in hospital for several days. If a seizure does occur it is recorded on video and used along with the EEG to help make a diagnosis.

## Neuroimaging

Neuroimaging means taking pictures of the brain. This is also called 'scanning'. It can help the specialist to see if a physical problem is causing your seizures.

You may not always need neuroimaging if you have been diagnosed with idiopathic generalised epilepsy. This is a type of epilepsy syndrome that is thought to have a genetic cause.

If you are offered neuroimaging, you should usually have a type of imaging test called an MRI, which uses magnetic fields to produce a picture of the brain. MRI is short for 'magnetic resonance imaging'. You should have this test within 4 weeks of the specialist requesting it. An MRI is particularly important if you are an adult when your epilepsy starts, if it looks like your seizures start in a specific part of the brain, or if your seizures continue after you have started taking medication. It is also important in children who develop epilepsy before they are 2 years old.

In some situations you may be offered a different imaging test called a CT scan, which uses X-rays to produce a picture of the brain. CT is short for 'computed tomography'. It may be offered if an MRI is not available or not suitable for you, or if information is needed quickly about whether your seizures are being caused by a brain injury or illness. CT scanning may also be more suitable for some children and young people who would need to have an anaesthetic to have an MRI but not for a CT scan.

## Other tests

You may be offered other tests to help confirm what is causing your seizures. These might include blood tests (and urine tests for children and young people), or a test on your heart called an ECG (which is short for 'electrocardiogram'). Depending on the results of your heart test you may be offered a referral to a cardiologist (a heart specialist).

## Questions you may want to ask about tests



- Please could you give me more details about the tests or investigations you think I should have?
- What can I expect when I have an EEG?
- What happens with a scan?
- Should I be having an ECG?
- What do these tests involve?
- Where will these be carried out? Will I need to have them in hospital?
- How long will I have to wait until I have these tests?
- How long will it take to get the results of these tests?

For some people with epilepsy it is important to assess learning disabilities, speech and memory (for example, if you are having difficulties at school or work, or if your memory isn't as good as it used to be). If this is the case, the specialist may offer to refer you to another healthcare professional for a 'neuropsychological assessment'.

## *After your diagnosis*

If you are diagnosed with epilepsy you should be given a chance to talk about your diagnosis and how you feel about it with a healthcare professional – this will most likely be your specialist. Your specialist should explain what type of seizures and epilepsy syndrome you have, their possible effects, and how they might change in the future. They should help you to decide on a plan to manage your condition, and should discuss with you the importance of learning skills to increase your confidence in living with epilepsy. They should also give you details about where to find more help and support.

## **Who will provide your care?**

When you are living with epilepsy you are likely to receive treatment and care from more than one healthcare professional. You should be given the name of one member of your healthcare team who is responsible for making sure you have all the information you need. This will usually be the healthcare professional you see most often, for example your GP or specialist. You should be

advised to register with a GP if you are not already registered, and you should be given details of how to contact a specialist service if you need to.

An epilepsy specialist nurse should also be involved in your care. These nurses are trained and have experience in caring for people with epilepsy. They can provide you and your family or carer with information about epilepsy, and they can make sure that you are getting the right help and support from other healthcare professionals. They can also provide a link between you and your specialist.

## Information about epilepsy

Your healthcare professional should offer you information about epilepsy in a format that you find useful. They should make sure you have relevant information when you need it (for example, before you make important decisions such as planning for a baby or decisions affecting your career or work). Every time you see your healthcare professional they should make time to check that you have all the information you need. They should use a checklist to make sure they cover everything you need to talk about.

You and your family or carer should be given information about:

- your diagnosis and treatment options available to you, including any possible side effects of medications
- what can trigger seizures and how to control or avoid them
- what's likely to happen in the future
- how to manage living safely with epilepsy, including advice about first aid
- psychological issues, such as depression and anxiety
- practical issues such as social security benefits, insurance issues, driving and road safety
- education and healthcare at school
- employment and independent living for adults
- the importance of telling an employer if you have epilepsy (contact support groups or charities if further information is needed)

- reducing the risk of sudden death caused by epilepsy (this is sometimes referred to as SUDEP, which stands for sudden unexpected death in epilepsy; see '[Sudden unexpected death in epilepsy](#)')
- status epilepticus (see '[If you have status epilepticus](#)')
- how epilepsy can be affected by, and can affect, your lifestyle (for example, the use of illegal drugs, alcohol, sexual activity and the effects of not getting enough sleep)
- family planning and pregnancy
- local and national support groups and charities, and how to contact them.

## Questions you may want to ask

- Does having sex increase my chance of having a fit?
- Is there some written information (like a leaflet) about epilepsy that I can have?
- Can you tell me about any support groups in the area?

## Children and young people

Children and young people with epilepsy should be offered special activities tailored to their age to help them learn to manage their condition. There should also be arrangements in place for when young people make the move to adult services (see '[Special considerations for young people](#)').

## People at risk of seizures

If you have never had a seizure but you have had a severe brain injury, you have a strong family history of epilepsy or you have learning difficulties, you are at risk of developing seizures. You should be given information about epilepsy and the possibility of having seizures as soon as possible (that is, before you have any seizures).

## Treatment and care

### *Agreeing an epilepsy care plan*

Once your condition is diagnosed your healthcare professional should discuss with you possible options for your treatment and care. They should agree an epilepsy care plan with you, your family or carer, your GP and your specialist. It should cover your treatment, what to do if you have another seizure or the treatment doesn't work, and any preferences and lifestyle issues you have discussed.

### *Starting on epilepsy medication*

You should only be offered medication for epilepsy after your diagnosis has been confirmed and if medication has been recommended by a specialist. Your specialist should have a full discussion with you about all your treatment options before you consider taking medication for epilepsy. The decision whether or not to take medication for your epilepsy should be made jointly by you (and your family or carer if appropriate) and your specialist, after the specialist has explained to you the risks and benefits of epilepsy medication, including the possible side effects of different medications and which would be most suitable for you.

Your specialist should explain that medication is usually an option once you have had two epileptic seizures. However, there are some circumstances when it may be started earlier; your specialist should discuss these with you.

### **Choice of medication**

There are many drugs available for treating epilepsy. The one that you are offered will depend partly on your seizure type and epilepsy syndrome. Some drugs for treating epilepsy are not suitable for everyone. Your specialist should talk to you about which one might be best for you. If you want to find out more about the drugs that you may be offered, the versions of this guidance for healthcare professionals (such as the NICE guideline or the epilepsy pathway) contain more detailed information and are available at [www.nice.org.uk/guidance/CG137](http://www.nice.org.uk/guidance/CG137).

Usually you will start treatment with just one epilepsy drug. This is known as monotherapy. You should be advised to keep to the same brand and not to change from one form of the drug to another, for example, changing from tablets to a liquid. This is because different preparations may work slightly differently in the body and may not control the seizures as well or may increase the side effects.

## *If the first drug for treating your epilepsy doesn't help*

If the first drug you try doesn't control your seizures or you have side effects, you should normally be offered another drug. Your specialist should help you to switch gradually from one drug to the other. There should be a short period when you are taking both of the drugs.

If the second drug you try isn't helpful, then the dose of either the first or second drug should be gradually reduced, as outlined above, before another drug is tried. Which of the medicines to stop will depend on how well each one has worked and what side effects it has had.

If using just one drug doesn't control your seizures, your specialist may suggest taking another one at the same time. This is known as combination therapy, or sometimes adjunctive or add-on therapy or polytherapy.

If combination therapy doesn't control your seizures, you and your specialist should discuss which drugs and combinations have helped most with the seizures and caused the fewest side effects. The drug or combination that has been best is usually the one to carry on with. If you have certain types of epilepsy seizures or syndromes, and combination therapy has not worked well or you had a bad reaction to the drugs, you may be offered a referral to a specialist centre (see '[Referral to a specialist centre](#)') to discuss other drugs you could try.

If you are still having seizures even though you are taking the most appropriate drug for you, your diagnosis should be reviewed. This may mean that you are offered more tests or referral to a specialist centre (see '[Referral to a specialist centre](#)').

## *Continuing your medication*

If you are taking medication for epilepsy it is likely that you will need to take it for several years. Your specialist should discuss this with you, including the possible side effects of taking your medication and what you should do if your seizures continue. These discussions should be included in your epilepsy care plan. If you are having no problems managing your epilepsy you should usually be able to get your prescription for your medication from your GP.

## *Taking your medication regularly*

For epilepsy drugs to work best they need to be taken regularly. Your healthcare professional should make this as easy as possible, for example, by keeping your schedule for taking your

medication as simple as possible so that you are less likely to forget a dose. You should also be given information about what to do if you miss a dose or have sickness or diarrhoea.

## Blood tests

You should not usually be asked to have blood tests when you are taking medication for epilepsy. However, sometimes blood tests may need to be done to check how certain types of drugs for epilepsy are working. You may also need blood tests if you are taking medication for something other than epilepsy in case the different types of drugs don't work well together. Other reasons for blood tests include certain situations in pregnancy, concern that one of the body's organs is not working properly, or status epilepticus (see '[If you have status epilepticus](#)').

For a child, blood tests should only be done if they're recommended by a specialist.

## *Stopping medication*

If you haven't had a seizure for at least 2 years, your specialist should discuss with you the risks and benefits of continuing with your medication, or slowly stopping some or all of the drugs you are taking. Your specialist should discuss with you the possible impact of stopping treatment on the likelihood of having seizures and on your daily life before you make your decision.

If you decide to stop your medication, this should be done slowly over a period of at least 2–3 months, and a specialist should be involved. If two or more drugs are being taken, only one should be stopped at a time.

Before stopping your medication, you and your specialist should agree a plan about what should happen if your seizures start again. This should include going back to the dose level you were taking just before your seizures started again and contacting your healthcare professional.

## *Referral to a specialist centre*

### Referral for children, young people and adults

In some circumstances you may be offered a referral to a team of healthcare professionals in a specialist centre. This is also known as a 'tertiary centre' or 'tertiary service'.

The team of healthcare professionals who work at the specialist centre should be experienced in assessing people with epilepsy that is hard to treat or complicated for other reasons. The team should include people with different types of training and experience, from psychology (assessing

and helping with behaviour) to occupational therapy (helping people to carry out activities in everyday living). It should include specialist nurses, and doctors who have specialised in treating conditions involving the brain with medication (a neurologist) and with surgery (a neurosurgeon).

You should be referred to a specialist centre (and seen within 4 weeks) if:

- there is uncertainty about the type of epilepsy syndrome or seizures you have
- your seizures are not controlled with drugs within 2 years of starting them
- you have tried two different types of drugs but these have not worked
- you are having, or are at risk of, severe side effects from medication
- you have a psychological or psychiatric condition (one affecting your behaviour or your mind), or
- there is an abnormality affecting the structure of part of your brain.

If you lose skills you had earlier (for example, a child loses the ability to talk or walk) or you develop behavioural problems, your specialist should refer you immediately to a specialist centre.

You should be referred to a specialist centre if your specialist thinks it is necessary, even if the results of the tests you have had previously are normal.

You should also be referred if you are diagnosed with a particular type of epilepsy syndrome, such as Sturge–Weber syndrome, Rasmussen's encephalitis, the hemispheric syndromes or hypothalamic hamartoma. (The organisations listed in '[More information](#)' may provide information on different types of epilepsy syndromes.)

## Referral for children and young people

In addition to the above, it is very important that children who are suspected of having developed epilepsy in the first few years of life (particularly those under 2 years old) are referred to a specialist centre as soon as possible so that they can be diagnosed and, if necessary, treated to prevent seizures from affecting their development.

If a child or young person has a certain type of epilepsy syndrome, they may also be referred to a specialist centre. For example, if an infant has infantile spasms, or a child is suspected of having Dravet syndrome or Lennox–Gastaut syndrome, they may be referred to a specialist centre to see a

tertiary paediatric epilepsy specialist. This is a doctor who specialises in treating children and also specialises in treating epilepsy. If a child or young person has been diagnosed with an epilepsy syndrome such as continuous spike and wave during slow sleep, Landau-Kleffner syndrome or myoclonic-astatic epilepsy, they should also be referred to a specialist centre. (The organisations listed in '[More information](#)' may provide information on different types of epilepsy syndromes.)

## *Other ways of treating epilepsy*

### **Relaxation, cognitive behavioural therapy and biofeedback**

If your seizures aren't being controlled well by medication, other approaches can be tried. Some people find it useful to learn ways of relaxing or of controlling negative thoughts and their responses to them (this is called 'cognitive behavioural therapy' or CBT). Another technique is 'biofeedback', which involves learning ways of changing the brain activity. These approaches don't replace medication, but they can be tried as an extra option.

Learning techniques (such as relaxation or CBT) may also be tried for a child if they have focal epilepsy (which means that the abnormal electrical activity is happening in a particular area of the brain) and medication on its own hasn't helped.

### **The ketogenic diet**

The ketogenic diet is a special diet that is high in fat and low in carbohydrates. If seizures in a child or young person are not being controlled by medication, the child or young person may be offered a referral to a specialist centre to see a tertiary paediatric epilepsy specialist to discuss trying this diet. This is a doctor who specialises in treating children and also specialises in treating epilepsy. See '[Referral to a specialist centre](#)' for more information on referral to a specialist centre.

### **Brain surgery**

If epilepsy has been very difficult to control with medication, brain surgery may be considered for some people.

There are many different tests you might be asked to have before you are offered brain surgery. The tests are carried out at a specialist centre (see '[Referral to a specialist centre](#)') and will help to find out whether brain surgery would reduce or stop your seizures without causing any new problems.



If the tests show that brain surgery might help, you and your family or carers should have the reasons for this explained to you, and you should have the chance to discuss these with a healthcare professional. The possible risks and benefits of the surgery should be explained in detail before you decide whether or not to have it. If you were to have surgery, this would be carried out by surgeons working in a specialist centre (see '[Referral to a specialist centre](#)').

## Vagus nerve stimulation

Vagus nerve stimulation involves having a small generator implanted into the chest. The generator stimulates the left vagus nerve, which is one of the main nerves in the body. The stimulation travels up the vagus nerve and into the areas of the brain where the seizures might begin. Vagus nerve stimulation can reduce seizures in some people. If medication hasn't worked and surgery isn't an option, you may be offered this procedure.

## Regular reviews

You should have regular reviews of your epilepsy and treatment. Usually this is done with your GP, although you may prefer or need to have the review with your specialist.

Children and young people should have their review with a specialist. The specialist should be a doctor who treats and cares for children (a paediatrician) and who has also had special training in diagnosing and treating epilepsy.

You should have a review at least once a year (in children and young people, it may take place as often as once every 3 months). Reviews can take place more often if you prefer or if your epilepsy needs closer attention.

If you continue to have seizures, have side effects from your medication, or need specialist advice (for example, you are a woman and are planning a pregnancy), you should be able to see a specialist or be referred to a specialist centre (see '[Referral to a specialist centre](#)').

## *What your reviews should cover*

At your reviews the healthcare professional should ask whether you are having seizures, how you are getting on with your treatment, and whether you are having side effects or any difficulties taking your medication (for example, remembering when to take it). If there are any problems, they should discuss your treatment plan with you and whether changing medication might help.

During your review you should be offered information about epilepsy (see '[After your diagnosis](#)') and about voluntary organisations that may be of help to you (for example, organisations that can provide you with more information about epilepsy, or support groups). You should also be offered:

- an opportunity to see an epilepsy specialist nurse
- access to counselling services
- further tests or investigations if you need them
- referral to a specialist centre if needed.

## Special considerations for certain groups

Epilepsy is a condition that can affect anyone. Whoever you are, and whatever your age, you can expect the same level of care as everyone else with epilepsy. This includes the standard of treatment, access to specialist services and provision of information, all of which should be available at a time and in a way that is appropriate to you as an individual.

### *Special considerations for women and girls*

Women and girls with epilepsy need particular information and support to make informed decisions about their care. All healthcare professionals who treat or support women and girls with epilepsy should be familiar with the issues affecting them and the information available in these areas. They should be able to put women and girls in contact with counselling services if this is necessary.

Women and girls with epilepsy (and their partners, if appropriate) should be offered relevant information and counselling about how epilepsy and epilepsy medication may affect contraception, becoming pregnant, the pregnancy itself, breastfeeding, caring for children, and the menopause. This information should be tailored to each woman or girl's needs and should be offered before they become sexually active, become pregnant or reach the menopause.

If it's needed, the information should also be passed on to people who are close to the woman or girl; this may include her family or parent or carer.

## Contraception

Taking contraceptives and epilepsy medication at the same time can cause either of these to be less effective. A woman's healthcare professional should discuss this with her, and the different forms

of contraception and options available to her. This discussion should also take place with girls who may need to carry on taking medication as they get older and become sexually active.

## **Folic acid supplements**

If there's a chance that a woman or girl taking epilepsy medication could become pregnant, she should be offered a daily supplement of folic acid (5 mg per day). This is because some drugs used to treat epilepsy can damage a developing baby and taking folic acid is thought to help stop this from happening.

## **Information about the chances of having a child with epilepsy**

Epilepsy can be passed on in the genes from a parent to their child. The risk of this happening is small overall, but will depend on both parents' family history. An appointment with a 'genetic counsellor' may be offered if one parent has epilepsy, particularly if they have epilepsy that is thought to have a genetic cause or they have a family history of epilepsy. Discussions with a genetic counsellor can help people make decisions about their individual risk of having a child with epilepsy.

## **Pregnancy**

The UK Epilepsy and Pregnancy Register has been set up to collect information about how epilepsy and epilepsy medication can affect pregnancy, labour and the baby. The more women who join it, the more useful the results will be. So all pregnant women and girls with epilepsy are encouraged to put their details on the register or to let a healthcare professional do it for them (see [www.epilepsyandpregnancy.co.uk](http://www.epilepsyandpregnancy.co.uk)).

Most women and girls with epilepsy have healthy pregnancies, but complications in pregnancy and labour are more common than in those who don't have epilepsy. For the best possible care, a woman or girl with epilepsy should receive care during her pregnancy from both her epilepsy specialist and an obstetrician (a doctor who specialises in pregnancy and childbirth).

It is important to try to make sure that a woman or girl with epilepsy does not have seizures while she is pregnant or when she is trying to get pregnant. Generally, the number of seizures doesn't tend to go up during pregnancy or in the first few months after the birth. The healthcare professional should discuss with the woman or girl the type of epilepsy that she has, the risk of having seizures during pregnancy, and what effect having a seizure would have on her and her unborn baby.

However, if the woman or girl wants to reduce or stop taking medication when she is pregnant, the risks and benefits of doing this should be discussed with her. She should be told about her risk of status epilepticus (see '[If you have status epilepticus](#)') and of unexpected death (see '[Sudden unexpected death in epilepsy \(SUDEP\)](#)'). Where appropriate, her specialist should be consulted before the woman or girl and her GP make decisions about medication.

## Tests during pregnancy

Normally blood levels of epilepsy medication don't need to be checked during pregnancy. But if seizures happen more often or it seems likely that this will happen, then it may be useful to keep a check on levels of medication in case the dosage needs changing.

If a woman or girl is taking epilepsy medication, she should be offered an ultrasound scan at 18–20 weeks to check that the baby has developed as expected (this is called the anomaly scan). Earlier scanning may be offered to allow any major deformities to be detected sooner.

## The labour and birth

Because there is a small risk of having a seizure during labour, women and girls are recommended to give birth in a maternity unit with procedures and facilities in place to care for those with epilepsy.

If a mother is taking an enzyme-inducing form of epilepsy medication, she should be advised that her baby should have a vitamin K injection at birth.

## Breastfeeding

Mothers who have epilepsy should be encouraged to breastfeed, however they should be supported in their choice of how to feed their baby. Healthcare professionals should discuss with the mother any potential risks associated with taking epilepsy medication while breastfeeding and how these balance against the benefits of breastfeeding so that she can make a decision that suits her and her baby.

## Caring for the baby

Parents can take some simple steps to reduce the risk of accidents or injuries to the baby or mother if the mother has a seizure. A healthcare professional should provide information on these to parents during the pregnancy.

## *Special considerations for people with learning disabilities*

Epilepsy is common in people with learning disabilities, and people with learning disabilities and epilepsy should receive the same standard of care as those without learning disabilities. People who have epilepsy and a learning disability have a higher risk of unexpected death (see '[Sudden unexpected death in epilepsy \(SUDEP\)](#)') or of dying from an accident or injury. Healthcare professionals should discuss these risks with them and their advocates, family or carers. Potential safety problems should also be assessed (see 'Checking the effect of the epilepsy' below).

### **Diagnosing epilepsy**

Epilepsy can be difficult to diagnose in a person with learning disabilities. When assessing a person with learning disabilities, the specialist should make sure that they take a full medical history. They should also ask any witnesses what happened during the person's seizure, and if possible get other information about the seizure such as a video recording, to help them with the diagnosis. When necessary, healthcare professionals should provide information and advice to help people to describe clearly and accurately what they see happening when a person is having a seizure.

For children and young people with a learning disability, investigations should be carried out to try to find out the cause of the epilepsy.

If needed, the person with learning disabilities should be referred for a neuropsychological assessment.

### **Help during the tests**

A person with learning disabilities may need particular care and attention while they're having some of the tests for epilepsy. For example, it might be necessary to give a person an anaesthetic before an MRI scan to help ensure they stay still during the scan.

### **Epilepsy care plan**

Healthcare professionals should encourage, support and work with the person with learning disabilities, and their advocate, family or carers, to develop an epilepsy care plan. They should make sure there is enough time during appointments to help with this.

A person with epilepsy and learning disabilities should have access to the same treatments and care as any other person with epilepsy. However, some epilepsy medication may affect the behaviour or

memory of a person with learning disabilities, and this should be considered when decisions are being made about which medication to try as part of the epilepsy care plan.

## Checking the effect of the epilepsy

The combination of learning disabilities and epilepsy can present some potential safety problems which need to be thought about. Healthcare professionals should assess how safe a person with learning disabilities is likely to be if they have a seizure at certain times, for example, while having a bath or a shower, preparing food or using electrical equipment.

They should also assess:

- what might happen if the person had a long seizure or repeated seizures (for example, would there be someone around to help?)
- what effects there might be if the person has a seizure when they are out or with other people
- the risk of unexpected death (see '[Sudden unexpected death in epilepsy \(SUDEP\)](#)'), and
- whether the person's living arrangements are suitable for their circumstances (for example, if they live on their own).

## *Special considerations for young people*

Healthcare professionals should be aware of the different ways that having epilepsy can affect a young person's life. They should also know that good relationships with family and friends and at school can help a young person deal with their epilepsy. Healthcare professionals should consider these issues when they're talking to a young person about their epilepsy, and when they are offering treatment and support.

Healthcare professionals should ensure that they encourage young people with epilepsy to be fully involved in discussions and decisions about treatments and ways of managing their seizures. They should listen to the young person's wishes and beliefs (and, if appropriate, those of their family or carers) and should take these into account during these discussions.

## Reviewing the diagnosis and treatment

As they get older and start to move towards or into their teenage years, young people should have their diagnosis and treatment looked at again. This is to make sure that they're still getting the care that's most suited to them.

## Changing over to adult care

The arrangements for care of adults with epilepsy are different from those for children and young people. It's important that the changeover is handled smoothly and that the young person is given help and support. For example, a young person should have one doctor in their teenage years who they can get to know, and who should help them as they change over to the adult service.

Before a young person moves to the adult service, they should have a review of their diagnosis and treatment. They should also be given up-to-date information on support groups and charities and help to contact them.

## *Special considerations for older people*

Older people with epilepsy should receive the same standard of care as other people with epilepsy. When agreeing an epilepsy care plan with an older person with epilepsy, healthcare professionals should also take into account:

- any other conditions the person may have
- possible reactions between epilepsy drugs they may offer and any other medication the person may be taking, and
- how taking multiple drugs may affect the person.

## *Special considerations for people from black and minority ethnic groups*

People from black and minority ethnic groups may have different cultural and communication needs which should be considered during diagnosis and management. An interpreter may be needed or other means of ensuring that a person's needs are appropriately met.

If an interpreter is needed, they should have both cultural and medical knowledge so that they can translate any information accurately. Interpreters from the family are generally not suitable because of issues such as confidentiality, privacy and personal dignity.

Information (see '[After your diagnosis](#)'), including information about employment rights and driving, should be available in an appropriate format or through other appropriate means for people who do not speak or read English.

## Care in particular situations

### *Long or repeated seizures away from a hospital*

The box below describes the emergency care and treatment you should receive if you have a convulsive seizure (jerking movements made by the body during a seizure) that lasts for 5 minutes or more, or if you have 3 or more seizures in an hour.

### **Emergency care and treatment you should receive if your convulsive seizure lasts for 5 or more minutes or you have 3 or more seizures in an hour**

- A trained healthcare professional should give you the emergency medication that is most appropriate for you. However, you may have agreed beforehand which emergency medication should be used as part of your epilepsy care plan. If it has been agreed that a family member or a carer will give you the medication, they should have been trained to do this.
- A drug called midazolam may be placed in your mouth to control your seizures quickly. In some circumstances another drug called diazepam may be given to you rectally (into the bottom), or a drug called lorazepam may be given to you through a tube into your vein.
- It may be necessary to call an ambulance, depending on the circumstances and how you respond to the emergency medication. In particular, an ambulance may be needed if:
  - it's the first time you have needed emergency medication (as described above)
  - your seizures continue for more than 5 minutes after receiving emergency medication
  - you have a history of repeated or prolonged seizures that happen frequently, or
  - there is concern or difficulty checking your breathing and other vital signs.



## *If you have status epilepticus*

A prolonged seizure or series of seizures when the person does not regain consciousness for 30 minutes or more is called 'status epilepticus'. Status epilepticus can occur with any type of seizure but if it occurs with convulsions ('convulsive status epilepticus') it is a medical emergency.

If you have convulsive status epilepticus then you will be treated in hospital. Healthcare professionals in the hospital should make sure that you can breathe properly, and should check that your heart is beating normally. You should also be given some oxygen and have your blood glucose levels checked. You should also be given some medication to try to stop your seizures.

## **If you keep going into status epilepticus**

If you frequently go into status epilepticus, you and your specialist should discuss and draw up an individual treatment plan of what to do when this happens.

## **If there are no convulsions**

Very occasionally someone can go into status epilepticus without convulsions. This isn't such a medical emergency. Medical advice should be sought but an ambulance is not usually needed.

## **Sudden unexpected death in epilepsy (SUDEP)**

If a person with epilepsy dies suddenly and no obvious reason can be found after a post-mortem examination has been carried out, it's called sudden unexpected death in epilepsy (or SUDEP for short). Although it's rare, it does happen.

Healthcare professionals should give you and your family or carers information about SUDEP and should discuss with you your individual risk of SUDEP and how to reduce this risk.

## *If a person has died unexpectedly*

If a member of your family, or someone you care for, with epilepsy has died unexpectedly, healthcare professionals should contact you so that you can talk about the death. They should also offer to help you contact a SUDEP support group or bereavement counsellors.

## More information

The organisations below can provide more information and support for people with epilepsy. NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- Dravet Syndrome UK, 07775 347234, [www.dravet.org.uk](http://www.dravet.org.uk)
- Epilepsy Action, 0808 800 5050, [www.epilepsy.org.uk](http://www.epilepsy.org.uk)
- Epilepsy Bereaved, 01235 772852, [www.sudep.org](http://www.sudep.org)
- Epilepsy Research UK, 020 8747 5024, [www.epilepsyresearch.org.uk](http://www.epilepsyresearch.org.uk)
- Epilepsy Society, 01494 601400, [www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)
- Friends of Landau Kleffner Syndrome (FOLKS), [www.friendsoflks.com](http://www.friendsoflks.com)
- Matthew's Friends – Dietary Treatments for Epilepsy, 01342 836571 or 07884 054811, [www.matthewsfriends.org](http://www.matthewsfriends.org)
- Young Epilepsy, 01342 831342, [www.youngepilepsy.org.uk](http://www.youngepilepsy.org.uk)
- Joint Epilepsy Council, [www.jointepilepsycouncil.org.uk](http://www.jointepilepsycouncil.org.uk)

You can also go to NHS Choices ([www.nhs.uk](http://www.nhs.uk)) for more information.

## Changes after publication

October 2015: Minor maintenance.

## Accreditation

