

The diagnosis and care of children and adults with epilepsy

Understanding NICE guidance –
information for people with epilepsy, their families
and carers, and the public

October 2004



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Information about NICE Clinical Guideline 20

The diagnosis and care of children and adults with epilepsy
Understanding NICE guidance – information for people with epilepsy, their families and carers, and the public

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About this information

This information describes the guidance that the National Institute for Clinical Excellence (called NICE for short) has issued to the NHS on epilepsy. It is based on 'The epilepsies: diagnosis and management of the epilepsies in adults and children in primary and secondary care' (NICE Clinical Guideline no. 20), which is a clinical guideline produced by NICE for doctors, nurses, and others working in the NHS in England and Wales. (See page 10 for an explanation of why the NICE guideline uses the term 'epilepsies'.) This booklet has been written chiefly for people with epilepsy, or who are concerned that they may have epilepsy. It may also be useful for relatives and carers of people with epilepsy, and anyone with an interest in epilepsy or in healthcare in general.

There is a list at the back of this booklet that explains some of the words used.

Clinical guidelines

Clinical guidelines are recommendations for good practice. The recommendations in NICE guidelines are prepared by groups of health professionals, lay representatives with experience or knowledge of the condition being

discussed, and scientists. The groups look at the evidence available on the best way of treating or managing a condition and make recommendations based on this evidence.

There is more about NICE and the way that the NICE guidelines are developed on the NICE website (www.nice.org.uk). The booklet 'The Guideline Development Process – An Overview for Stakeholders, the Public and the NHS' can be downloaded from the website, or a copy can be ordered by phoning 0870 1555 455 and quoting reference number N0472.

What the recommendations cover

NICE clinical guidelines can look at different areas of diagnosis, treatment, care, self-help or a combination of these. The areas that a guideline covers depend on the topic.

The recommendations in 'The epilepsies: diagnosis and management of the epilepsies in adults and children in primary and secondary care', which are described here, cover the diagnosis, treatment and management of epilepsy in children, young people, adults and older people. The guideline makes recommendations for treatment and care provided by GPs and by specialists. (See page 13 for more information about specialists.) It also

makes recommendations about when someone should be referred to a specialist centre (a clinic or unit with particular experience and expertise in investigations or treatment of epilepsy that is difficult to diagnose or treat – sometimes called a tertiary centre).

Special considerations concerning the care of women with epilepsy and people with learning disabilities are covered.

The NICE guideline does not cover 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.

The information that follows tells you what the NICE guideline on epilepsy says. It doesn't attempt to explain epilepsy or the treatments in detail. If you want to find out more about epilepsy, the NHS Direct website may be a good starting point (www.nhsdirect.nhs.uk) or you can phone NHS Direct on 0845 46 47.

How guidelines are used in the NHS

In general, health workers in the NHS are expected to follow NICE's clinical guidelines. But there will be times when the recommendations

won't be suitable for someone because of his or her specific medical condition, general health, wishes or a combination of these.

If you think that the treatment or care you receive does not match the treatment or care described in the pages that follow, you should talk to your doctor or nurse.

Different versions of the guideline

There are five published versions of this guideline:

- this one
- the NICE guideline, 'The epilepsies: diagnosis and management of the epilepsies in children and adults in primary and secondary care', which includes all the recommendations
- two quick reference guides, which are summaries of the main points in the NICE guideline; NICE has sent copies of the quick reference guides to doctors and other people working in the NHS (there is one quick reference guide covering the care of adults with epilepsy and one covering the care of children with epilepsy)
- the full guideline, which contains all the details of the guideline recommendations and how they were developed.

All versions of the guideline are available from the NICE website (www.nice.org.uk). This version and the quick reference guides are also available from the NHS Response Line – phone 0870 1555 455 and give the reference numbers of the booklets you want (N0741 for this version, N0742 for this version in English and Welsh, N0739 for the 'adults' quick reference guide and N0740 for the 'children's' quick reference guide).

Epilepsy

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 disrupted 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. The seizure is a symptom of the disrupted electrical activity in the brain.

Having one seizure does not necessarily mean that someone has epilepsy. Many people have a

'one-off' seizure, but this is not epilepsy. People with epilepsy have **recurrent** seizures.

'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 and 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 seizure. The two main types of seizure are 'generalised seizures' and 'partial seizures'.

Generalised seizures occur as a result of disruption of electrical activity affecting **all** of the brain. There are different types of generalised seizure, the most recognised of which is the 'tonic-clonic seizure' (convulsions). During a generalised seizure, the person loses consciousness.

Partial seizures occur as a result of disruption of electrical activity starting in or involving **part** of the brain. These seizures are sometimes known as 'focal seizures'. The symptoms depend on the

part of the brain that is affected. A simple partial seizure does not affect consciousness and the symptoms may include rhythmical twitching of a limb, pins and needles in one part of the body, or disturbances to hearing, vision, smell or taste. A complex partial seizure does affect consciousness and the symptoms may include plucking at clothes, smacking lips, swallowing repeatedly or wandering around.

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 booklet, the term 'seizure' could mean 'seizures' for people who have more than one type of seizure.

Sometimes it's possible to find a cause of the epileptic seizures (for example, damage to the brain during a difficult birth, or a head injury): this type of epilepsy is called 'symptomatic epilepsy'. Sometimes there is no known cause for the seizures: this type of epilepsy is called 'idiopathic epilepsy'. When it is suspected that there is a cause but that cause is not as yet known, a person may be told they have 'cryptogenic epilepsy'.

Treating epilepsy

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'. An 'epilepsy syndrome' is defined by a unique 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.

Involving people in decisions about their health

One important recommendation of the NICE guideline is that all decisions about tests, treatments and care for a person's epilepsy should be made jointly by the person with epilepsy, and their family or carers as appropriate, and the doctor or other healthcare professional. The person's needs, wishes and concerns need to be talked through and taken into account, and information should be provided to help the person understand their position and the choices they have. (See pages 25–28 for more about information that should be provided.)

Good healthcare is a partnership between those who need treatment and the healthcare professionals who provide it.

After a first seizure

If a person goes into an A&E department

If a person goes into a hospital accident and emergency (A&E) department because they've had what could have been a seizure, they should see a doctor who can assess whether or not it might have been an epileptic seizure. A&E departments should have a protocol (a set of rules) that says how this assessment should be done.

If the doctor thinks that epilepsy is a possibility, the person should be offered an appointment with a specialist (see the box below) urgently. (The NICE guideline suggests that 'urgent' means being seen within 2 weeks.)

Specialists

For an **adult** (someone aged 18 or older), the specialist should be a doctor with training and expertise in the diagnosis, management and treatment of epilepsy. The specialist is usually based in or associated with a local hospital or clinic.

For a **child**, the specialist should be a doctor who

treats and cares for children (a paediatrician) who has had special training in the diagnosis, management and treatment of epilepsy.

In other situations

If a GP sees a person and it seems that they may have had an epileptic seizure, the GP should arrange an appointment with a specialist urgently. (The NICE guideline suggests that this means being seen within 2 weeks.)

Information that should be provided

If a person has had a possible epileptic seizure, they and their family or carers should be given information about how to recognise another seizure and what to do if one happens (including first aid information). Someone who has had a possible epileptic seizure should know that it's important to see their doctor if they have another seizure so that investigations can be carried out.

Seeing a specialist

The specialist should talk to the person (or their family or carers) about what happened when they had the seizure. It will be very helpful if the specialist can speak to someone who witnessed the event, because the person who had the seizure may not remember what happened.

The specialist should ask about previous illnesses or accidents and whether the person is taking any medicines.

The person should also have a physical examination. This will include checks on the heart and brain. The specialist may also ask the person to see professionals with training in other areas, such as a cardiologist (a doctor who has specialised in heart problems) or a clinical psychologist.

Making a diagnosis

Epilepsy can be very difficult to diagnose. Making a proper diagnosis means finding out whether the person has had an epileptic seizure (a seizure that starts in the brain) and if so, classifying the type of seizure(s) and epilepsy syndrome so that the right treatment can be offered.

Epilepsy should be diagnosed on the basis of the details of what happened when the person had the seizure plus information about the person's symptoms and the test results.

If there's any doubt about the diagnosis, the specialist should carry on with further tests, rather than make the wrong diagnosis. Sometimes it may be necessary for someone to go for further tests at a specialist centre.

Once treatment has been started (see page 29), if seizures still happen even with the most appropriate medicine, the diagnosis should be reconsidered. This may mean that further investigations are recommended or referral to a specialist centre.

Information that can help

To help with the diagnosis, the specialist may ask the person or their family or carers to write down what happens before and during a seizure and to keep a diary of when the seizures happen and what they were doing at the time. They may ask if it's possible to make a video recording of a seizure, so that the specialist can see it.

Tests

Some tests may be needed to help make an accurate diagnosis. Before agreeing to a test, a person will need an explanation of:

- why it's being done and what it's hoped to find out
- how and where the test will be carried out.

If the test or tests are for a child, they should be done in a child-friendly environment.

After the test, the results and what they mean should be explained to the person who has had the seizure and their family and/or carers, as appropriate.

An EEG

An EEG is a painless test that records the brain's

electrical activity (EEG stands for electro-encephalogram). It may show disrupted or abnormal patterns of electrical activity in the brain that indicate that the seizures are starting in the brain, in which case they would be epileptic seizures.

An EEG can only give information about the electrical activity that's going on in the brain at the time of the test. An EEG may show abnormal patterns of brain activity in some people who don't have epilepsy, while some people who have epilepsy have a normal or negative result from the EEG if they don't have a seizure while it's being carried out. So the EEG results on their own aren't enough to say definitely that a person has or hasn't got epilepsy. But they can sometimes provide very useful information. For example, the EEG results may help the specialist to identify which type of seizure and epilepsy syndrome the person has.

An EEG should not be carried out if it is thought that someone fainted or had a blackout rather than had an epileptic seizure, because the EEG may give inaccurate results.

If a person is going to have an EEG, it should be done 'soon', which the NICE guideline suggests should be within 4 weeks of its being requested by the specialist.

For a standard EEG, a person may have to breathe heavily (hyperventilate), and flashing lights may be used to try to trigger the abnormal electrical activity in the brain.

If someone is going to have an EEG, the possible effects of having a seizure during the EEG should be discussed with them and their family or carers beforehand. They can decide not to have the test if they prefer.

If a clear diagnosis can't be made after a standard EEG, further EEGs may be needed. The repeat EEG may normally be done when the person is very tired or is asleep (it's called a sleep-deprived or sleep EEG), because it is easier to see the abnormal brain activity then. When a child is going to have a sleep EEG, the parent or carer may be asked to change the child's normal sleep patterns so that they become extra tired. Or a substance called melatonin may be used to make the child sleepy. (Melatonin is not currently licensed for use in the UK.)

If it is especially difficult to make a diagnosis, the specialist may offer the person an 'ambulatory EEG' or an EEG combined with video recording (this is called 'video telemetry').

An ambulatory EEG allows brain activity to be recorded for several hours, days or weeks. For an ambulatory EEG, small electrodes are attached to

the scalp, under the hair, and are connected by wires to a small device, similar to a personal stereo, which is worn on a belt around the waist. This allows the person to move around and continue with most daily activities while the recording is made.

For EEG and video recording (video telemetry) the person will usually need to be admitted to hospital so that they can be constantly monitored for several days. If a seizure does occur, then there is both a video record of the event and an EEG record of the electrical activity in the brain and these can help in making a diagnosis.

Neuroimaging

Taking pictures of the brain using techniques known as neuroimaging (also called 'scanning') can help the specialist to identify physical reasons that can cause seizures.

Neuroimaging should not usually be carried out for a person who has already been diagnosed with idiopathic generalised epilepsy (see pages 10–11).

The two main imaging tests that can be used are MRI (which stands for magnetic resonance imaging) and CT scanning (CT stands for computed tomography).

MRI should be the usual choice for neuroimaging, and it's especially important if one of the following applies:

- a child under 2 years has started to have epileptic seizures
- an adult has recently developed epilepsy
- the abnormal electrical activity related to the seizure is thought to start in a particular part of the brain
- the seizures still happen even though the person is taking epilepsy medication.

If a person is going to have MRI, it should be done 'soon', which the NICE guideline suggests should be within 4 weeks of its being requested by the specialist.

CT scans are another form of neuroimaging. The information from a CT scan isn't quite as useful as that from MRI, but it can be helpful if MRI is not available or the person can't have MRI for some reason. A CT scan should be used for a child who would need general anaesthesia or sedation for the MRI, but not for the CT scan (sedation involves giving the child something to make them sleepy and more relaxed).

A CT scan may also be used if a doctor needs information quickly about whether a seizure might have been caused by a brain injury or

illness, so that they can give appropriate urgent treatment.

Other tests

Blood tests (and urine tests for children) should be considered if they might provide useful information about what's causing seizures or about other medical problems that might need to be taken into consideration.

If an adult is thought to have epilepsy, they should be offered a test on their heart called an ECG, to check if heart problems may be responsible for some of their symptoms. An ECG may be offered for a child if the specialist is unsure about the diagnosis of epilepsy. If there are concerns about the results of the ECG or the diagnosis of epilepsy is uncertain, the person should be offered referral to a cardiologist (a heart specialist).

For some people with epilepsy, it's important to assess learning disabilities, speech and memory. When this is the case, the specialist should consider referring them to another healthcare professional for further investigations called a 'neuropsychological assessment'. This should be offered if any of the following apply:

- the person is having problems in school or at work

- the person feels that they're having problems with their memory or other thought processes ('cognitive deficit' – see page 65)
- the MRI results showed an abnormality in a part of the brain that's known to be responsible for functions such as memory or speech.

After the diagnosis

If epilepsy is diagnosed, the person should be given clear information about the type of seizure and epilepsy syndrome that they have and their possible effects and how they might change in the future (see the next section).

Once they get the diagnosis, the person and their family or carers should be given the opportunity to talk about what it means and their feelings about it with a healthcare professional who has experience in these areas.

Everyone with epilepsy should be registered with a GP so as to ensure access to all necessary healthcare, and should be given details of how to contact a specialist if they need to.

Managing with epilepsy

Healthcare professionals should encourage and help people and their families or carers to find out as much as possible about their epilepsy and to learn skills to increase their confidence in living with the condition. For adults, information and education about epilepsy should be provided as part of the agreed plan of how they are going to manage their condition (see page 29). An individual care plan should be agreed between the person and their family or carers as appropriate, the person's GP and the specialist. For children and young people, special activities geared to their age-groups may be the best way for healthcare professionals to give support and help them live with and manage their condition. There should also be arrangements in place for when young people make the move to adult services – see page 59.

If someone is interested in learning more about how to manage their condition, healthcare professionals should discuss with them the programmes that have been set up to help people with long-term medical conditions. One example is the Expert Patients Programme (www.expertpatients.nhs.uk) and others are run by voluntary organisations.

Getting information about epilepsy

Once epilepsy is diagnosed or if it seems very likely that a person has epilepsy, healthcare professionals should provide information and education about epilepsy, the possible effects on a person's life, and the epilepsy treatments available. The areas that should be covered are listed in the box on pages 26–28.

It's important that people get information about epilepsy at the time when it's most useful to them (for example, **before** they make important decisions, such as planning for a baby, or decisions affecting a career or work).

People who have had a severe brain injury, people with a strong family history of epilepsy and people with learning difficulties are at risk of developing seizures. These people should be given information about epilepsy and the possibility of having seizures as soon as possible (that is, before the seizures start).

Every appointment with the doctor or epilepsy specialist nurse should be long enough for information to be passed on and discussed and for people to raise concerns and ask questions. Healthcare professionals should check whether people would like to go over again information they have received previously, or if they need

extra information about some aspects of their epilepsy.

Information for people with epilepsy

A person with epilepsy, and their family or carers as appropriate, should be given information on:

- epilepsy in general
- diagnosis and treatment options
- what's likely to happen in the future
- epilepsy medicines and side effects
- types of seizures, what can trigger them, and how they can be controlled or avoided
- how to manage living with epilepsy, and self-care
- possible risks and how to live with epilepsy as safely as possible
- safety and injury prevention at home, school and work
- first aid
- psychological issues (such as depression)
- social security benefits and help that may be available from social services
- insurance issues
- education and healthcare at school
- employment and independent living for adults
- the importance of telling an employer if a

person has epilepsy (contact support groups or charities if further information is needed)

- road safety and driving
- the risk of sudden death caused by epilepsy (this is sometimes referred to as SUDEP, which stands for sudden unexpected death in epilepsy; see page 62)
- status epilepticus (see page 68)
- how epilepsy can be affected by, and can affect, a person's lifestyle (this should include information on illegal drugs, alcohol, sex and the effects of not getting enough sleep)
- family planning and pregnancy
- local and national support groups and charities, and how to contact them.

This information should be provided in ways that are useful to the person concerned (for example, some people may find a video more helpful than a booklet). People should also be helped to find other sources of good-quality information if they haven't found them already (for example, the Joint Epilepsy Council has details of some support groups on its website: www.jointepilepsycouncil.org.uk). Epilepsy specialist nurses can also be a good source of information.

Checklists should be used to remind healthcare professionals and people with epilepsy about

the information that should be discussed during the appointments.

All healthcare professionals providing treatment and care for people with epilepsy should be able to provide essential information, but the person with epilepsy, and their family or carers as appropriate, should be given the name of one member of the healthcare team who is responsible for making sure they get the information they need at the times when it is most helpful. (Usually this will be one of the healthcare professionals they see regularly: their GP, specialist or epilepsy specialist nurse.)

Treatment and care

Discussing the options and agreeing a care plan

Once a diagnosis is made, the options for treatment and care should be discussed with the person and their family or carers as appropriate. The person with epilepsy (and their family or carers as appropriate) should talk about the person's lifestyle and their wishes, so that these can be taken into account in decisions about the next steps. If medication is an option (see the next section), the discussion should cover the benefits and possible side effects of the different medicines and the person's type of seizures or epilepsy syndrome. The healthcare professional should also talk about what might happen if the person didn't take medication, so they can balance the risks and benefits of treatment.

After the discussion, an individual care plan should be agreed between the person and their family or carers as appropriate, the person's GP and the specialist. This plan should include details of how a specific treatment was chosen, the possible side effects of the medication, what action to take if the person has more seizures, and the options if the treatment doesn't work.

The care plan should include lifestyle issues that have been discussed and agreed.

Educating others about epilepsy

Epilepsy is one of those conditions that aren't generally understood by most people. This lack of understanding can lead people to make assumptions and judgements about a person with epilepsy. Healthcare professionals should educate and provide information about epilepsy to those likely to encounter people with epilepsy, such as school staff and people working in the social services.

Starting on epilepsy medication

The decision to start epilepsy medication should be made by the person with epilepsy (and their family or carers as appropriate) and the specialist after a full discussion of the options. Healthcare professionals should understand that after a full discussion about the risks and benefits of epilepsy medication a person may decide they do not want to take it, or that their child should not take it.

The specialist should be involved in all decisions about starting on epilepsy medicines. The specialist should be responsible for starting a child on epilepsy medicine. An adult should only

start on epilepsy medicine if it is recommended by a specialist.

Epilepsy medication is usually an option once a person has had a second epileptic seizure. But it might be started earlier (after the first seizure) in some circumstances. There are two situations where this possibility should be discussed with the epilepsy specialist. The first is if the person or their family or carers think that they don't want to risk another seizure. The second is in particular circumstances such as when an EEG clearly supports a diagnosis of epilepsy or an obvious physical abnormality of the brain is shown by MRI or a CT scan.

Usually a person starts treatment with just one epilepsy medicine (this is known as monotherapy).

Choice of medicine

Information about the medicines that should usually be prescribed is given in the box on pages 32–33. The medicine used will depend on the seizure type and epilepsy syndrome, and there are other factors to be taken into consideration. Some medicines won't be prescribed if a person is taking certain other medicines for other medical conditions. Some medicines aren't suitable for children. And some medicines may have harmful effects on an

unborn child, while the effects of others on a pregnancy aren't known. A woman's or girl's doctor needs to have a full discussion with her about the possible risks before a choice is made. These issues may also need to be discussed when considering the treatment of a younger girl if it's likely that she'll carry on taking the medicine as she gets older.

It's a good idea for a person to keep to the same brand of a medicine and not to change from one form of the medicine 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. The quick reference guides for the guideline (see page 7) include summaries of side effects associated with some epilepsy medicines.

Medicines for epilepsy

- Usually a person tries one of the 'older' epilepsy medicines first. These are the ones that have been in use for many years – sodium valproate and carbamazepine are examples of these.
- If these don't help to control the person's seizures, the newer medicines should be tried (these include gabapentin, lamotrigine, levetiracetam, oxcarbazepine,

tiagabine, topiramate and vigabatrin*).

- If one of the following applies, the person may need to start with one of the newer medicines:
 - there are medical reasons for not trying the older medicines
 - the person is taking one or more other medicines that shouldn't be taken at the same time as an older epilepsy medicine (for example, care needs to be taken if a woman is taking the contraceptive pill)
 - it's known that the person has side effects with the older medicines
 - the person is a woman who could become pregnant or is a younger girl who would need to carry on with the medicine as she gets older and starts to have sex.
- If an infant is diagnosed as having infantile spasms (also called West syndrome), vigabatrin is recommended as the first medicine to try.

* Vigabatrin is used in addition to another epilepsy medicine for children with partial seizures.

If the first medicine doesn't help

If the first medicine doesn't control the seizures or there are side effects, a person should normally be tried on another single medicine (see the box above). The switchover between

medicines needs to be done carefully as sometimes seizures can happen during this time or there can be other adverse effects. Usually a person should continue to take the first medicine and begin a small dose of the second medicine. The dose of the second medicine should be gradually increased and then the dose of the first medicine gradually decreased.

If the second medicine isn't helpful, then the dose of either the first or second medicine 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 medicine doesn't control the seizures, the specialist may suggest adding in another medicine to take at the same time. This is known as combination therapy (or sometimes adjunctive or add-on therapy).

If combination therapy doesn't provide enough control of the seizures, the specialist and the person with epilepsy (and their family or carers as appropriate) should discuss which medicines and combinations have helped most with the seizures and have caused the least side effects. The medicine or combination that's been best is usually the one to carry on with.

Continuing the medication

If one or more medicines are to be taken, the person is likely to have to carry on taking them for several years. Continuing with medication should be part of the treatment plan agreed between the person with epilepsy and the specialist.

In some circumstances, the person's GP can provide the repeat prescriptions, if the person's epilepsy is relatively easy to manage and the arrangement suits the person with epilepsy (and their family or carers as appropriate). (In some cases whether GPs can provide the repeat prescription depends on which medicine is being taken or the local arrangements between health teams.)

Taking the medicine regularly

For epilepsy medicines to work best they need to be taken regularly. Healthcare professionals should try to help make this as easy as possible. For example, they should try to keep the schedule for taking the epilepsy medicines as simple as possible so that there's less chance of forgetting a dose.

The person with epilepsy (and their family or carers as appropriate) should be given information about what to do if the person misses a dose or has sickness or diarrhoea.

Blood tests

Blood tests are not usually needed for a person taking an epilepsy medicine, but they may need to be done if, for example, the body's levels of medicine need to be checked (this is the case for certain medicines). Other reasons for blood tests include pregnancy, concern that one of the body organs is not working properly, or status epilepticus (see page 61).

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

Some examples of blood tests that might be done are shown in the box below. Small changes in a person's test results don't always mean that the person has to change the medicine they're on.

Blood tests that may be done for a person taking epilepsy medication

- **Clotting test:** (for someone taking sodium valproate) done before an operation to check whether the valproate has affected the blood's ability to clot.
- **Full blood count:** to check that the medicine has not affected the blood cells.*
- **Electrolytes:** to check that the medicine has not affected the chemical balance of the body.*

- **Liver enzymes:** to check that the medicine has not affected the liver.*
- **Vitamin D levels and other tests of bone health (such as serum calcium and alkaline phosphatase):** to check that the medicine has not affected the bone strength.*

* These tests are usually done every 2–5 years for a person taking what's known as an enzyme-inducing medicine, which is one that changes the way that other medicines and hormones are used in the body (see page 66).

Stopping the medicines

If a person hasn't had a seizure for at least 2 years, the specialist or other healthcare professional should discuss with them the risks and benefits of continuing with the medicines, reducing the medicines, or slowly stopping some or all of the medicines. In each case, the healthcare professional should discuss with the person (and their family or carers as appropriate) the possible impact of stopping treatment on the likelihood of seizures and daily life. After these discussions with the specialist, the person with epilepsy (and their family and/or carers, as appropriate) should make the decision whether or not to stop the medicines.

If it's decided to stop the medicines, this should be done slowly over a period of at least 2–3 months, and the specialist should be involved. If two or more medicines are being taken, only one should be stopped at a time. If the medicine is a benzodiazepine or a barbiturate (see page 65), it may take 6 months or longer to stop.

Before stopping treatment, the person with epilepsy (and their family or carers if appropriate) should agree a plan about what should happen if the seizures start again. This should include going back to the dose level they were taking just before the seizures started again and contacting their doctor or nurse.

Referral to a specialist centre

Sometimes there are reasons why a person with epilepsy should be referred to a team of healthcare professionals in a specialist centre (sometimes called a 'tertiary centre'). See the box on pages 40–41 for information about the team at the centre.

A person should be referred if there is uncertainty about the diagnosis (for example, about the type of epilepsy syndrome they have) or if their seizures have not been controlled by the treatments that have been tried. Referral should be considered when:

- the seizures haven't been controlled despite trying medicines for 2 years
- two medicines have been tried, but the seizures haven't been controlled
- the person has or is at risk of having unacceptable side effects
- the person is a baby or young child (under 2 years old) – young children should see the specialist team as soon as possible
- there is an abnormality affecting the structure of part of the brain
- the person has in addition to epilepsy a psychological or psychiatric condition (one affecting their behaviour or their mind)
- it's still not clear what type of epilepsy or seizures the person has.

A person should also be offered an appointment at a specialist centre if they are diagnosed with certain epilepsy syndromes (Sturge–Weber syndrome, the hemispheric syndromes, Rasmussen's encephalitis or hypothalamic hamartoma).

Also, the person should be offered an appointment at a specialised centre if they lose skills they had earlier (for example, a child loses the ability to walk or talk) or develop behavioural problems.

Referral to a specialist centre when necessary should be available to everyone. Having normal results in some of the tests that are carried out

should not stop a person being referred to a specialist centre if they or their specialist think it is necessary. Having a mental illness should not be used as a reason for not referring a person to a specialist centre.

It's particularly important that children who are suspected of having developed epilepsy in the first few years of life are referred to a specialist centre so that they can be diagnosed and if necessary treatment can be started to prevent seizures.

The team at the specialist centre

The team of healthcare professionals who work at the specialist centre (or 'tertiary centre') should be experienced in assessing people with epilepsy that's hard to treat or complicated for other reasons.

The team should include people with training and experience in a range of areas from psychology (assessing and helping with behaviour) to occupational therapy (using adapted or specialised equipment to make life easier). 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). A full list of the health

professionals who should be in the team is given in the NICE guideline (see page 7 for more details).

The specialist centre should have an MRI scanner and facilities for combined video and EEG recording. This is called video telemetry (see page 19).

The neurosurgeon in the specialist centre should have specialist experience of and/or training in carrying out operations for epilepsy and access to facilities for specialised EEGs that are needed to help to investigate whether surgery would be a suitable treatment.

If surgery is an option

If epilepsy is very difficult to control with medication, brain surgery may be considered for some people. Many tests need to be done to find out whether surgery would be a suitable treatment.

Brain surgery would be carried out by the surgeons working in a specialist centre. If surgery is a possibility, the person or their family or carers should be given information on the reasons for surgery. The possible benefits and problems of the specific operation should be

explained in detail before the person decides whether or not to have the operation.

Other ways of treating epilepsy

Relaxation, CBT and biofeedback

If a person's seizures aren't being controlled very 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 behaviour therapy' or CBT). Another treatment that might be tried is 'biofeedback', which involves learning ways of changing the brain activity. These techniques don't replace medication, but they can be used as well as the medicines if the person or the specialist thinks that the seizures are not being controlled well enough with medication on its own.

Learning techniques may also be tried for a child if medicines haven't helped on their own and they have focal epilepsy (which means that the abnormal electrical activity is happening in a particular area of the brain).

The ketogenic diet

The ketogenic diet is a special diet that's high in fat and low in carbohydrate. If medicines haven't

really helped a child's epilepsy, then the doctor or other healthcare professional may discuss this diet with the family or carers with a view to trying it.

The ketogenic diet isn't recommended for adults with epilepsy.

Vagus nerve stimulation

Vagus nerve stimulation involves having a tiny 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 the numbers of seizures in some people. If medicines haven't worked and brain surgery isn't an option, vagus nerve stimulation may be offered (for a child or an adult).

Seeing an epilepsy specialist nurse

Epilepsy specialist nurses are trained and have experience in caring for people with epilepsy. They have a key role in providing care to people with epilepsy. For example, they can provide information and education to people with epilepsy and their families and carers, and they can make sure that people are getting the right

help and support for their epilepsy from other healthcare professionals. They can also provide a link between the specialist and the person with epilepsy.

Regular reviews

Adults

Adults should have regular reviews of their epilepsy and their treatment. Usually this is done with the GP, though some people may prefer or need to have the review with their specialist (in which case it may be best done in a clinic especially for people with epilepsy). The reviews should happen at least once a year, but they can be done more often if the person wants more frequent reviews or their epilepsy needs closer attention. In addition, if a person continues to have seizures or side effects of treatment or needs specialist advice (for example if a woman is planning a pregnancy), the person should be able to see a specialist or be referred to a specialist centre.

Children

Children with epilepsy should have regular reviews with their specialist. The reviews should happen at least once a year, and may happen as often as once every 3 months. The specialist should agree how often the reviews should be done with the child and their family or carers. It will depend on the child's epilepsy

and the wishes of the child and their family or carers.

What the reviews should cover

The doctor should check whether or not the person is having seizures, how they are getting on with the treatment, whether there are any side effects and whether they are having any difficulties with the arrangements for taking medication (for example, how often they need to take it). If there are any problems, they should discuss the treatment plan and whether changing medicine might help.

The reviews are also a time when the doctor should give the person information (including leaflets) about epilepsy, support groups, epilepsy charities, and information services. Other things that should be available at the review are:

- an opportunity to see an epilepsy specialist nurse
- an opportunity for access to counselling services
- further tests or investigations if necessary
- referral to a specialist centre.

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.

People from black and minority ethnic groups

Healthcare professionals should consider the cultural needs of a person with epilepsy when discussing and planning diagnosis or treatment. If appropriate, an interpreter who has experience of the person's culture together with some medical knowledge should be present during appointments to help with discussions and explanations. Normally, the interpreter should be someone who is not from the person's family, to protect privacy and confidentiality and ensure accurate interpretation.

If a person doesn't speak or read English, they should be given information in a format or way they can understand. This information should

include details on driving and employment rights for people with epilepsy.

Women

Women with epilepsy need particular information and support to make informed decisions about their care.

Women with epilepsy and their partners as appropriate must be provided with relevant information and offered counselling about how epilepsy and epilepsy medicines may affect contraception, becoming pregnant, the pregnancy itself, breastfeeding, caring for children, and the menopause, and the options open to them. This information should be tailored to their individual needs and should be offered **before** women 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 girl or woman, such as their family.

All healthcare professionals who treat or support women with epilepsy should be familiar with the issues affecting women and the information available in these areas. They should be able to put women in contact with counselling services if this is necessary.

Contraception

Some epilepsy medicines may make the contraceptive pill less effective and a woman's doctor should discuss this with her and talk about her specific situation, what's important for her and the options and the different forms of contraception. This discussion should also be had with girls who may need to carry on taking the medicine as they get older and start having sex.

There are special considerations if a woman taking one of the enzyme-inducing epilepsy medicines decides to take the combined contraceptive pill or have 'depot injections' of contraceptive. (Depot injections mean that a contraceptive hormone is injected into a muscle and slowly released into the body from the injection site over several weeks.) The issues to be talked through by the woman and her doctor include the appropriate dosage, timing of tablets or injections, and the need for additional contraceptive protection.

Folic acid supplements

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

Pregnancy

The UK Epilepsy and Pregnancy Register has been set up to collect useful information about how epilepsy and epilepsy medicines can affect pregnancy, labour and the baby. The more women who join it, the more useful the results. So all pregnant women with epilepsy are encouraged to put their details on the register or to let their doctors do it for them (see www.epilepsyandpregnancy.co.uk).

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

All the healthcare professionals involved should work together so that everyone knows what has been done and what is planned. Maternity units that take women with epilepsy should have agreed procedures for care of the mother and baby and have facilities for providing emergency treatment, including treatment of seizures during labour.

Information about the chances of a child having epilepsy

Epilepsy can be passed on in the genes from a parent to his or her child. The risk of this happening is small overall, but is higher for people with certain types of epilepsy. Referral to a professional (a 'genetic counsellor') who can provide information about the risk of epilepsy being inherited from either partner should be considered, particularly if the person has 'idiopathic epilepsy' (see page 11), or has a family history of epilepsy. Discussions with a genetic counsellor can help people make decisions about their individual risk and treatment choices.

Treatment of epilepsy during pregnancy

It is important to try to make sure that a woman with epilepsy does not have seizures while she is pregnant.

Some women may want to reduce or stop their epilepsy medicine(s) when they become pregnant. If the plan is to stop taking the epilepsy medicines during the pregnancy, the woman should be told about her risk of status epilepticus (see page 61) and of unexpected death (see page 62).

When appropriate, the specialist should be consulted before the woman and her GP make decisions about medication.

Problems during pregnancy

Although most women with epilepsy are likely to have a healthy pregnancy, they should be told about the chances of problems happening and the evidence in this area.

In brief, current evidence shows that if a woman has a tonic–clonic seizure (when the person has convulsions) there is a small risk of the seizure causing a miscarriage or injury to the unborn baby, but overall the chances of this happening are very low. But women should be reassured that there's no evidence that other types of seizures are harmful unless the woman falls and injures herself or the baby.

Generally, the number of seizures doesn't tend to go up during pregnancy or in the first few months after the birth.

Tests

Blood tests: normally a woman won't need to have her blood levels of medicine for epilepsy checked during her 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 her levels in case the dosage needs changing.

Ultrasound scans: if a woman is taking epilepsy medication, she should be offered a high-resolution ultrasound scan at 18–20 weeks to check that the baby has developed as expected. Earlier scanning may be offered to allow major deformities to be detected sooner.

The labour

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

Giving vitamin K: if a mother is taking one of the enzyme-inducing epilepsy medicines, a vitamin K injection for the baby at birth is recommended. A list of some of the enzyme-inducing medicines is given on page 66.

Breastfeeding

Healthcare professionals should encourage all women with epilepsy to breastfeed, except in very rare circumstances, while supporting them in the choices they make. The woman and her doctor should discuss any potential risks associated with taking epilepsy medicines and

how these balance against the benefits of breastfeeding and then decide whether to make any changes to the medication.

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. Information on these should be given to parents during the pregnancy. (There is more information on this in Appendix D of the full guideline, which is available from the NICE website.)

People with learning disabilities

Epilepsy is common in people with learning disabilities, and people with learning disabilities and epilepsy should receive the same care as people without learning disabilities. They should also get help and support from a learning disabilities team (a team of professionals that cares for people with learning disabilities). The person's epilepsy care should be provided by a specialist who is part of the learning disabilities team.

Diagnosing epilepsy

Epilepsy can be difficult to diagnose in a person with learning disabilities. The specialist should

talk through the person's full medical history. The specialist should also ask for eye-witness accounts of what happened during the person's seizure, and any other information that could be helpful for the diagnosis, such as a video recording of a seizure. When necessary, healthcare professionals should provide information and advice to help eye witnesses to describe clearly and accurately what they see happening when the person has a seizure.

If a child has learning disabilities and epilepsy, investigations should be carried out to try to find out the cause of the epilepsy.

The person with learning disabilities should be referred for a neuropsychological assessment if necessary (see page 22).

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 the MRI scan.

Care plan

A person with epilepsy and learning disability should have access to the same treatments and monitoring of treatments as any other person

with epilepsy. However, some medicines for epilepsy may affect the behaviour or memory of a person with learning disabilities, and this should be considered when decisions are being made about which medicines to try as part of the care plan.

People who have epilepsy and learning disability have a higher risk of unexpected death (SUDEP, see page 62) or of dying from an accident or injury. Healthcare professionals should discuss these risks with the person with epilepsy and their family and carers. Potential safety problems should be assessed (see the next section).

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. In particular, health professionals should assess how safe a person with learning difficulties is likely to be if they have a seizure in certain situations, including:

- having a bath or a shower
- preparing food
- using electrical equipment.

An assessment should also be made of:

- what might happen if the person had a long seizure or repeated seizures (for example, would there be someone around to help?)
- the effect of having a seizure when the person is out or with other people
- the risk of unexpected death (SUDEP – see page 62)
- whether the person's living arrangements are suitable for their circumstances (for example, if they live on their own).

Young people

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

Healthcare professionals should ensure that their approach to caring for a young person encourages him or her to be fully involved in discussions and decisions about treatments and ways of managing with the seizures. The young person's wishes and beliefs should be listened to by doctors and taken into account during these

discussions, as should the wishes and beliefs of their family or carers. If the young person needs extra information to help them understand what's going on and the choices that they have, this should be given in a format that is useful to them. The standard information that young people should be given is shown in the box below.

Information that should be provided to young people

- General information about epilepsy
- Diagnosing epilepsy
- Treatments, including side effects and possible problems with different medicines
- Why it's important to take epilepsy medicines regularly
- The effect of having seizures on a person's life
- What it means to control seizures
- The risk of injury during a seizure
- How epilepsy may affect a person's lifestyle and possible career decisions
- Epilepsy and driving and insurance
- Social security benefits
- The risk of sudden unexpected death from epilepsy (SUDEP – see page 62)
- The possible effects of illegal drugs, alcohol and not getting enough sleep
- Epilepsy and sex

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 their individual circumstances.

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 teenager is given help and support. For example, a young person should have one doctor in their teenage years whom they can get to know, and he or she should help them as they change over to the adult service. This doctor should also be responsible for making sure that the person gets other types of help and support if they need it. In some areas, children's and adults' epilepsy teams may share clinics or other services and this can help young people make the change to adult care.

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 national and local support groups and charities and help to contact them.

Care in particular situations

Long or repeated seizures away from a hospital

The box below shows the guideline's recommendations about what should be done if a person has a convulsive seizure that lasts for 5 minutes or more, or if they have three or more seizures in an hour.

If the convulsive seizure lasts for 5 or more minutes or there are three or more seizures in 1 hour

- Urgent treatment and care is needed.
- Diazepam may be given rectally (into the bottom) to control seizures quickly. In some circumstances another medicine called midazolam* can be placed in the mouth instead. The decision about which to use should have been agreed beforehand and if it's a family member or a carer who gives the medicine, they should have been trained to do it.
- When the paramedics or a GP arrive, they should make sure that the person can breathe properly, and that their heart is beating.

- It may be necessary to call an ambulance, depending on the circumstances and how the person responds to the emergency medicine. In particular, an ambulance may be needed if:
 - it's the first time a person has had repeated or prolonged seizures
 - it's likely that there will be another episode of repeated or prolonged seizures
 - status epilepticus develops (see below)
 - the person's circumstances mean that it may be hard to check that they're all right later.

* Midazolam isn't currently licensed for use in this way. This means that although it's approved for use in the UK, the risks and benefits of using it in this way were not considered when the approval was given.

If the person is in 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. A person with convulsive status epilepticus should be treated in hospital. NICE recommends that hospitals should have an agreed procedure ('protocol') for treatment in

place. Appendix C of the full guideline contains recommendations for the treatment of status epilepticus. It is available from the NICE website (www.nice.org.uk/CG020).

If someone keeps going into status epilepticus

If someone frequently goes into status epilepticus, an individual treatment plan of what to do when this happens should be drawn up for them by their specialist.

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. Recommendations for the treatment of this condition are given in Appendix C of the full guideline (available from the NICE website).

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 (SUDEP for short). Although it's not common, it

does happen. There may be factors that increase the risk of SUDEP, such as poor control of seizures, having convulsive seizures, having seizures during sleep, having a learning disability, being a young adult male, not taking medication as prescribed or having abrupt or frequent changes to medication.

The risk of SUDEP is very much lower if a person's seizures are being controlled and they and their family or carers are alert to the risks of night-time seizures.

Healthcare professionals should provide a person with epilepsy and their family or carers with general information about SUDEP, to show why controlling seizures is important. They should also discuss with the person with epilepsy (and their family or carers, as appropriate) their individual risk of SUDEP.

If a person has died unexpectedly

When a person with epilepsy has died unexpectedly, healthcare professionals should contact the family or carers and give them the opportunity to talk about the death. They should also offer to help the family or carers to contact a SUDEP support group or bereavement counsellors.

Further information

Individuals have the right to be fully informed and to share in decision-making about their healthcare. If further information is needed about epilepsy, a GP or relevant member of healthcare team should be contacted. This guideline may be part of that discussion.

For further information about the National Institute for Clinical Excellence (NICE), the Clinical Guidelines Programme or other versions of this guideline (including the sources of evidence used to inform the recommendations for treatment and care), see the NICE website (www.nice.org.uk).

Words and terms used in this booklet

Barbiturates: A group of drugs that affect brain activity and have sedative effects. Phenobarbital and primidone are barbiturate drugs used to control some types of epileptic seizures.

Benzodiazepines: A group of drugs that affect brain activity and have sedative effects. Clobazam and clonazepam are benzodiazepines used to control epileptic seizures. Another benzodiazepine, diazepam, is used in the treatment of status epilepticus.

Cognitive deficit: A difficulty in thinking, reasoning, understanding or memory.

Convulsion (convulsive seizure): Jerking movements made by the body. See tonic–clonic seizure.

CT scan: A brain scan that uses x-rays to produce a picture of the brain. It's used to see if there are any physical problems in the brain that may be causing seizures. CT stands for computed tomography. Sometimes it may also be called a CAT scan, where CAT stands for computed axial tomography.

EEG: A painless test that involves attaching electrodes to the scalp. These measure the electrical activity of the brain. The EEG does not give a definite diagnosis and the results should be considered with other information about the seizures. EEG stands for electroencephalogram.

Enzyme-inducing epilepsy medicine: Epilepsy medicines that affect how the body deals with other medicines and hormones. They include:

- phenytoin
- phenobarbitone
- primidone
- carbamazepine
- topiramate.

Epilepsy: A tendency to have recurrent seizures that begin in the brain.

Epilepsy specialist nurse: A nurse with specialist training and experience in caring for people with epilepsy.

Epilepsy syndromes: A unique combination of symptoms and signs, which includes the type of seizure(s), the age of the person when seizures start, how the person responds to drug treatment, whether there are other brain problems, and the findings from examinations and tests. One epilepsy syndrome can have different causes in different people. Defining an epilepsy syndrome enables the specialist to begin

the best treatment for the individual and also helps to predict the likely course of the epilepsy.

MRI (of the brain): A type of brain scan that uses magnetic fields to produce a picture of the brain. It is used to detect physical abnormalities in the brain. MRI can show much more detail than a CT scan. MRI stands for magnetic resonance imaging.

Seizure: An epileptic seizure happens when normal electrical activity in the brain is suddenly disrupted. 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.

Specialist (for adults with epilepsy): A doctor with specialist training and expertise in the diagnosis, management and treatment of people with epilepsy. The specialist is usually based in or associated with a local or general hospital.

Specialist (for children with epilepsy): A doctor who specialises in the care and treatment of children (a paediatrician) who has had special training and expertise in the diagnosis, management and treatment of children with epilepsy. The specialist is usually based in or associated with a local or general hospital.

Specialist centre: A clinic or unit with particular experience and expertise in investigations or treatment of epilepsy that is difficult to diagnose or treat. It is sometimes called a tertiary centre.

Status epilepticus: Status epilepticus is a condition in which a seizure lasts for 30 minutes or more, or there are several seizures one after the other over 30 minutes or more, and the person does not regain consciousness in between them. Status epilepticus with tonic–clonic seizures (convulsions) is a medical emergency.

SUDEP: ‘Sudden unexpected death in epilepsy’ – when a person with epilepsy dies suddenly and no obvious cause can be found after post-mortem examination.

Tonic–clonic seizure: A seizure where a person loses consciousness, their body stiffens, then they fall to the ground. This is followed by jerking movements. They may become pale or blue in colour, especially around their mouth, if their breathing is difficult. They may become incontinent (wet themselves). After a minute or two the jerking movements should stop and consciousness may slowly return. After the seizure the person may feel tired and confused, have a headache and need to rest to recover fully.



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