

during pregnancy and the benefits and risks of treatment with AEDs while you are pregnant. The small risk of some malformations can be reduced by taking 5mg (milligrams) of folic acid per day.

Emergency care

Seizures usually end of their own accord, but some people experience prolonged and/or repeated seizures. These are medical emergencies and need urgent care and treatment. At diagnosis and review, all people with epilepsy should be given information about what to do and who to contact in an emergency situation. This should all be covered in your care plan.

Sudden unexpected death in epilepsy (SUDEP)

If a person with epilepsy dies suddenly and, after investigation, there's no obvious reason, it is called sudden unexpected death in epilepsy (SUDEP for short). Although SUDEP is rare for many types of epilepsy, risks need to be assessed individually. You should be given information about it and how to reduce the risk. SUDEP is less likely to happen if your seizures are being controlled effectively and you and your family or carers are alert to the risks of night-time seizures. When SUDEP has happened the family should be offered referral to bereavement counselling and a SUDEP support group.

If care does not match these standards

The Joint Epilepsy Council and its members believe the new NICE guideline sets excellent standards of care for people with epilepsy and believe all people should have access to care that meets these standards.

If you think that the care you or your family member is receiving does not meet the standards in the NICE Guideline, you can take the following action:

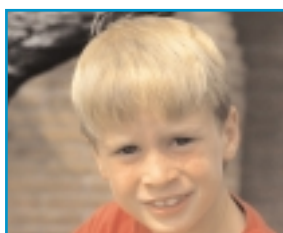
- Speak to your GP, Epilepsy Nurse or other health professional, and refer to the NICE Guideline.
- Contact your local Patient Advisory and Liaison Service (PALS) for help with making a complaint (details in your local phone book).
- Contact NHS Direct on 0845 46 47 or contact their website: www.nhsdirect.nhs.uk
- Contact us - see over for details.



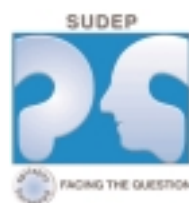
Full copies of the NICE Guideline

This leaflet is just a summary of the guideline. Full details of the guideline can be found in the following ways:

- On the NICE website - www.nice.org.uk/CG020
- A version of the NICE guideline for people with epilepsy, their families and/or carers, and for the public is available from from the NHS Response Line - 0870 1555 455; quote reference number N0741 for an English version and N0742 for an English and Welsh version.
- Quick reference guides for healthcare professionals are also available from the website or from the NHS Response Line (quote reference numbers N0739 and N0740 for the quick reference guides on the diagnosis and management of epilepsy in adults and children, respectively).



Further information on epilepsy



The UK's leading organization on SUDEP (Sudden Unexpected Death in Epilepsy)

Website: www.sudep.org
Email: epilepsybereaved@dial.pipex.com

Contact line for bereaved :
01235 772852
(24 hour answering machine)

Post: PO Box 112, Wantage,
Oxfordshire, OX12 8XT

Advice & information is also available from:

Epilepsy Action - Helpline: **0808 800 5050**
National Society for Epilepsy -
Helpline: **01494 601 400**

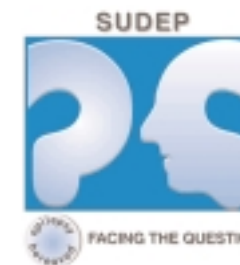


The Joint Epilepsy Council is an umbrella body representing epilepsy-related organisations.

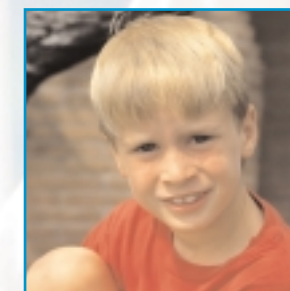
For details of all members please contact the following:

Website:
www.jointepilepsycouncil.org.uk

Email:
sharon.jec@btconnect.com



The Epilepsies: You, epilepsy & the NICE Guideline



A brief guide about how the NICE Guideline for the treatment and management of epilepsy affects you.



NICE Guideline, The Epilepsies: diagnosis and management of epilepsy in children and adults

The epilepsies

If you have a diagnosis of epilepsy, you are not alone. Around 440,000 people in the UK have epilepsy, that is one in every 133 of the population.

There are many types of epilepsy (over 50). Many only last a short time, whilst others are life-long. Some rarer forms of epilepsy can result in premature death and are associated with abnormalities in the brain. While most epilepsies respond effectively to anti-epileptic drug (AED) treatment and seizures are controlled, some do not. While some respond to brain surgery, others don't.



What is the NICE Guideline?

The National Institute for Clinical Excellence (NICE) is part of the NHS. It is the independent organisation responsible for providing national guidance on treatments and care for people using the NHS in England and Wales. The guidance is intended for healthcare professionals, patients and their carers to help them make decisions about treatment and healthcare.

The information that follows is a summary of the newly published NICE Guideline for the diagnosis and management of epilepsy. It applies to adults and children with epilepsy, including the move for young people from children's to adult services. It aims to make you, as a person with epilepsy or carer of a child or adult with

epilepsy, aware of the services available and to have the confidence to ask for the treatment and information you need. (Where we mention you or your child this should be read to include their family and/or carers where appropriate).

What the guidelines say about epilepsy

Diagnosis

NICE says that any person who has had a possible seizure should be seen within two weeks by a specialist medical practitioner with training and expertise in epilepsy (referred to as a specialist in this leaflet). This specialist should make a diagnosis, using tests such as EEG (electroencephalogram) and MRI (magnetic

resonance imaging) where appropriate. The tests should be available within four weeks of a specialist asking for them.

If your diagnosis is epilepsy, the specialist should classify it by seizure type and syndrome. A care plan should be agreed with you and should include information about lifestyle as well as medical issues.

Treatment

Anti-epileptic drugs are the main treatment for epilepsy and should be started under the guidance of the specialist. Other treatment options are available, for example diet (for children) and surgery. The guideline says you should be fully involved in all discussions about the benefits and risks of your treatment. The doctor should discuss the following with you:

- The diagnosis and the seizure type, syndrome and likely course of the condition.
- The benefits and risks of AED treatment.
- Your lifestyle and personal preferences, which must be considered when deciding the best drug for you.
- Individual risks of epilepsy, living with seizures and prevention of accidents.
- Your care plan that explains what other options are available if the first drug does not stop the seizures.

After two years without seizures you should have the opportunity to discuss with the specialist the benefits and risks of withdrawing or continuing AED treatment. The withdrawal of anti-epileptic drugs must be managed by, or under the guidance of, the specialist.

Information

You should be empowered to manage your condition as well as possible, and be fully involved with your specialist and GP as a partner in all decisions about your healthcare and lifestyle. Information should be available (in a format that is useful to you) on a range of issues such as: epilepsy as a condition; diagnosis and treatment options; risk management; first aid; driving; employment and education.

Access to voluntary groups is important as they can provide additional information and support. Their details should be made known to all people with epilepsy.



Review

Adults with epilepsy should have a review at least once a year by their GP or specialist. If you continue to have seizures or side effects or need particular advice (for example if you are a woman planning a pregnancy), you should be referred to a specialist by your GP.

Children should be reviewed by a specialist at least once a year, but more often if necessary.

Difficult to manage epilepsy

You should be referred to a specialist centre when one or more of the following apply:

- Your epilepsy is not controlled with medication within two years.
- Your epilepsy is not controlled with medication after two drugs have been tried.
- You have, or are at risk of, unacceptable side-effects from medication.
- Your epilepsy is associated with a psychological and/or psychiatric condition.
- When there is possible doubt over the diagnosis of the seizures and/or syndrome.

This service should include a multi-disciplinary team who are experienced in the assessment of people with complex epilepsy and have access to investigations and both medical and surgical treatment.

If you have controlled epilepsy but have concerns about issues such as pregnancy, you should also have access to this service.

Learning disabilities

If you have epilepsy and learning disabilities, you should receive the same support and care for your epilepsy as everyone else. You will also need the care of the learning disabilities team. The management and treatment of your epilepsy should be carried out by a specialist.

Women

All women with epilepsy should be given information and counselling about contraception, conception, pregnancy, breastfeeding, caring for children and the menopause as and when appropriate.

Preconception counselling should be available for any girl or woman who is sexually active because there is a risk that some AEDs can harm the unborn child. Your doctor should discuss with you the benefits of remaining seizure free