Epilepsy and the NICE guideline

This information is relevant for people who live in England, Northern Ireland and Wales. If you are looking for information about medical care in another country, please contact your local epilepsy organisation.

NICE clinical guideline 137, issued January 2012

The National Institute for Health and Clinical Excellence (NICE) guideline

NICE is an independent organisation that provides guidelines for treatment and care for people using the NHS in England, Northern Ireland and Wales. The guidelines are for healthcare professionals, and patients and their carers, to help them make decisions about treatment and healthcare. They aim to make you aware of the services available, and to have the confidence to ask for the treatment and information you need.

The information that follows is a summary of the NICE guideline on epilepsy. It applies to children, young people and adults, but not to newborn babies. This is because epilepsy in newborn babies is very different to epilepsy in older children.

What the guideline says about epilepsy

Diagnosis

If you have had a possible seizure, you should have an appointment with a specialist medical practitioner with training and expertise in epilepsy. This should be within two weeks. This specialist should make a diagnosis, using tests such as an EEG (electroencephalogram) and MRI (magnetic resonance imaging) where appropriate. You should be able to have the tests within four weeks of the specialist asking for them.
If you are diagnosed with epilepsy, the specialist should classify it by seizure type and syndrome. A syndrome is a group of signs and symptoms that, added together, suggest a particular medical condition. The specialist should agree a care plan with you that should look at lifestyle as well as medical issues.

Epilepsy Action has more information about diagnosing epilepsy, seizure types and syndromes.

**Treatment**

Epilepsy medicines are the main treatment for epilepsy. They should be started under the guidance of the specialist. Some medicines work better for some seizure types. And some make some seizure types worse. NICE recommends which medicines to use for different types of seizures. They also give information about using epilepsy medicines in pregnancy.

Other treatments are sometimes available, for example the ketogenic diet and surgery. The ketogenic diet is a special diet for children with difficult to control epilepsy.

The guideline says you should be fully involved in all discussions about the benefits and risks of your treatment. The specialist should discuss the following with you.

- Your diagnosis and the type of seizures you have, whether it is an epilepsy syndrome, and what the long-term outlook is.
- The benefits and risks of epilepsy medicines.
- Your lifestyle and personal preferences. These must be considered when you are agreeing the best medicine to use for your epilepsy.
- How epilepsy might affect your life, including safety issues.
- Your care plan, including what options you have if the first medicine you try does not stop your seizures.

After two years without seizures, you should have the opportunity to discuss withdrawing, or continuing epilepsy medicines, with your specialist. If you decide to withdraw your epilepsy medicines, this must be managed by your specialist.

Epilepsy Action has more information about epilepsy medicines, pregnancy, the ketogenic diet, surgery and safety issues.

**Information**

You should be given the information to manage your condition as well as possible. Your GP and specialist should agree all decisions about your healthcare and lifestyle with you. They should provide information (in a format that is useful to you) about a range of issues such as:

- epilepsy as a condition
• diagnosis
• treatment options
• risk management
• first aid
• driving
• employment
• education.

You should also be given information about voluntary groups and organisations, such as Epilepsy Action, who can give you more advice and information.

Epilepsy Action has more information about all of the issues listed above.

Reviews

You should have regular reviews of your epilepsy and treatment. For adults, this is usually once a year with your GP or specialist. If you continue to have seizures or side-effects from your epilepsy medicines, or need particular advice, you should be referred to a specialist by your GP. An example would be if you are a woman planning a pregnancy.

Children and young people should have their review with a specialist, at least once a year, but more if necessary. The specialist should be a doctor who treats and cares for children (a paediatrician). They should have had special training in diagnosing and treating epilepsy.

Epilepsy Action has more information about planning a pregnancy and children.

Difficult to control epilepsy

If your epilepsy is difficult to control, you may be offered a referral to a team of very highly trained healthcare professionals in a specialist centre. This is known as a tertiary centre or tertiary service.

You should be referred to a specialist centre if:

• the doctors are not sure what type of epilepsy syndrome or seizures you have
• your seizures are not controlled with epilepsy medicines within two years of starting them
• you have tried two different epilepsy medicines, but these have not worked
• you have, or are at risk of, severe side-effects from epilepsy medicine
• you have a psychological or psychiatric condition
• there is something abnormal in your brain.

This specialist service should include a team of professionals who are experienced in assessing people with complex epilepsy. They should have access to investigations and medical and surgical treatment.

If your epilepsy is not difficult to control but you have concerns about issues such as pregnancy, you should also have access to the specialist service.

Epilepsy and 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.

Women

You should be given information and counselling about how epilepsy and epilepsy medicines may affect:

• periods
• contraception
• becoming pregnant
• pregnancy itself
• breastfeeding
• caring for children
• the menopause

You should be given this information before you become sexually active, pregnant, or reach the menopause.

Epilepsy Action has more information about epilepsy and women's issues.

Emergency care

Seizures usually end of their own accord, but some people have long or repeated seizures. These seizures may need to be treated with emergency medicines. These are usually midazolam or diazepam. When you are diagnosed, you should be given information about what to do, and who to contact, in an emergency. This might happen at your review. The named person should be included in your care plan.

Epilepsy Action has more information about seizures that last a long time.
Sudden unexpected death in epilepsy

If a person with epilepsy dies suddenly, and no obvious reason can be found after a post-mortem examination has been done, it's called sudden unexpected death in epilepsy (SUDEP). It’s estimated that SUDEP causes about 500 deaths each year in the UK. Some people with epilepsy have a higher risk of SUDEP than other people with epilepsy.

Healthcare professionals should tell you about SUDEP. They should discuss your own risk of SUDEP, and how to try to reduce this risk.

Epilepsy Action has more information about sudden unexpected death in epilepsy

If care falls below the standards set out in the NICE guidelines

If you think that the care you or your family member is receiving falls below 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 Advice and Liaison Service (PALS) for help with making a complaint
  Tel: details in your local phone book
  Website: http://www.pals.nhs.uk/
- Contact NHS Direct
  Tel: 0845 46 47
  Website: http://www.nhsdirect.nhs.uk/
- Contact Epilepsy Action’s Helplines
  Freephone: 0808 800 5050
  Email: helpline@epilepsy.org.uk

Getting copies of the NICE guideline

This information is just a summary of the guideline.

- Full details of the guideline can be found on the NICE website www.nice.org.uk/CG137
- A short version of the NICE guideline for people with epilepsy, their families and/or carers, and for the public is available from NICE publications
  Tel: 0845 003 7783 (quote reference number N2697).
  Website: http://www.nice.org.uk/
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About this publication

This information is written with input from people with epilepsy and professionals. Epilepsy Action makes every effort to ensure the accuracy of information but cannot be held liable for any actions taken. If you want to know our sources, or give us feedback, contact us.

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Epilepsy Helpline

Freephone 0808 800 5050, text 0753 741 0044, email helpline@epilepsy.org.uk, tweet @epilepsyadvice

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