

Newer drugs for epilepsy in children

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

April 2004



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197

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Copies of this booklet can be ordered from the NHS Response Line; telephone 0870 1555 455 and quote reference number N0550. A version in Welsh and English is also available, reference number N0551. Mae fersiwn yn Gymraeg ac yn Saesneg ar gael hefyd, rhif cyfeirnod N0551. The NICE technology appraisal on which this information is based, Newer drugs for epilepsy in children, is available from the NICE website (www.nice.org.uk). A short version of the guidance (a 'quick reference guide') is also available on the website (www.nice.org.uk/TA079quickrefguide) and from the NHS Response Line, reference number N0549.

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Contents

What is NICE guidance?	4
What is epilepsy?	5
What are the newer drugs for epilepsy?	6
What has NICE recommended on newer drugs for epilepsy in children?	7
What should I do next?	11
Will NICE review its guidance?	11
Further information	12

What is NICE guidance?

The National Institute for Clinical Excellence (NICE) is part of the NHS. It produces guidance (recommendations) on the use of medicines, medical equipment, diagnostic tests and clinical and surgical procedures within the NHS in England and Wales.

To produce this guidance, NICE looks at how well the medicine, equipment or procedure works and also how well it works in relation to how much it costs. This process is called an appraisal. The appraisal process involves the manufacturers of the medicine or equipment for which guidance is being produced and the organisations that represent the healthcare professionals, patients and carers who will be affected by the guidance.

NICE was asked to look at the available evidence on the use of some relatively new medicines for epilepsy in children. NICE was asked to provide guidance that will help the NHS in England and Wales decide when these newer medicines should be used.

What is epilepsy?

People with epilepsy have repeated seizures (sometimes called fits), when the brain stops working normally for a few minutes. There are many different types of seizure. One type, which mainly affects children, is brief 'absences' where the child stops moving and loses attention for a second or two. Another type is tonic-clonic seizures, in which the person's body becomes rigid for up to a minute, then the muscles start to contract and relax in quick succession, resulting in jerking movements of the limbs for a few minutes. When this stops, the body goes limp and the person slowly regains consciousness.

Medicines are the main treatment for children with epilepsy. These are called antiepileptic drugs, and the aim is to stop the child having seizures. Some antiepileptic drugs work better for one type of epilepsy than another, or for some children better than for others. Finding the best drug for each child can mean trying more than one drug, to see which works best and has the least unwanted effects. It is not always possible to stop a child's seizures completely.

What are the newer drugs for epilepsy?

Some antiepileptic drugs, such as sodium valproate and carbamazepine, have been used to treat epilepsy for many years. But between 1989 and 2000 six new drugs that can be used to treat children under 16 came on to the market in the UK. These newer drugs are called gabapentin, lamotrigine, oxcarbazepine, tiagabine, topiramate and vigabatrin. NICE has looked at these drugs and recommended how they should be used to treat children with epilepsy.

NICE has also produced guidance on how these drugs should be used in adults (see page 12 for details). Another drug – called levetiracetam – can be given to young people over 16, and this is covered by the guidance on using the newer drugs for adults.

What has NICE recommended on newer drugs for epilepsy in children?

During the appraisal, NICE's Appraisal Committee read and heard evidence from:

- clinical studies of the new antiepileptic drugs
- doctors with specialist knowledge of epilepsy and its treatment
- individuals with specialist knowledge of the issues affecting children with epilepsy
- organisations representing the views of people who will be affected by the guidance (because they care for a child with epilepsy, or because they work in the NHS and are involved in providing care for children with the condition)
- the manufacturers of the newer antiepileptic drugs.

The evidence is summarised in the full guidance (see page 12 for details). More information about the studies is provided in the Assessment Report for this appraisal (see page 12 for details).

NICE has made the following recommendations about the use of newer drugs to treat children with epilepsy in the NHS in England and Wales.

If the older drugs do not stop the child from having seizures, one of the newer drugs can be tried, as long as it is suitable for the type of epilepsy the child has, and for the child's age. Lamotrigine, oxcarbazepine and topiramate can be given to children as their only treatment for epilepsy. They can also be given with another drug when that drug on its own does not stop a child's seizures (this is called combination therapy). Gabapentin, tiagabine and vigabatrin are generally used as combination therapy with another drug.

A newer drug can also be tried if the older drugs are unsuitable for the child. This could be because there is a reason why the child cannot take the older drugs (for example, some drugs are not suitable for people with liver disease), or because they cause unwanted effects that the child cannot tolerate. The older drugs might also be unsuitable if they affect another drug the child is taking. For young women with epilepsy, and girls who will probably need treatment into their adult life, some antiepileptic drugs are unsuitable because they might harm an unborn child.

NICE has recommended that vigabatrin is a suitable first treatment for young children with a rare type of epilepsy called infantile spasms or West's syndrome.

NICE recommends that children should be treated with just one antiepileptic drug where possible. If the first drug doesn't stop the child having seizures, another can be tried instead. The child's doctor will need to take special care when changing over from one drug to another.

If the child has tried different drugs that are appropriate for the type of seizures he or she has, and none of them stops the seizures on its own, another drug can be added. This is called adjunctive or combination therapy. If the first combination does not work, other combinations can be tried. If none of them completely stops the seizures, the child should take the single drug or combination of drugs that works best for him or her. The decision on what drug or drugs a child takes will depend on the drugs' unwanted effects as well as how good they are at preventing his or her seizures.

Particular care is needed when deciding what drug to use for young women and girls who will need treatment into their adult life. When women take antiepileptic drugs during pregnancy, this can sometimes harm the baby. There is not yet enough information to say what precise effects the newer drugs have on an unborn child. The choice of antiepileptic drug may also affect a young woman's choice of contraceptive so this needs to be discussed as well.

A child who has a seizure for the first time should see an epilepsy specialist as soon as possible, unless the seizure is a type called a febrile seizure, which only happens when the child has a fever. The specialist will try to find out exactly what type of epilepsy the child has, so that the best treatment can be started.

Children with epilepsy should see a doctor regularly to make sure they are taking the drug or combination of drugs that works best for them, and that they are taking it correctly.

NICE's recommendations apply to all children with epilepsy, including children with learning disabilities.

What should I do next?

If you are a child or young person with epilepsy, or a child you care for has epilepsy, you should discuss this guidance with your epilepsy specialist.

Will NICE review its guidance?

Yes. The guidance will be reviewed in December 2006.

Further information

The NICE website (www.nice.org.uk) has further information about NICE and the full guidance on newer drugs for epilepsy in children that has been issued to the NHS. The assessment report, which contains details of the studies that were looked at, is also available from the NICE website. A short version of the guidance (a 'quick reference guide') is available from the website and from the NHS Response Line by phoning 0870 1555 455 and quoting reference N0549.

NICE has also produced guidance on using the newer antiepileptic drugs in adults, which is available on the website. For printed copies, phone the NHS Response Line and quote N0453 for the quick reference guide, N0454 for the information for the public in English, and N0455 for the information for the public in English and Welsh.

If you have access to the Internet, you can find more information about epilepsy on the NHS Direct website (www.nhsdirect.nhs.uk). You can also phone NHS Direct on 0845 46 47.



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