epilepsy society

Epilepsy care – your rights

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Appropriate treatment and consistent medication

Our 'Epilepsy care – your rights' factsheets explain your rights and choices with regard to your epilepsy care and treatment. 'Rights' are in the NHS Constitution and the Handbook to the NHS Constitution, and you are entitled to them by law. Where we say 'you should', you may not have a legal right, but these are recommendations made in the NICE (National Institute for Health and Care Excellence) guideline on epilepsy.

You have a right to access NHS services and to treatment options that are appropriate for you.

> *You have the right to access NHS services. You will not be refused access on unreasonable grounds. NHS services will always be available for the people who need them. No one can deny you the right to access these services because of your age, disability, race, gender or gender reassignment, sexual orientation, pregnancy and maternity, religion or belief, or marital or civil partnership status. Handbook to the NHS Constitution*
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> *You have the right to drugs and treatments that have been recommended by NICE for use in the NHS, if your doctor says they are clinically appropriate for you. NHS Constitution*

If your treatment is available on the NHS, you have a right to access this treatment. No one can deny you this right on unreasonable or discriminatory grounds. If the drug that is most suitable for your epilepsy is recommended by NICE and by your doctor, you have a right to receive it. This depends on:

- the drug being 'clinically appropriate' (that it is the right drug for your epilepsy, seizures, and for you); and
- the drug has been through a health technology appraisal.

The NICE guideline lists anti-seizure medications (ASMs), previously known as anti-epileptic drugs or AEDs, that are recommended for different types of epilepsy and seizures, which have been recommended through health technology appraisals.

In addition to the guideline on epilepsy, NICE also publishes 'technology appraisal' guidance (TAs). This type of guidance evaluates the clinical and cost effectiveness of different medicines, tests, or devices, so that patients receive the best treatments, and the NHS makes the best use of its resources. They are often done for new treatments so that these can be recommended within the NHS. NICE uses evidence for the appraisal, which is reviewed and evaluated by an independent review group to look at the benefits and costs.

There may be other drugs that have not been through an appraisal (for example, newer drugs), which may be useful for you.

Consistency of supply

Most ASMs have two names, a generic name (for example carbamazepine) and a brand name given by the manufacturer (for example Tegretol). Some ASMs have more than one generic version, each of which can be given its own name. These are called branded generics. For some ASMs, different versions of the drug can vary slightly, and this could affect seizure control.

The Medicines and Healthcare products Regulatory Agency (MHRA) has issued guidance on prescribing ASM, and have split ASMs into three categories. They say that ASMs in category 1 must be prescribed with the same version (consistency of supply), and that for other ASMs, in categories 2 and 3, this is less important.

This aims to help doctors decide whether they should prescribe a particular version. However, your doctor should look at your individual circumstances to see what will be best for you.

The MHRA also advises that 'patient perception' should be considered. So if you are worried about being switched from one drug to another, this should be considered.

For more information visit:
epilepsysociety.org.uk/generic-branded
gov.uk/drug-safety-update/antiepileptic-drugs-updated-advice-on-switching-between-different-manufacturers-products
nhs.uk/NHSConstitution
gov.uk/government/publications/supplements-to-the-nhs-constitution-for-england
nice.org.uk/guidance/ng217

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