epilepsy society

Epilepsy care – your rights

Your care plan/review

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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 should have a care plan agreed with your healthcare professionals, which should include details of your care and support. You should also be able to have reviews of your epilepsy.

> *Your specialist should “develop an individualised antiseizure medication treatment strategy with the person, and their family and carers if appropriate. NICE clinical guideline*
>
> *Make a joint decision or plan about treatment or care, and agree together when this will be reviewed. NICE clinical guideline*

When you are discussing a treatment plan with your specialist, they will identify the treatment best suited to your epilepsy and seizures. For example, some anti-seizure medications (ASMs), work better for certain types of seizures than others.

However, this should be a shared decision with you and they should also take into account your overall health (such as whether you take drugs for any other condition), personal circumstances, and preferences. For example, some ASMs might make you feel tired so they might be best avoided if you are working or studying.

There is specific guidance about prescribing the ASM Sodium Valproate for people under the age of 55. Topiramate and some other ASMs are a particular issue for women and girls.
Visit epilepsysociety.org.uk/sodium-valproate
Visit epilepsysociety.org.uk/women-and-girls
Visit epilepsysociety.org.uk/living-epilepsy/pregnancy-and-epilepsy

You should be offered a care planning session with your epilepsy specialist nurse (ESN), if you have one. This session should take account of your emotional and mental well-being and should provide you with information and encourage you to fully take part in your own treatment and care.

A care plan for your epilepsy should be like a ‘road map’ of your condition, and its treatment and management. It should have information about your epilepsy and seizures, and your treatment, including what treatment you are on, any treatments you are starting, or what might be considered in the future.

The care plan should also cover other issues that may be important to you, such as education, work, driving, wellbeing, and starting a family.
Visit epilepsysociety.org.uk/living-epilepsy

The care plan should be made by you and your healthcare professionals together. You might want to involve your family, carers, or anyone else important to you, as they may help you to make decisions about your epilepsy.

Developing a care plan together means that you can make informed choices about your epilepsy and know what to do if things change over time. Your plan should be reviewed and updated when needed.

Reviews of your epilepsy

> *Patient-initiatied reviews should be available to all people with epilepsy. NICE clinical guideline.*

You can ask for a review of your epilepsy with either your GP, ESN, or your specialist, depending on how your epilepsy is. The review should look at your epilepsy, how it is managed, and your care plan. It should also include leisure and lifestyle issues, as well as mental health and psychological issues. It should be an opportunity for you to discuss if anything has changed and any other issues that are important to you at that time.

Certain groups of people should be offered regular, at least yearly, reviews, for example, people with complex epilepsy, other health conditions such as learning difficulties (see below), children, or girls and women taking high risk ASM.
Visit epilepsysociety.org.uk/pregnancy-and-epilepsy
epilepsysociety.org.uk/your-appointment-or-review

If your epilepsy is not well controlled, your doctor may suggest that a referral would be helpful. This might be to a specialist in tertiary care to help improve your epilepsy management. 'Tertiary care' refers to specialist hospitals or units that focus on specific care for different conditions. For example, if someone is being considered for epilepsy surgery, they might be seen in tertiary care. You have to be referred to tertiary care from either primary or secondary care.
Visit epilepsysociety.org.uk/about-epilepsy/care-and-treatment/referral-tertiary-care

The doctor may also suggest that a referral to other support services might be helpful, such as to an occupational therapist.

If your seizures have been well controlled for a couple of years, your doctor may discuss with you the benefits and risks of gradually stopping your medication.

Other health conditions

Your care plan and treatment should take account of any other issues, such as mental health difficulties (and the impact a diagnosis of epilepsy can have on this), learning disabilities, autism, or dementia. You should receive appropriate support and your epilepsy care and treatment may need to involve other medical specialists in a multi-disciplinary team. You should be communicated with appropriately and in a way that you (or your carer) can understand, and you should be offered regular reviews (see above).

For more information visit:
nhs.uk/NHSConstitution
gov.uk/government/publications/supplements-to-the-nhs-constitution-for-england
nice.org.uk/guidance/ng217

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For a printed copy of this information, call our helpline.

Helpline
0300 102 0024
Information and emotional support.
Confidential.

Visit epilepsysociety.org.uk/helpline