

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 be involved in your health and care and to be given enough information to make informed decisions. Women and girls with epilepsy should be given information and support that is tailored to their needs.



You have the right to be involved in planning and making decisions about your health and care with your care provider or providers....and to be given information and support to enable you to do this. NHS Constitution



You should be as involved as you want to be in all discussions and decisions about your health and epilepsy management. Your healthcare professionals should make sure you have the information you need at the time you need it, and that it is given in a way that is useful for you so that you can understand how it affects you individually.

They should support you to make decisions. For example, making an informed decision about whether to start treatment with medication means having information about the options available, including the risks and benefits of taking, or not taking, medication, and having time to consider your decision.

Your situation, and your choices about treatment and care, may change over time. It is important that you are given information and support to make decisions at future appointments, or as your situation changes. In some situations, it might be appropriate for you to be referred back to services, or to new services, if they are better suited to meet your needs. For example, when young people transfer to adult services (usually at around 16 – 18 years of age) they should be given clear information and support in moving from paediatric services to adult services and they should be involved in planning the transition.

Both the NHS Constitution and NICE guideline recognise the importance of involving your family and carers in helping you to make informed decisions, if you would like them to.

Information for you



You have the right to be given information about the test and treatment options available to you, what they involve and their risks and benefits. NHS Constitution



Information is important to help you make choices throughout your epilepsy diagnosis, treatment, and management. This information must be clear, understandable, and balanced. Your healthcare professionals might use checklists of topics that you might want information on, or to discuss.

You should be given information and support to enable you to self-manage your epilepsy. You, and your family and carers, if appropriate, should also be given information about sources of information and support.

You should be given information about:

- epilepsy, including specific information about your epilepsy, seizures, and triggers;
- treatment options, including medication and the risks and benefits of medication and the importance of taking medication regularly, or surgery, depending on your type of epilepsy;
- any relevant issues around education or employment, depending on your age;
- practical issues such as driving, benefits, and financial support;
- lifestyle issues such as leisure activities, alcohol, and sleep;
- self-management issues such as looking after yourself;
- emotional and psychological issues such as the impact on memory and mood; and
- risk, and ways of reducing risks, accidents, and injuries, and first aid for seizures.

Some people with epilepsy may experience status epilepticus (prolonged or repeated seizures). Also, it is possible, but rare, to die due to epilepsy. Where appropriate, your specialist should give you information on your specific risk of sudden unexpected death in epilepsy (SUDEP) and how to minimise any risk.

For more information on SUDEP visit epilepsysociety.org.uk/SUDEP

Information for women and girls

You should be given information, that is appropriate to your age and development, about:

- contraception;
- folic acid supplements;
- conception;
- pregnancy;
- breastfeeding;
- caring for children; and
- menopause.

This information should be reviewed regularly.

If you are of child-bearing age or are likely to be taking anti-seizure medication (ASM) when you reach child-bearing age, you should be given information about the risks to an unborn child while taking ASM during pregnancy.

Visit epilepsysociety.org.uk/living-epilepsy/pregnancy-and-epilepsy/are-there-risks-my-baby

Specifically, you should be given information about the risks of using sodium valproate or topiramate during pregnancy. The Medicines and Healthcare products Regulatory Agency (MHRA) has issued guidance and information on the risks of taking ASM and particularly any form of sodium valproate and topiramate during pregnancy.

If you are thinking of starting a family it is essential to talk to your neurologist about planning your epilepsy treatment for your pregnancy and for when your baby arrives. It is important to have this discussion before you become pregnant. If you are already pregnant, you should see your specialist as soon as possible.

For more information visit:

gov.uk/government/publications/epilepsy-medicines-and-pregnancy

gov.uk/guidance/valproate-use-by-women-and-girls

epilepsysociety.org.uk/women-and-girls

nhs.uk/NHSCConstitution

gov.uk/government/publications/supplements-to-the-nhs-constitution-for-england

nice.org.uk/guidance/ng217

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Every effort is made to ensure that all information is correct at the time of printing. Please note that information is intended for a UK audience. This information is not a substitute for advice from your own doctors. Epilepsy Society is not responsible for any actions taken as a result of using this information.

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

Helpline

0300 102 0024

Information and emotional support.
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Visit epilepsysociety.org.uk/helpline

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