

## **Epilepsy care – your rights**

Early access to specialist diagnosis and care

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.



After a first seizure, or a seizure after a period of being seizure free, you should see a specialist within two weeks. You have a right to be treated by appropriately qualified and experienced staff.



Refer children, young people and adults urgently (for an appointment within 2 weeks) for an assessment after a first suspected seizure. NICE clinical quideline

People presenting with a suspected first seizure should be referred urgently to ensure that a specialist is involved early in diagnosing epilepsy. Diagnosing epilepsy can be complex and involving a specialist can help avoid misdiagnosis and ensure that the person receives the right care and support. NICE clinical guideline

The staff who provide NHS services must be appropriately qualified and have the experience needed to do their jobs well. Handbook to the NHS Constitution



You have the right to be treated by qualified and experienced NHS staff. If epilepsy is suspected, adults should be referred to a specialist and children and young people should be referred to a paediatrician (children's doctor). Both should be experts in diagnosing and assessing first seizures and epilepsy.

You should be referred for any necessary diagnostic tests (such as an Electroencephalogram - EEG or Magnetic Resonance Imaging – MRI) which should be done within six weeks. There is no single test to diagnose epilepsy but an MRI or EEG can help. The two week referral and six week referral times are guidelines and it can take longer. You might get an earlier appointment if you tell the hospital you can take a cancellation at short notice.

If you have been seen after one seizure, you should be given an individual assessment of your risk of having another seizure. You should be given information about how to recognise another seizure, first aid and safety, how to minimise any risk, and what to do if another seizure happens. The sooner epilepsy is diagnosed, the quicker you and your specialist can start planning your treatment. Getting your seizures under control as soon as possible can mean fewer seizures, and less impact on your physical and emotional health. You should also have access to an epilepsy specialist nurse (ESN) for information, education, and support.

For more information visit: epilepsysociety.org.uk/diagnosis epilepsysociety.org.uk/after-a-first-seizure nhs.uk/NHSConstitution 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.

0300 102 0024

Confidential. Visit epilepsysociety.org.uk/helpline for opening hours.

Information and emotional support.

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