Epilepsy care pathway

Care and treatment: your rights and choices - "You have a right" indicates things you are entitled to by law. "You should" indicates things that are a recommendation. For more, visit epilepsysociety.org.uk/care-and-treatment epilepsy society

- 1. After a first seizure, you should see a specialist within two weeks.
- 2. You have a right to choose who provides your care.
- 3. If your epilepsy is difficult to diagnose or manage, you should be referred to a 9. You are entitled to free prescriptions. tertiary service for specialist care and treatment.
- 4. You have a right to access NHS services and to treatment options that are appropriate for you.
- 5. You have the right to be involved in your health and care and to be given enough information to make informed decisions.
- 6. You should have a care plan agreed with your healthcare professionals.

- 7. You have a right to access your own health records.
- 8. You have a right to NHS dental care.
- 10. You, and your carer, are entitled to ask for a health and social care assessment. You may be entitled to welfare benefits.
- 11. You have a right to be treated with dignity and respect and to not be discriminated against.
- 12. You have a right to complain about NHS services or treatment.
- 13. You have responsibilities as well as rights.

Primary care

First Seizure

Visit epilepsysociety.org.uk/ after-a-first-seizure

Epilepsy specialists

Visit the website of your local NHS Hospital trust for details of epilepsy specialists and services near you.

For a list of trusts visit england.nhs.uk/publication/ nhs-provider-directory/

See your GP

If your GP suspects epilepsy, they will refer you to hospital to see a specialist with expertise in epilepsy. You should be seen within 2 weeks and you should be able to choose the hospital you go to.

A & E

Examination and investigations eg scans and blood tests.

Definitions

- **Primary care** includes your GP surgery or pharmacy. It is usually the first place you will go for help with anything medical.
- Secondary care includes local hospitals and clinics, with specialists such as neurologists or paediatricians. You usually have to be referred by your GP. It also includes A&E.

Secondary care

Hospital appointment with neurologist

Your medical history will be taken and you should be referred for tests to be done within 6 weeks. Bring someone who has seen your seizures, or a recording of seizures on a mobile phone if possible. You should be given information and advice about the risk of a second seizure.

Tests

These could include an MRI (magnetic resonance imaging) scan, EEG, (electroencephalogram), blood tests, and any other appropriate tests with a relevant specialist.

Visit epilepsysociety.org.uk/ tests-for-epilepsy

Second seizure/ diagnosis of epilepsy

Discuss treatment, safety and risks, and any other relevant information with your specialist, and involve a family member or friend if appropriate.

Initial treatment

Most people begin by taking a single anti-seizure medication (ASM), starting at a low dose and gradually increasing it until the most effective dose is found. If seizures continue, an alternative ASM may be tried. If seizures are not controlled with a single ASM another drug may be added.

Visit epilepsysociety.org.uk/anti -seizure-medication

Time to think

You should be given information and have time to think, discuss, and ask questions about how your epilepsy affects you. This might include lifestyle issues such as driving, work, education, leisure activities, and starting a family. You may want to talk to our helpline (see below).

See warnings and guidance about sodium valproate for people under the age of 55, and topiramate in pregnancy.

Visit epilepsysociety.org.uk/sodium-valproate epilepsysociety.org.uk/are-there-risks-my-baby

Starting treatment

Your neurologist should discuss the choice of ASM and possible side effects, and talk about what to do if your seizures continue or if you are concerned about side effects. This is a time to develop an epilepsy care plan with your specialist or epilepsy specialist nurse (ESN). This is an overview of your epilepsy, its treatment and management, and other issues important to you.

It might help to keep a record of your seizures in a seizure diary. Visit epilepsysociety.org.uk /seizure-diaries Taking the treatment. Monitoring the outcome.

The aim is to get the best seizure control with minimum side effects.

Seizures controlled. You are getting on well with treatment

After a year seizure free, you may be discharged back to your GP. You can ask your GP for a review of your epilepsy. You should be referred back to a specialist if other conditions are diagnosed or if you need specific advice such as about starting a family.

Seizures not controlled or concerns about side effects

You can ask for a review of your treatment with your specialist or ESN.

Your specialist may try alternative ASMs or a combination of ASMs.

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Further treatment

Alternative ASMs may be tried but, if these are not working, other forms of treatment may be considered, such as specialist diet, brain surgery, vagus nerve stimulation (VNS) therapy, and supportive therapies (eg psychology for memory problems or occupational therapy for help with daily living).

Visit epilepsysociety.org.uk/treatment

Seizures continue despite trying different drugs

You should be referred to tertiary care for a further assessment of your epilepsy. Other treatment options may be appropriate.

You should be referred to an alternative specialist if you have a diagnosis of non-epileptic seizures.

For more detailed information visit epilepsysociety.org.uk/care-and-treatment

For the full NICE guideline visit nice.org.uk/guidance/ng217

Prolonged or repeated seizures/status epilepticus

Emergency treatment. Your specialist should talk to you about emergency treatment options.

Definition

Tertiary care – specialist care in hospitals or units for specific conditions (for example, detailed assessment or surgery for epilepsy). You have to be referred to tertiary care from either primary or secondary care.

Epilepsy Society is grateful to Dr F J Rugg-Gunn, Consultant Neurologist & Honorary Associate Professor, Clinical Lead, Chalfont Centre for Epilepsy, who reviewed this information.

Epilepsy Society

Tertiary care

Chesham Lane, Chalfont St Peter, Buckinghamshire SL9 ORJ

For a printed copy of this information contact our helpline.

Helpline 01494 601400

epilepsysociety.org.uk/helpline Information and emotional support. Confidential, national call rate.

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.

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