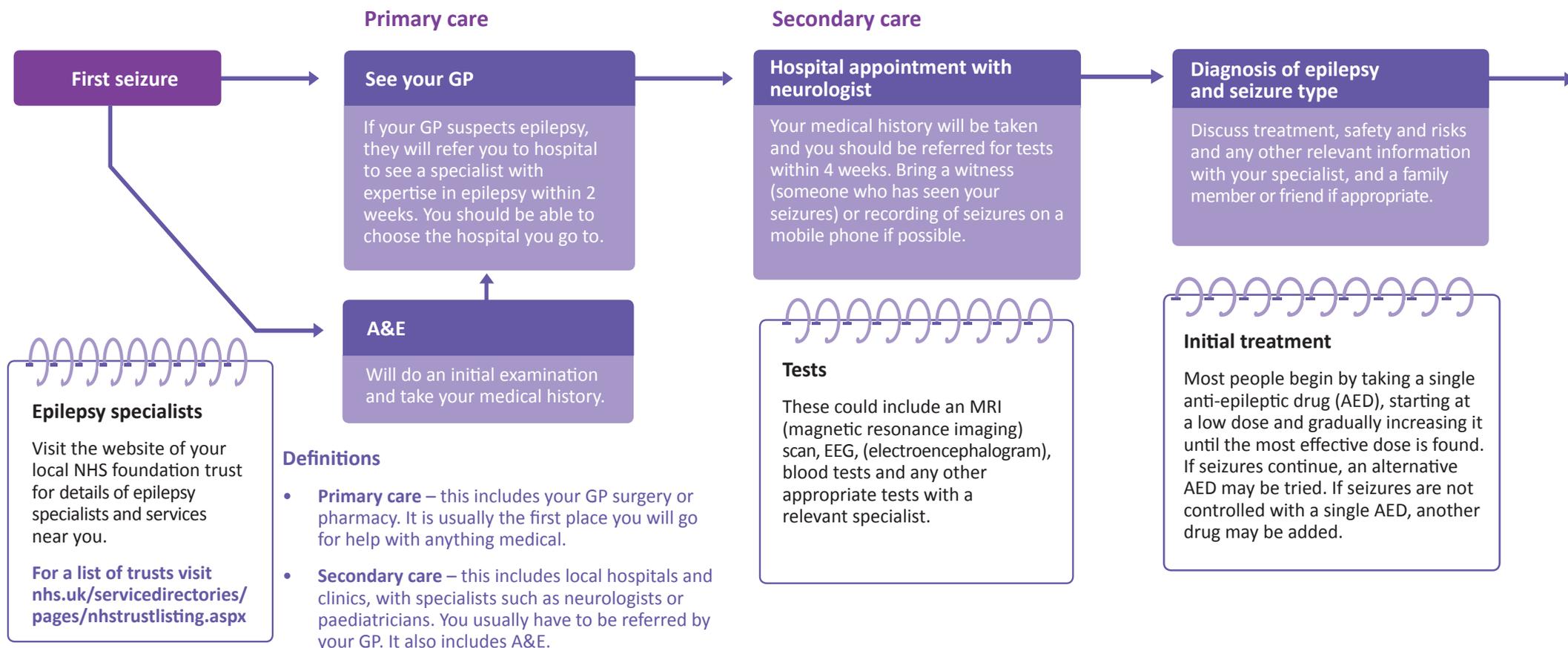


- After a suspected seizure you should be seen by an epilepsy specialist within two weeks.
- If your seizures are not controlled, or your diagnosis is not clear, you should be referred to tertiary care.
- You have the right to appropriate treatment options, and should have a consistent supply of your medication.
- You are entitled to nhs dental care and free prescriptions.
- You have the right to be involved in your healthcare.

- You should have a comprehensive care plan.
- You have the right to choose who provides your care.
- You have a right to access your own health records.
- You are entitled to ask for a health and social care assessment.
- You have the right to be treated with dignity and respect and to not be discriminated against.
- You have a right to complain about services or treatments.
- You have responsibilities as well as rights.



“You have a right” indicates things you are entitled to by law. “You should” indicates things that are a recommendation.

**Time to think**

You should 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 the Epilepsy Society helpline.

See warnings and guidance about sodium valproate for women and girls [gov.uk/guidance/valproate-use-by-women-and-girls#toolkit](http://gov.uk/guidance/valproate-use-by-women-and-girls#toolkit)

**Starting treatment**

Your neurologist should discuss the choice of AED 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. 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.

**Taking the treatment and monitoring the outcome**

**Seizures controlled and you are getting on well with treatment**

You should have an annual review with your GP. They should refer you back to your specialist if other conditions are diagnosed or if you need specialist advice, such as on starting a family.

**Seizures not controlled or you have concerns about side effects**

Your GP should refer you back to your specialist to try alternative treatments or to tertiary care for a further assessment of your epilepsy.

Aim to get the best seizure control possible with minimum side effects. You should have a review of your treatment, every 6 months to 1 year, with your specialist.

**Tertiary care**

**Seizures continue despite trying different drugs**

You should be referred to an epilepsy specialist centre for investigations, such as videotelemetry or MRI. You might consider other treatment options (see further treatment box).

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

**Prolonged or repeated seizures/status epilepticus**

Your specialist should talk to you about emergency treatment options.

**Further treatment**

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

**Definition**

- **Tertiary care** – this is 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.

For more detailed information visit [epilepsysociety.org.uk/care-treatment-rights-choices](http://epilepsysociety.org.uk/care-treatment-rights-choices)

Visit [nice.org.uk/CG137](http://nice.org.uk/CG137) for the full NICE guideline.

**epilepsysociety.org.uk**

f i t

**helpline**  
**01494 601 400**

Monday and Tuesday 9am to 4pm,  
Wednesday 9am to 7.30pm.  
Confidential. National call rate.