Getting the right treatment and care for your epilepsy

On this page we explain what should happen at each stage of your epilepsy treatment and care. We explain what your rights are, and what standards you should be able to expect from health and care services.

We also talk about the different organisations, guidelines and initiatives that can help you get the right treatment and care. You can find out more about them at the bottom of the page.

The information on this page applies to people in England and Wales. Sometimes we mention something that only applies in England. Where this is the case, we make it clear. We will update this page with information about epilepsy treatment and care in Scotland and Northern Ireland in the future.

What should happen if I've had a suspected first seizure?

If you go to A&E (Accident and Emergency) after your first seizure, they might do some tests to try and work out what caused it. It’s unlikely you’ll be diagnosed with epilepsy after a single seizure. If the doctors at A&E suspect you may have epilepsy they should arrange for you to have an outpatient appointment with an epilepsy specialist. Or they might ask your GP to arrange this. An epilepsy specialist is a neurologist with training and expertise in diagnosing and treating epilepsy.

You may not need to go to A&E after a suspected first seizure, but might go to your GP. If they think you’ve had an epileptic seizure, they should arrange an appointment for you with an epilepsy specialist.

The hospital or your GP should give you advice on what to do if you have another seizure while you are waiting for your appointment with the specialist.

How long should I have to wait to see a specialist for the first time?

The National Institute for Health and Care Excellence (NICE) guidelines on epilepsy say that after a first suspected seizure, you should see an epilepsy specialist within 2 weeks of your GP making the referral. ¹

The NICE guidelines are recommendations, and not law. The actual length of time it takes to see a neurologist for the first time is likely to depend on how many appointments are available and how many people are on the waiting list. But you should be seen within NHS maximum waiting times. In England, the NHS Constitution says you have a legal right to see

¹ Epilepsies: diagnosis and management | after-a-first-seizure | Information for the public | NICE. Available at: https://www.nice.org.uk/guidance/cg137/ifp/chapter/After-a-first-seizure [Accessed November 1, 2016].
a specialist and start treatment within 18 weeks of your GP making a referral. In Wales, NHS targets say you should be able to start treatment within 26 weeks.

**What should happen when I see the specialist for the first time?**

The epilepsy specialist should use information about what happened before, during and after your seizure, and any other symptoms you have, to help them make a diagnosis. Sometimes they will be able to tell you there and then if they think you have epilepsy. Sometimes they may ask you to have some tests to help them make their diagnosis. They should explain what will happen during the tests, and why they want you to have them.

**How should my epilepsy be treated?**

**Care plans**

If the specialist diagnoses you with epilepsy, they should tell you about possible treatment options. They should also agree an epilepsy care plan with you. This should cover your treatment, what to do if you have a seizure, and any preferences or lifestyle issues you have discussed. See our information about care plans to download or order a template care plan.

**Epilepsy medicines**

The main way to control your seizures is with epilepsy medicine. NICE has a list of medicines it recommends for treating epilepsy. In England, the NHS Constitution says that if NICE recommends a medicine or treatment, you have a legal right to have access to it. This is as long as your specialist thinks it is the best treatment for you. The NHS in Wales also follows NICE’s recommendations of which medicines to prescribe.

Sometimes an epilepsy medicine comes onto the market in the UK, but NICE doesn’t look at it straight away. When this happens your specialist may still be able to prescribe the medicine for you, but only if the NHS in your local area has decided it will pay for it. In England, the organisations that make these decisions are called Clinical Commissioning Groups. In Wales, the All Wales Medicines Strategy Group makes these decisions.

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4 Epilepsies: diagnosis and management | appendix-e-pharmacological-treatment | Guidance and guidelines | NICE. Available at: [https://www.nice.org.uk/guidance/CG137/chapter/Appendix-E-Pharmacological-treatment](https://www.nice.org.uk/guidance/CG137/chapter/Appendix-E-Pharmacological-treatment) [Accessed November 1, 2016].


7 All Wales Medicines Strategy Group. Available at: [http://www.awmsg.org/industry_nice.html](http://www.awmsg.org/industry_nice.html) [Accessed November 9, 2016].
Epilepsy medicine is available in different versions made by different companies. NICE says that while you are taking an epilepsy medicine, you should be able to stay on the same manufacturer’s version of it. This is unless you and your doctor don’t feel that switching versions would cause any problems. For more information see getting the same version of your epilepsy medicine every time.

Free prescriptions

If you take medicine to treat your epilepsy, you can get all your prescription medicines for free. Find out more about free prescriptions.

How often should I have a review of my treatment? NICE says you should have a review of your epilepsy treatment at least once a year. For adults, this is usually with your GP, but sometimes it should be with an epilepsy specialist. Examples of times you might need to see a specialist for your review include:

- If you continue to have seizures
- If you have side-effects from your epilepsy medicines
- If you are a woman planning a pregnancy
- If you want to stop taking epilepsy medicine

Children and young people should have their review with a specialist, at least once a year, but more often if needed.

Can I choose which hospital I see a specialist at?

In England, the NHS Constitution says you have a right to choose which hospital you see a specialist at, as long as that hospital offers the services you need. But if you need to see a specialist urgently (for example after you’ve had a seizure for the first time), it’s unlikely you will be able to choose which hospital you go to. This is because there may not be a choice of hospitals that can see you quickly. In this case, it’s likely your doctor will refer you wherever the earliest appointment is available.

Examples of situations where you might get to choose which hospital you go to include:

- You and your doctor think you need a second opinion
- You already have a diagnosis of epilepsy but have never seen an epilepsy specialist
- You already have a diagnosis but haven’t seen an epilepsy specialist for many years

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8 Epilepsies: diagnosis and management | I-guidance | Guidance and guidelines | NICE. Available at: https://www.nice.org.uk/guidance/CG137/chapter/1-Guidance#management [Accessed November 1, 2016].

9 Epilepsies: diagnosis and management | I-Guidance | Guidance and guidelines | NICE. Available at: https://www.nice.org.uk/guidance/cg137/chapter/1-Guidance#review [Accessed November 10, 2016].

• You already have a diagnosis of epilepsy but have been discharged from your epilepsy specialist and now need a specialist review of your epilepsy

**What if my seizures are difficult to control?**

If your epilepsy is difficult to control, your specialist might refer you to a specialist epilepsy centre. This is sometimes called a tertiary centre or tertiary service. NICE says your specialist should refer you to a specialist centre if:

• Your seizures are not controlled with epilepsy medicines within 2 years of starting them
• You have tried 2 or more different types of epilepsy medicine, but these have not worked
• They are not sure what type of epilepsy or seizures you have
• You have, or are at risk of, severe side-effects from epilepsy medicine
• You have a psychological or psychiatric condition
• There is something abnormal in your brain\(^\text{11}\)

NICE also says that all children with epilepsy aged under 2 should be referred to a specialist centre.\(^\text{12}\)

The specialist centre should have a team of professionals who are experienced in assessing people with epilepsy that is difficult to control. They should have access to investigations and medical and surgical treatment.

**What can I do if I’m not happy with my treatment or care?**

If you are unhappy with any part of your epilepsy treatment or care, you could:

• Talk to the people involved
• See a different healthcare professional
• Make a complaint

**Talk to the people involved**

Talking to the people involved can sometimes be the easiest way to resolve any problems. You could talk to your GP, the GP practice manager, your epilepsy specialist or epilepsy nurse. They may be able to reassure you, or make sure that the problem doesn’t happen again. Your specialist should be able to explain why they have made their diagnosis, or why they think the treatment they are recommending is right for you.

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\(^\text{11}\) Epilepsies: diagnosis and management | 1-guidance | Guidance and guidelines | NICE. Available at: https://www.nice.org.uk/guidance/CG137/chapter/1-Guidance#referral-for-complex-or-refractory-epilepsy [Accessed November 3, 2016].

\(^\text{12}\) Epilepsies: diagnosis and management | 1-guidance | Guidance and guidelines | NICE. Available at: https://www.nice.org.uk/guidance/CG137/chapter/1-Guidance#referral-for-complex-or-refractory-epilepsy [Accessed November 3, 2016].
See a different healthcare professional

If you’re not happy with your treatment from a GP, you could book an appointment with a different GP at the same surgery. If you don’t feel happy seeing any of the GPs at your current surgery, you have the right to leave and register with a different surgery.

If you want to see a different specialist, see Can I get a second opinion from a different specialist?

Make a complaint

You have the right to complain about any aspect of NHS care or treatment, and to have your complaint dealt with properly. See the end of this page for details of organisations that can help if you want to make a complaint. You can also find out more about how to complain about an NHS service on the NHS Choices website.

Can I get a second opinion from a different specialist?

If you’re not happy with the diagnosis or treatment recommended by your current specialist, you might consider asking for a second opinion. You don’t have a legal right to a second opinion, but if you ask for one your GP or specialist should consider your request.

There are 2 ways you can ask for a second opinion:

- Ask your current specialist to arrange for you to see someone else
- Ask your GP to refer you to a different specialist

Getting a second opinion from a different specialist doesn’t automatically mean they’ll take over your care. If you want to be treated by the new specialist you’ll need to arrange this with the hospital. The Patient Advice and Liaison Service (PALS) may be able to help. See useful organisations for more information about PALS.

What if I need extra care and support?

If your epilepsy means that you need extra care and support, you may qualify for help from your local social services. You have the right to ask your local authority for a needs assessment to see if this is the case. A carer, friend, family member or your GP can also ask for a needs assessment for you.

During a needs assessment, your local social services team will look at how you cope with day-to-day living, and identify if you might need support from social care services. The type of support you get will depend on your individual needs, but can include things like:

- Getting you a seizure alarm
- Making adaptations to your home to make it safer for you
- Getting you some help with household tasks, such as cooking and cleaning
- Moving you to more suitable accommodation
Carers UK has more information about needs assessments.

Local authorities are legally obliged to carry out a needs assessment for anyone who might need extra care and support. If they decide you are eligible to get help through social care services, they also have a duty to provide this help to you. How much of this help they pay for and how much you have to pay towards it is based on your individual circumstances.\(^\text{13}\)

If you need extra care and support, you may also be entitled to some benefits.

Complaints about social care services

If you are not happy with your needs assessment, you can complain to your local authority. They have a duty to investigate your complaint. If they can’t resolve your complaint, you can ask the Local Government Ombudsman to investigate.

Guidelines and initiatives

National Institute for Health and Care Excellence (NICE)

NICE gives advice to the NHS on caring for people with specific conditions or diseases and the treatments they should receive. NICE’s advice about epilepsy is set out in its guideline The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. The advice in this guideline applies to England and Wales.

The NHS Constitution

The NHS Constitution sets out your legal rights as an NHS patient in England. These rights include access to health and community care services, and to quality care and treatment. They also cover your right to confidentiality, information, and the right to complain if things go wrong.

Useful organisations

Clinical Commissioning Groups (CCGs)

CCGs are NHS bodies responsible for the planning and commissioning of health care services for their local area. This includes deciding what medicines and treatments people in their area can have. Your local CCG can give you information about how to get involved with decisions about services and treatment in your area. The NHS choices website has a search tool to help you find your local CCG.

Patient Advice and Liaison Service (PALS)

Most hospitals in England have a PALS office. PALS gives free, impartial advice to help you resolve any issues with your NHS treatment or care. They can also give you information on how to complain, and tell you where to get help with making a complaint.

You can find your nearest PALS office on the NHS choices website.

Healthwatch England

Healthwatch England gathers evidence on issues in health and social care and uses this evidence to influence national health policy. They have a network of local offices throughout England. To find your local Healthwatch office visit the Healthwatch England website.

Advocacy services

An advocate is someone who can speak up for you if you find it difficult to do so yourself. This could involve them talking to the healthcare professionals involved in your care, attending meetings and appointments with you, or helping you to make a complaint. Advocate services are free and independent of the NHS and social services.

Contact your local council to find an advocacy service near you.

Community Health Councils in Wales

If you want to make a complaint about an NHS service in Wales, the Community Health Council (CHC) in your area can give you advice and support. You can find your local CHC on the CHC website.

Citizens Advice

Citizens Advice provides advice to everyone on their rights and responsibilities. They have information about your rights as an NHS patient and how to complain about NHS or social care services.
About this information
This information is written by Epilepsy Action’s advice and information team, with guidance and input from people living with epilepsy, and medical experts. If you would like to know where our information is from, or there is anything you would like to say about the information, please contact us at epilepsy.org.uk/feedback

Epilepsy Action makes every effort to ensure the accuracy of information but cannot be held liable for any actions taken based on this information.

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Your support
We hope you have found this information helpful. As a charity, we rely on donations to provide our advice and information. If you would like to make a donation, here are some ways you can do this.

- Visit www.epilepsy.org.uk/donate
- Text ACT NOW to 70700 (This will cost you £5 plus your usual cost of sending a text. Epilepsy Action will receive £5.)
- Send a cheque payable to Epilepsy Action to the address below.

Did you know you can also become a member of Epilepsy Action from as little as £1 a month? To find out more, visit epilepsy.org.uk/join or call 0113 210 8800.

Epilepsy Helpline
Freephone 0808 800 5050, text 0753 741 0044, email helpline@epilepsy.org.uk, tweet @epilepsyadvice

Contact details
Epilepsy Action, Gate Way Drive, Yeadon, Leeds LS19 7XY, UK, +44 (0)113 210 8800. A registered charity (No. 234343) and company limited by guarantee (No. 797997) in England.

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