

What benefits may I be entitled to?

Having epilepsy does not automatically entitle you to claim benefits. These are some of the benefits you may be eligible to apply for, depending on how your epilepsy affects you, and your financial situation.

Attendance Allowance

Attendance Allowance helps with extra costs if your epilepsy means that you need someone to help look after you. You need to have reached State Pension age to claim Attendance Allowance.

Visit [gov.uk/attendance-allowance](https://www.gov.uk/attendance-allowance)

Visit citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/attendance-allowance

Disability Living Allowance (DLA) for children

Disability Living Allowance (DLA) for children may help with the extra costs of looking after a child with epilepsy who is under 16, and who needs more looking after than a child who does not have epilepsy.

Visit [gov.uk/disability-living-allowance-children](https://www.gov.uk/disability-living-allowance-children)

Visit citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/disability-living-allowance

Employment and Support Allowance (ESA)

You can apply for Employment and Support Allowance (ESA) if your epilepsy affects how much you can work.

Visit [gov.uk/employment-support-allowance](https://www.gov.uk/employment-support-allowance)

Visit citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/employment-and-support-allowance

Personal Independence Payment (PIP)

You may be able to claim for Personal Independence Payment (PIP), to help with extra costs, if you have a long-term disability or health condition, and have trouble doing some everyday tasks, or with getting around.

You can get PIP even if you're working, have savings, or are getting most other benefits.

Visit [gov.uk/pip](https://www.gov.uk/pip)

Visit citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip

Universal Credit

Universal Credit is a payment to help with your living costs. It's paid monthly - or twice a month for some people in Scotland. Universal Credit has replaced these benefits for most people:

- Housing Benefit;
- income-related Employment and Support Allowance (ESA);
- income-based Jobseeker's Allowance (JSA);
- Child Tax Credit;
- Working Tax Credit; and
- Income Support.

You may be able to get Universal Credit if you're on a low income, out of work, or if you cannot work.

Visit [gov.uk/universal-credit](https://www.gov.uk/universal-credit)

Visit citizensadvice.org.uk/benefits/universal-credit

What do I need to think about when claiming benefits because of my epilepsy?

If you are applying for a benefit, you will need to complete a form about how your condition affects you. Depending on the benefit you are applying for, the form may be online, or you may need to request a form by phone. Whether or not you are eligible for the benefit, and the amount of money you could be awarded, will depend partly on the answers you give on the form.

There are organisations that can give you advice about how to apply for benefits, and some may also be able to help you to complete the forms.

See back page 'Organisations that can help'.

Focus on how your condition affects you

Being eligible for benefits does not rely on your diagnosis, but on how your condition affects you. So when filling out the form, you need to focus on explaining how your condition affects you.

For example, instead of writing 'because I have epilepsy' you could write 'because my epilepsy affects me in the following ways...'

Include anything that you can't do because of your epilepsy. What do you need to do, or would like to do, that your epilepsy stops you doing?

You may be eligible to apply for some benefits. This factsheet signposts to information on what benefits may be available, and things to think about when you are claiming benefits because of your epilepsy.

Epilepsy Society Helpline
01494 601400
helpline@epilepsysociety.org.uk
Confidential, national call rate.
Information and emotional support.

Focus on a bad day

Although it can be difficult to do, always answer the questions on the basis of how things are on a 'bad day'. On a bad day, what happens to you and what could happen? What can't you do that you need to do?

What might you need help with? This might be help from a family member, a paid carer, or another person. But it also includes help such as grab rails, alarm reminders for medication, and seizure alarms. Whether you actually get this help or not, it is important to say what help you need, and what would happen if you didn't, or don't, get this help.

About your seizures

- What are your seizures like and how do they affect you? For example, do you lose consciousness, is your awareness affected, are you confused? How often do you have seizures?
- What happens to you before a seizure? What is a risk to you at these times?
- Do you get a warning that a seizure is going to happen? If you do, how long is it? Are you able to get to a safe place?
- If you do not get a seizure warning, how does the unpredictability of seizures affect you? For example, does this make you anxious about going out, or does it mean that you can't plan ahead?
- Do your seizures have any specific triggers?
- When are your seizures (day, or night time, or both)? Do you wander around during seizures and need someone to keep you safe?
- Are you incontinent (wet or soil yourself) during a seizure?
- Do you, or might you, injure yourself during a seizure? Use examples of when this has happened to you. If you have reports from your GP or hospital about injuries, you could include these.
- Do you need help when you have a seizure? This might be to keep you safe, to help if you injure yourself, or to help as you recover from the seizure. What could happen if there is no one around to help?
- After a seizure do you need to sleep and recover? Where might you be when this happens, and do you need help with this?
- How do you feel after a seizure – do you recover quickly or do you feel the after effects for a long time? Explain if your seizures have a lasting effect on you, such as feeling tired or confused. Are there any effects on your memory or changes in mood?

Risks to your safety

- What are the risks to your safety if you have a seizure? For example, if you fall without warning.
- Do you need to have a shower rather than a bath in case you have a seizure?
- What are the risks to you in situations such as gardening, shopping, or using public transport?

- If you have had any accidents or injuries in these situations, include real examples on the form.

Visit epilepsysociety.org.uk/safety-and-risk

Do you need 'supervision'?

Do you need someone with you most, or all of the time, perhaps because you have frequent or unpredictable seizures? Focus on what would happen if no one was around to support you when you have a seizure, and explain why this may be dangerous for you. You can write about how you need to have someone to help you, even if you don't already have that help.

Are there any practical things you don't do because of your epilepsy?

For example, if the risk of accidents during a seizure means that someone else currently does your ironing or cooking, you might say you don't need help with these tasks (because someone else does them for you). However, rather than saying 'I don't need help with these tasks' you could say 'I cannot do these tasks because of the risk of accident/injury'.

This helps to build up a picture of how epilepsy can stop you doing everyday tasks. Include any tasks that you can do but that you need help with. Explain what the help is and why you need it.

How does epilepsy affect all aspects of your life?

Does your epilepsy restrict your life, work, studying, or social or leisure activities? If so, in what ways? Epilepsy is not just a physical condition – it can also have a psychological impact. So include any effects on your emotional or mental health and your quality of life, so that this can be taken into account.

- Does your epilepsy, or living with seizures, affect your mood, such as worrying about seizures?
- Do you have mood swings, anxiety, stress, or depression?
- Do any mood problems you have affect your seizure control (make seizures more likely)?
- If you have concentration or memory problems, explain this in the form, including if you need help to remind or motivate you to do things.

Taking medication

- Do you take medication for your epilepsy? If so, does it affect you (for example, does it make you sleepy or drowsy)? Do you have any side effects?
- Do you always remember to take your medication or do you need help to remind you?

Medical results and other conditions

If you are waiting for the results of any tests or procedures, you can say this on your form, and then send the results when you get them.

Remember to describe the impact of any other medical conditions you have which also affect your daily living and activities.

Equipment and aids

- Do you need any equipment or safety aids, such as a seizure alarm, to help keep you safe?

Completing the form

Benefit forms can be long and complicated. Here are some general suggestions which you may find helpful.

Give yourself time to focus on the form

Your form will often be date-stamped, and give you a date when you need to return it by. The benefit may be back-dated (you get payment from the date you made the claim not from the date of the decision).

Although you need to complete it within the time limit, don't rush filling it in. The answers you give could make the difference between getting, or not getting, a benefit that supports your needs.

Tackle the form in sections and use pencil first

The forms are long and can feel daunting, so break the task into sections. Complete the form in pencil first so that you can change anything after you have written it. Perhaps come back to the form the next day so you can look at it with fresh eyes.

Imagine you are the person reading and assessing your form. Would you get a clear understanding of all the ways in which this person's epilepsy affects their everyday life?

Be honest

Some of the questions cover things which may seem very personal or embarrassing, such as going to the toilet, or washing and dressing yourself. It is important to honestly describe any difficulties you have with these tasks. These may be difficulties which your partner, family, or close friends don't even know about, but it's really important to provide a complete, and clear, picture of all aspects of your daily living.

Remember that it will be a professional reading your form. They need to understand fully how your condition affects you in order to assess your situation, and make an accurate decision on your claim, so that you get the help that you need.

Use words that work for you

Don't worry about using the correct 'medical jargon' when describing things – use whatever words you would normally use. If you know a medical name for the types of seizure you have, you can use it, but it is more important to describe what happens to you. This is because not everyone's seizures will be the same, and assessors reading your form may not know about seizure types.

For example, if you use the term 'tonic clonic seizures', also say 'this means that the following happens to me in my seizures...' Likewise, if your medication gives you 'the runs' or 'a runny tummy' then it's OK to say that instead of 'diarrhoea'.

Be clear and explain your epilepsy

Remember that the person reading the form may not know much about epilepsy, nor understand how epilepsy can affect someone's life. Also, every individual living with epilepsy will have their own experience. Something that affects you may not have the same impact on someone else.

Explain what your epilepsy is like and how it affects you. Think of a 'bad day' when you have had a seizure and write about what happened. Also include what could have happened, such as if you had injured yourself or been in a dangerous situation.

Use a seizure diary

If you keep a diary of your seizures, this might help to show how often you have seizures and what happens.

Give as much relevant information as possible

Think about your everyday routine: what you do, what you would like to do, and how your epilepsy affects this. If you need to use extra sheets of paper for your answers, put your name and reference number on each sheet, and attach them firmly.

Answer all questions fully and **repeat information** each time it is relevant. Do not assume that the person reading the form will remember how you have answered one question when reading the next. Imagine that a different person reads each answer on your form separately. Would they be able to understand each answer as it stands on its own?

Provide additional information if the form asks for it

This might be medical information (such as a clinic letter or a psychological report) from your doctors, or information from a social worker or occupational therapist, for example. Keep a copy of all this information for your own records.

Talk it through with someone

Your friends or family may also be able to help you work out what you want to say in your form. They might be able to remind you of situations where your epilepsy has affected your daily living. If you find it difficult to describe something, you could practise what you want to say with someone else before writing it on the form.

If you find it difficult to talk to someone you know about some questions, then perhaps speak to a professional from an organisation which offers help with filling in benefit forms. You can also call our helpline. Although our helpline cannot fill in the forms for you, talking it through may help you to work out what you want to say on your forms.

See next page for 'Organisations that can help' and page 1 for helpline details.

Check your completed form

Does it make sense when you read it all together?

Have you used examples to explain how your epilepsy affects you? Remember, try to focus on how your epilepsy makes things difficult, rather than on how well you are coping with your epilepsy.

Keep a photocopy of your form

Keeping a copy of your form means you can refer to it at a later date, or use it to help you fill in other forms. This is particularly helpful when it comes to noting the dates of when things happened. It can also be helpful if you need to ask for your claim to be reconsidered or if you need to appeal against a decision. Appeals may have a higher success rate than initial applications.

Also, if your condition changes and you need to reapply for your benefit, you can use your original form for comparison, to make it quicker to fill in new forms.

If possible, get 'Proof of Posting' from the Post Office when you send in your form. This is a free service and is helpful if there are any queries about when your application was sent and received.

What if my claim is unsuccessful?

When a decision is made about your claim for a benefit, the Department for Work and Pensions (DWP) will write to tell you about the decision and why it was made.

If you are not happy with the outcome and you decide to challenge a benefits decision, the next steps need to happen in the following order, and you need to respond quickly (usually within one month) at each stage.

1. Challenge the benefits decision - ask for mandatory reconsideration.
2. Appeal the benefits decision if you are unhappy with the mandatory reconsideration decision.

For more about mandatory reconsideration and appeals visit gov.uk/browse/benefits/manage-your-benefit

or citizensadvice.org.uk/benefits/benefits-introduction/problems-with-benefits-and-tax-credits/challenging-benefit-decisions

Organisations that can help

If you are applying for benefits for the first time, reapplying after a change in your circumstances, or appealing a benefits decision, here are some organisations that may be able to help you.

Citizens Advice

0800 144 8848 (England)
0800 702 2020 (Wales)
0800 028 1456 (Scotland)

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.

028 9590 6505(Northern Ireland)

citizensadvice.org.uk

Information about benefits. Can also make an appointment at your local Citizens Advice.

Community Money Advice

01743 341929

communitymoneyadvice.com

A national charity offering free advice, through community money advice centres, to help people overcome their money, or debt, problems.

Contact a Family

0808 808 3555

cafamily.org.uk

A charity for families with disabled children up to age 25. Offers benefits advice and information. They can help to explain complex decisions and how to proceed with appeals.

Disability Service Centre

gov.uk/disability-benefits-helpline

(gives different helpline numbers for each benefit).

Advice or information about a benefits claim you've already made.

Money Advice Trust

National Debtline 0808 808 4000

moneyadvicetrust.org

nationaldebtline.org

A charity offering free, confidential and independent advice on money and debt management.

Scope

0808 800 3333

scope.org.uk

Information and advice on benefits for people with disabilities.

Turn2us

0808 802 2000

turn2us.org.uk

Help with accessing benefits, grants and other financial help, including a benefits calculator.

For a printed copy of this information contact our helpline.

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