

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.



You, and your carer if you have one, are entitled to ask for a health and social care assessment. You may both be entitled to welfare benefits.

You can ask your local social services for a health and social care assessment (sometimes called a 'needs assessment') to see if you are eligible for help with care or support. This assessment looks at what difficulties or challenges you have due to your condition, and what help or support might be useful to overcome these.

Under the Care Act 2014, local authorities in England have a duty to provide assessments to people who need them and produce a care and support plan where necessary. Scotland, Wales, and Northern Ireland all have their own legislation.

Assessments look at how you are managing different aspects of your life such as daily living and practical tasks such as washing, dressing, and cooking.

The assessment might include:

- doing a risk assessment of your living arrangements to see if any equipment or adaptations might be helpful, such as a seizure alarm, furniture protection such as padding, or a shower; and
- whether you might benefit from having extra support, such as a carer or personal assistant, at home or when you go out.

Having an assessment does not mean that you are automatically entitled to help. What help you can get depends on your needs (how your epilepsy affects you) and your financial situation. You may be offered a financial assessment to identify what you might get local authority funding for.

Your local authority may fund some of your needs (depending on their criteria for funding). If your local authority agrees to pay for your care needs it must offer you choice and control. You should be offered a personal budget. If your local authority is not able to fund meeting your needs, you will usually be told what services and help are available, but you will have to fund these yourself.

Assessments are arranged through adult social care or social services from your local authority. You can either contact your local authority directly or ask your GP to refer you.

For more about health and social care assessments visit nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/getting-a-needs-assessment

To apply for a health and social care assessment visit gov.uk/apply-needs-assessment-social-services

NHS continuing healthcare

If your health needs are long-term, complex, or severe, you may be eligible for NHS continuing healthcare (CHC). If so, the NHS will fully fund your package of care. With NHS continuing healthcare, the NHS is responsible for funding some types of healthcare equipment and may also pay for meeting some social care needs. Usually this would be when the needs are mostly around healthcare rather than social care.

Visit nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare

Unpaid carers are entitled to a carer's assessment

If you have someone who cares for you (such as a family member or friend), but does not get paid to do so, they may be entitled to a carer's assessment. This is an assessment from social services to identify help or support needs for themselves. This might include the need for home help, equipment, or for respite care. Under the Care Act 2014, local authorities have a legal duty to provide services to carers if their carers assessment shows that they have support needs that fit the authority's criteria.

If you have had an assessment through your local authority, your carer should already have been told about their right to an assessment. Otherwise, your carer can still ask for their own assessment by contacting the local authority directly.

Benefits

People with epilepsy, and carers who care for them in an unpaid capacity, may be entitled to welfare benefits, for example, Disability Living Allowance (DLA – for children under 16 years), Personal Independence Payment (PIP – for working-age people) and Attendance Allowance (AA – for people over 65). These are benefits that do not depend on your income, or whether you work.

To be eligible for these benefits you need to have daily living, care, or mobility needs. You may be entitled to other benefits if you're on a low income, out of work, or if you're unable to work because of a health condition.

Some carers can claim Carer's Allowance. This benefit depends on their income and savings and is usually paid to people between the ages of 16 and 65, who spend at least 35 hours a week caring.

For your carer to be entitled to Carer's Allowance, you must get Attendance Allowance, Disability Living Allowance, or Personal Independence Payment yourself.

For more information visit:

nhs.uk/conditions/social-care-and-support

epilepsysociety.org.uk/carers

nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers

epilepsysociety.org.uk/epilepsy-benefits

citizensadvice.org.uk/benefits

gov.uk/check-benefits-financial-support

epilepsysociety.org.uk/what-help-available

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.

Helpline

0300 102 0024

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