

Who is a carer?

A carer is someone who looks after a family member, partner, or friend, who needs help because of a health condition, disability, or frailty, and who would not be able to manage without this help. All the care they give is unpaid. This information does not refer to someone who is in paid employment as a care worker.

Research carried out by Carers UK estimates the number of unpaid carers in the UK could be as high as 10.6 million and nearly 6 in 10 unpaid carers (59%) are women.

Not all carers are adults: in the 2023 school census, 38,983 pupils in England were recorded as young carers. However, research by the University of Nottingham and the BBC suggests that there are around 800,000 young carers under 18 in the UK.

Some people are carers for a short period of time, others for many years. Most of us provide care for someone else at some point in our lives.

Carers and epilepsy

Epilepsy can be different for each person, so the need for care can vary greatly. Some people with epilepsy do not need any additional care from others to live independent lives. Other people with epilepsy may need a lot of care, some, or all of the time. Some people only need care when they have had a seizure.

Even if a person does not have seizures very often, the need for care during or after a seizure may be urgent. Seizures can be unpredictable. Someone with epilepsy may not be able to plan when they will need help. If you care for someone with epilepsy, the things you do to support them may include:

- keeping them safe during a seizure;
- calling for medical help, or giving first aid or emergency medication;
- staying with them or seeing them home safely after a seizure;
- noting any pattern or trigger to their seizures, which may help if they don't remember their seizures;
- helping with their routine of taking medication;
- going with them to appointments, helping to take notes, or providing descriptions of seizures to the person with epilepsy and/or their doctor;

- acting as a representative or advocate for the person, with doctors, or others involved in their care;
- joining in with activities that might pose a safety risk if they were to have a seizure, such as swimming;
- providing transport if necessary; and
- helping them to adapt their home or lifestyle to provide a safe living environment.

Any of the above may be very valuable but may also mean a lot of responsibility for you as a carer.

People with epilepsy may also have other conditions, with additional care needs. Because seizures can be infrequent or unwitnessed by others, epilepsy can be a hidden condition. This can mean that other people do not see the need for care. For example, some local authorities providing social services may not always recognise epilepsy as a condition that has particular care needs.

For some people, living with epilepsy can have a psychological impact which may also affect you as their carer. This could include stress, depression, or mood changes.

The multi-skilled nature of caring

Caring can involve a number of skills: technical tasks such as dealing with medical equipment, emotional support, being able to adapt if needs change, or working with medical or care professionals. These roles may be in addition to other demands: your family, other relationships, work, home, financial needs, social life, your own health, and your hopes and wishes. You may cope well with multi-tasking in this way, or you may find that some areas of your life are being neglected.

Caring and relationships

If your child, parent, partner, or friend has epilepsy, you may find that you have a caring role that goes beyond that of being 'just' family, or friend. It may not be easy to recognise yourself in the role of 'carer', or even to see what the additional needs are for your loved one.

"A carer's role is often invisible. They are a precious resource that is often neglected and undervalued" (Healthcare professional in epilepsy).

Helpline 01494 601400
Confidential, national call rate.
Information and emotional support.
Visit epilepsysociety.org.uk/helpline
for opening hours.

Often someone's epilepsy is accepted as part of who they are, so taking on any additional care because of their epilepsy can be seen as 'just the way it is'.

When situations change

As epilepsy is an individual condition, it can change over time. The amount of care you need to provide may become more, or less.

Your own situation could change. You may become less physically able, or have your own health needs. Or you might want to regain some independence.

You could even be caring for more than one person, which may cause more strain for you. There may be an expectation from others that you can continue to cope because you always have done before.

Looking after yourself

Many people in a caring role find it rewarding, and many would not want their situation to change. However, for some people, being a carer can be exhausting.

Emotions such as guilt, resentment, anger, anxiety, or helplessness can be common. Some carers give up their income and career prospects to care for someone. Sometimes, even if you care very deeply for the person, it can feel as though the focus is always on them and that your needs and wishes go unnoticed.

It can be very important to look after yourself, and have some time to yourself. Carers often deal with their situation alone and can feel very isolated. If you are a carer, there is information, support, and help available.

What help is available

You may be entitled to a Carer's assessment. This may identify the need for home help, respite care, emotional support, or other services. You can ask your adult social services at your local council, or trust (in Northern Ireland), for an assessment.

Some carers can claim Carer's Allowance. This benefit depends on your income and is usually paid to people over 16, who spend at least 35 hours a week caring for someone who receives Attendance Allowance, Disability Living Allowance or Personal Independence Payment (PIP), or other benefits.

If you are not entitled to Carer's Allowance you may be able to apply for Carer's Credit. Carer's Credit can help you to protect your future entitlement to a state pension.

Visit gov.uk/carers-credit or gov.uk/carers-allowance

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 more information about benefits visit epilepsysociety.org.uk/epilepsy-benefits Or visit gov.uk/browse/benefits

Further information

NHS

nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/
Information for carers from the NHS.

Carers UK

020 7378 4999 (England)
029 2081 1370 (Wales)
0141 378 1065 (Scotland)
02890 439 843 (Northern Ireland)
carersuk.org

Campaigns for better support for carers. Provides information, and practical advice and support.

Carers Trust

0300 772 9600 (London office)
0300 772 7701 (Glasgow office)
0300 772 9702 (Cardiff office)
carers.org

Provides information, an online community, and local support and services for adult and young carers through its websites. It also offers advice on money and benefits.

Care Quality Commission

0300 061 6161
cqc.org.uk

Monitors, inspects, and regulates adult social care services and publishes what they find.

For a printed copy of this information contact our helpline.

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