

“A carer’s vital role is often invisible – they are a precious resource that is often neglected and undervalued.”  
(Healthcare professional in epilepsy)

## 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. The term ‘carer’ does not mean someone who is in paid employment as a care worker.

There are six million carers in the UK today (one in eight people) and nearly 60% (six in ten) of carers are women. Not all carers are adults: there are at least 175,000 young carers under 18 in the UK (2001 census). Every year, more than two million people become carers for the first time.

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 need care only 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 be unlikely to 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 recall 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 their 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, mood changes or frustration.

## 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 professionals involved in the person’s health or care.

These roles may be in addition to other demands: your family, other relationships, work, home, financial needs, social life, your health, and your own 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. 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 position as carer 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 local social services for an assessment, or your GP can ask for this on your behalf.

Some carers can claim **Carer's Allowance**. This benefit depends on your income and is usually paid to people between the ages of 16 and state pension age, who spend at least 35 hours a week caring for someone who receives Attendance Allowance or Disability Living Allowance. You can contact your local Benefits agency or call the Benefits Enquiry Line on 0800 882 200 for information.

## other organisations

### The Princess Royal Trust for Carers

0844 800 4361 (London office)

0141 221 5066 (Glasgow office)

[www.carers.org](http://www.carers.org)

[www.youngcarers.net](http://www.youngcarers.net)

Provides information and support to carers and young carers through its websites, young carers' services and Carers' Centres across the UK.

### Carers UK

0808 808 7777 (Advice line) open Wed and Thurs  
10am – 12pm and 2pm – 4pm.

[www.carersuk.org](http://www.carersuk.org)

Campaigns for better support for carers. Provides guidance and information through local branches.

### Crossroads Care

0845 450 0350

[www.crossroads.org.uk](http://www.crossroads.org.uk)

Provides support for carers and offers short breaks in the form of respite care.

### Directgov

[www.direct.gov.uk/en/caringforsomeone](http://www.direct.gov.uk/en/caringforsomeone)

Information on benefits, services and legislation.

### Expert Patients Programme (EPP CIC)

0800 988 5550

[www.expertpatients.co.uk](http://www.expertpatients.co.uk)

Provides free training courses for people who live with any long-term health condition. 'Looking After Me' is a course for adults who care for someone living with a long-term health condition or disability. There are also courses to support young carers, and parents of children with life-long conditions.

[www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)



helpline

01494 601 400

Monday to Friday 10am to 4pm  
Confidential (national call rate)

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