


# finding support

Epilepsy and seizures can affect people in different ways. Support can mean finding understanding, ways to cope, or to feel more in control about living with epilepsy. This factsheet looks at various ways that you can find support if you need it.

## other people around you

For some people the support that feels most important is from others around them – family, friends, colleagues, or community groups. Epilepsy varies so much from person to person that other people don't always need to know a lot about epilepsy to offer you support. They may just need to know how your epilepsy affects you and what kind of support from them you would find helpful. For example, you may want to give them some information about first aid, or tell them how you feel after a seizure, and what helps you to recover.

Other people's reactions to epilepsy can be very positive, but some people don't know what to say, or may feel helpless or worried. Information and support is available for everyone, including those who care for someone with epilepsy.

 **See our leaflet *first aid* and our factsheet *carers for more information*.**


## your healthcare team

The doctors that you see for your epilepsy will focus on your medical care, but they can also help support you through good communication. Feeling supported by your healthcare team may include being able to ask them questions, and tell them honestly how you feel, and knowing who to contact if you have a query about your treatment in between appointments. Your GP may also be able to support you by liaising with specialist doctors or services on your behalf.

## helpline

You may feel that talking face-to-face to someone about epilepsy is daunting. Sometimes it is easier to talk to somebody anonymously, over the phone.

Epilepsy Society has a confidential helpline that offers time to talk, information and emotional support. This gives you the space to explore your thoughts or feelings for as long as you need to and in as much depth as you feel comfortable with.

 **See over the page for contact details.**

## support groups

While people around you may be very supportive, you may feel you would like to talk to other people with epilepsy or to those who care for someone with epilepsy. There are support groups run by volunteers around the country. These groups are often popular with people who want face-to-face contact with people who are in similar situations.


**For contact details of groups call our helpline.**

## information and resources

Finding out about epilepsy may help you understand more about how it affects you personally and help you feel more confident. Your doctors may be able to give you specific information about your epilepsy, and you may also find our information about epilepsy helpful.

Epilepsy Society supplies free 'I have epilepsy' cards and first aid cards that you can put in your bag or pocket. This can help other people know that you have seizures and how to help if a seizure happens.

We also have information on safety in general and about other aspects of living with epilepsy. Our booklet 'The Bigger Picture' has information about epilepsy and mood and looks at ways to deal with the anxiety and low mood that may come alongside epilepsy for some people.

 **To order these items call our helpline or visit [epilepsysociety.org.uk/shop](http://epilepsysociety.org.uk/shop) and [epilepsysociety.org.uk/safety-and-risk](http://epilepsysociety.org.uk/safety-and-risk)**

## just diagnosed

Being diagnosed with epilepsy may affect you in different ways. Some people feel relieved to be given a name and treatment for their condition. Sometimes a diagnosis can be confusing or hard to come to terms with. Talking about any worries, asking questions, and sharing information may help you, and your family and friends, to make sense of what is happening.


 **See our pack *just diagnosed* for more information.**



Call us for a large print version

## practical and financial support

If you have epilepsy you can get free prescriptions and discounted or free public transport. Depending on your situation you may also be entitled to benefits or support from social services or other agencies.


 **See our factsheet *what help is available?* or visit [epilepsysociety.org.uk/benefits](http://epilepsysociety.org.uk/benefits)**

## counselling

Some people find it helpful to talk to a counsellor or psychologist. Counsellors give you the opportunity to talk things through at your own pace. Although some counsellors may make suggestions, they don't normally tell you what you should or shouldn't do. They will listen and help you to see how you can develop ways to cope emotionally and practically. Counsellors won't necessarily have expertise in epilepsy, but they can work with you to focus on what you want to do to manage your specific situation.

There are various counselling styles, including Person-Centred Counselling and Cognitive Behavioural Therapy (CBT). Person-Centred Counselling uses a flexible approach, and sessions focus on allowing the person themselves to decide what is right for them and how they would like their lives to change. CBT follows a structured style focused on achieving goals over a set number of weekly sessions. CBT is popular with people who like to have goals to aim for.

Most GPs can refer people for counselling, and the counselling offered is usually weekly for 6 sessions. There may be a waiting list for counselling. Some people find their own counsellor, and there will be a charge for this.

 **For information and to find a qualified counsellor visit the British Association for Counselling and Psychotherapy (BACP) at [bacp.co.uk](http://bacp.co.uk)**


## self-management courses

If you are interested in structured sessions and working in a group setting, you may be interested in the Expert Patients Programme (EPP) and other self management support. The EPP is a free course for anyone living with a long-term health condition (and is not epilepsy-specific). The course runs once a week, for 6 weeks and aims to provide support and develop self-confidence to help you feel more in control of your condition. It includes:

- dealing with pain and extreme tiredness;
- coping with feelings of depression;
- relaxation techniques and exercise;
- healthy eating;
- managing medication;
- communicating with family, friends and professionals; and
- planning for the future.

Your GP can help you to access EPP sessions, which are run by trained tutors who have long-term conditions. There is also a course for carers, and some courses that are run online.

 **Visit [selfmanagementuk.org](http://selfmanagementuk.org) or call 0800 988 5560 or 03333 445 840 from a mobile for more information.**

 **Contact your doctor's surgery, local library or council to see if there are any other courses in your area.**

## further information

### Epilepsy Society information

Benefits – see our website

The Bigger Picture – epilepsy and mood

Carers

First aid

First aid cards

'I have epilepsy' card

Just diagnosed

Risk

Safety

What help is available?

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Epilepsy Society, Chesham Lane  
Chalfont St Peter, Bucks SL9 0RJ

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



**helpline**

**01494 601 400**

**Monday and Tuesday 9am to 4pm**

**Wednesday 9am to 7.30pm**

**Confidential (national call rate)**