Factsheet 22

Finding support



Support from other people

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 would help you. 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. Visit epilepsysociety.org.uk/seizure-first-aid and epilepsysociety.org.uk/information-carers

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.

Epilepsy Society has a confidential helpline that offers time to talk, information, and emotional support over the phone, by email, or by web chat. 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 details below.

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' ID 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 have information on safety in general and about other aspects of living with epilepsy.

Epilepsy affects people in different ways. This factsheet looks at various ways that you can find support if you need it.

Helpline 01494 601400 Confidential, national call rate. Information and emotional support. Visit epilepsysociety.org.uk/helpline for opening hours. We also have information about epilepsy and mental health which may help you to look at ways to deal with anxiety and low mood that may come alongside epilepsy for some people.

Visit epilepsysociety.org.uk/mental-health-epilepsy and epilepsysociety.org.uk/medical-id-cards-and -jewellery and epilepsysociety.org.uk/safety

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.

Visit epilepsysociety.org.uk/just-diagnosed

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.

Visit epilepsysociety.org.uk/what-help-available

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 six sessions. There may be a waiting list for counselling.

Some people find their own counsellor, and there will be a charge for this.

The British Association for Counselling and Psychotherapy (BACP) has a list of registered and accredited members. Visit bacp.co.uk

For a printed copy of this information contact our helpline.

Epilepsy Society

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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.



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