

This factsheet looks at a number of ways that you can find support in living with your epilepsy.

Epilepsy and seizures can affect different people in different ways. Some people may need some form of support in order to cope with, or feel more confident about living with, their epilepsy.

Helpline

You may feel that talking face-to-face to someone about your epilepsy is too daunting. If this is the case you may find it easier to talk to somebody, in confidence, over the phone. 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.

NSE has a confidential helpline that offers time to talk, information and emotional support. Call 01494 601 400 Monday – Friday 10am – 4pm.

Support groups

Even though you may have friends, family members or colleagues to talk to, you may feel that they do not understand your epilepsy. If you are keen to talk to other people with epilepsy, or to those who care for someone with epilepsy, then you may find it helpful to attend a support group. 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 more information on support groups contact NSE's Epilepsy Helpline.

Counselling

Some people find it helpful to talk to a counsellor or psychologist. Counsellors offer you the chance to talk through things at your own pace and although some may make suggestions, they do not normally tell you what you should or should not do. They will listen and help you to see how you can develop ways to cope emotionally and practically with your condition. There are various counselling styles, including two common forms called Person Centred Counselling and Cognitive Behavioural Therapy (CBT). Person Centred Counselling uses a flexible approach and sessions are focused on allowing the person themselves to decide what is right for them and how they would like their lives to change. CBT differs to Person Centred Counselling in that it follows a structured, goal-orientated style which often suits a set number of weekly sessions. CBT is popular with people who like to have goals to aim for. However, some people may need more flexible sessions that allow them extra time to explore just how their epilepsy affects them.

Most GPs can refer people for counselling, and the counselling offered is usually six weekly sessions that follow a CBT style of approach.

→ For information on other styles of counselling and to find a qualified counsellor visit the British Association for Counselling and Psychotherapy (BACP) at www.bacp.co.uk

Expert Patients Programme

If you like the idea of structured sessions and working in a group setting, then you may be interested in the Expert Patients Programme (EPP CIC).

The EPP is a free course for anyone living with a long-term health condition. Group members attend one session a week, for six weeks. The programme aims to provide support and develop self confidence to help you feel more in control of your condition.

The course includes:

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

All sessions are run by trained tutors who are also living with a long-term condition. There are also 'Staying positive workshops' run by, and for, 11-18 year olds. There is also a course aimed at carers called 'Looking after me'. Some courses are also run online.

→ To find Expert Patients Programme courses in your area visit 'Find Courses' at www.expertpatients.co.uk/courses

Forum

If you have access to the internet, then another way to contact other people affected by epilepsy is through web forums. Forums are chat rooms where you can read other people's messages and experiences of epilepsy, and send a reply. Some people find it a helpful way to get to know people who are in similar situations to them. NSE has a forum with nearly 6000 members from across the UK and worldwide, many of whom visit the website on a regular basis.

→ Visit www.epilepsysociety.org.uk/Forum

Useful resources and contacts

If you have seizures there are resources that may give you peace of mind. NSE supplies free 'I have epilepsy' ID cards and first aid cards that can be placed in your bag or pocket. Both these items can be ordered from our helpline.

We also produce a factsheet on 'personal safety equipment and alarms' and have leaflets about 'safety' and 'leisure'.

NSE's leaflet 'The bigger picture' contains information about epilepsy and mood and looks at useful ways to deal with the anxiety and low mood that may come alongside your epilepsy.

→ To order any of these items call our helpline on 01494 601 400 (national call rate) Monday – Friday 10am – 4pm or visit NSE's online shop at www.epilepsysociety.org.uk/shop

To become an associate member call 01494 601 402 or email members@epilepsysociety.org.uk
For a fundraising pack call 01494 601 300 or email fundraising@epilepsysociety.org.uk

Epilepsy Information Services National Society for Epilepsy

Chesham Lane, Chalfont St. Peter, Bucks SL9 0RJ
www.epilepsysociety.org.uk

Epilepsy Helpline

01494 601 400 (national call rate)
Monday – Friday 10am – 4pm
(Translation service available)

