Our values and beliefs

We care about people with epilepsy and their families. We listen to them, we respond to their needs, we reflect their ambitions and we understand their lives. We never forget that epilepsy is about people.

We represent by providing identity, unity and a voice for people with epilepsy, their families and anyone else with an interest in the condition.

We lead by being creative and innovative in our thinking and decisive in our actions.

We inspire by being positive about epilepsy, by being courageous in what we do and confident in the way we do it.

We organise resources by raising money, encouraging and supporting volunteers and by working with others who share our goals.

We work locally where people with epilepsy live and nationally across all countries of the United Kingdom.
As technology changes so too does the way people look for information. In 2014 1.15 million people used our online epilepsy information on their mobile phones, tablets and computers. However, there will always be those who need more personalised support.

The Epilepsy Action Helpline team provides advice and information in many ways. From phone and printed materials to email, Twitter, live online chat and, of course, the website. The freephone service still plays a vital role as a valued one-to-one service. We also provide information through our local groups and events, reaching people where they live.

Most of our feedback shows that many people are still very much in the dark about their or their loved one’s epilepsy. Our information fills this gap. Time and again people tell us that using our services gives them confidence and reassurance. And that can make a big difference in so many ways.

“IT has eased my mind that what I am experiencing could be the results of my medication instead of something more sinister.”
Phone service user
Neil tells how a newspaper article about Jayne Burton’s struggle to get an accurate diagnosis and a call to the Epilepsy Action Helpline changed his life. Jayne is an Epilepsy Action member, volunteer and trustee.

“After seven years of experiencing seizures I have only recently been diagnosed with epilepsy. In that time I saw a variety of healthcare professionals, had numerous tests and many hospital stays. Before my diagnosis I had loads of tests for a lot of different conditions – pretty much everything except epilepsy! The problems I was having included things like memory loss, appearing to be in a trance-like state, twitches in my arms and problems with my vision. Early on I was told I was having migraines. Then I was diagnosed with stress and anxiety. I was referred for cognitive behaviour therapy – it didn’t work. I saw psychologists who said I didn’t have a stress or anxiety disorder. I became really frustrated with the whole thing and began to question my sanity.

I was in hospital late in 2014 when I read an article in my local paper. It featured an interview with a woman who had epilepsy and she told how it had taken her 19 years to get a diagnosis of epilepsy after being told she was having panic attacks. It struck a chord with me as I realised many of her symptoms were similar. I wondered if I too had epilepsy and rang the Epilepsy Action Helpline for advice.

The advice they gave me was to try and film what was happening to me and then to share that with my neurologist. I did this and yes – I was showing classic signs of epileptic seizures. The doctors think I may have developed epilepsy following a head injury.

If I hadn’t read the article about Jayne I wouldn’t have called the Epilepsy Action Helpline and I truly believe I would still not have been diagnosed with epilepsy. I wouldn’t have thought about filming what was happening. It was crucial to finally getting an accurate diagnosis and treatment.

After my experience I want to stop other people going through the same thing I did. I decided to volunteer for Epilepsy Action and I’m going to train as an Accredited Volunteer. People seem to be aware of tonic-clonic seizures but not other types. Now some of the signs of my seizures seem obvious. But part of the problem was that I couldn’t remember what happens during a seizure so I couldn’t explain it. That’s why filming my seizures proved to be so important.

Thanks to Jayne sharing her story and the helpline staff my life has changed. I now hope to help others through sharing my own story.”

“I just wanted to say thank you so much to Diane who I spoke to this afternoon in relation to my son who has just been diagnosed with benign rolandic epilepsy. Our conversation was able to allay my fears and make sense of what is happening at the moment. I feel a little bit lost with it all at the moment… Your website and support provided on the phone today have been a great source of comfort, reassurance and further knowledge. So I just wanted to say thank you.”

Web and phone service user

“I just want to say that your booklet… called Photosensitive epilepsy, is truly excellent and genuinely reflects the way it feels to have [it]. So I just want to say – well done and thank you.”

Web service user

“If someone has a seizure I feel confident to help.”

Attendee at epilepsy training

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**Epilepsy Action Helpline services in 2014**

- 10,327 people came to us for personalised information
- 1,155,114 people came to our website for advice and information
- 98,065 items of printed information material were ordered
- 46,417 printed items were ordered by healthcare professionals for their patients
- 61% (nearly two thirds) of people leaving feedback reported feeling more confident about talking to their GP, specialist or nurse
- 55% (over half) of those people said they were more confident talking to other people about their epilepsy
- 5,751 first aid instruction cards were ordered
- 6,404 epilepsy ID cards for children and teenagers were ordered
- 8,284 people used our smartphone app

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Epilepsy Action raises awareness about epilepsy

Tell people about epilepsy and sharing what it is like to live with epilepsy is one of our biggest challenges. It is also an area of our work where our unique position as a membership association gives us great strength.

In 2014 our members and volunteers did a wonderful job in sharing their personal stories with the media. Megan shared her story on Purple Day and that prompted many others to share their stories. The ‘what does epilepsy look like’ campaign reached over 2.7 million people in the printed press alone, with many more seeing it online and on social media.

In National Epilepsy Week, our volunteers shared their experiences of being newly diagnosed. During the week, epilepsy featured across all media, including online, print, radio and TV. We saw a 19% increase in coverage over the same week in 2013.

Raising awareness isn’t only about getting epilepsy in the paper and on TV. It’s also about telling the people on my street and your town about epilepsy. And here again, our members and volunteers worked hard and really made a difference. Epilepsy Action’s work in local communities gives people a much-needed face-to-face opportunity to meet, learn more about epilepsy and develop supportive friendships. The rapidly growing network of local groups is providing invaluable support and giving epilepsy a powerful local voice across the UK.

Our local volunteers wrote articles, organised and staffed events, shared their stories with healthcare bodies and promoted Epilepsy Action’s work. They weathered storms and long hot days to run information stands and support fundraising events.

Our Seize Control campaign aimed to help people with epilepsy to influence their own epilepsy care. All too often people are not given enough information on alternative options for treating their epilepsy. The campaign was particularly effective thanks to the number of people who shared their own stories of finding their way through the treatment maze. Endorsed by the Royal College of GPs, the campaign reached both people with epilepsy and healthcare professionals.

“Listening to others’ stories and experiences allowed you to sit back for a few minutes and think how lucky you were, or what you might have missed out on for years, or what you could do. Very interesting.”
Attendee at Belfast event
After a childhood with difficult to control epilepsy, brain surgery and a long road to seizure control, Sean has become passionate about helping others with epilepsy. Starting out as a volunteer fundraiser, Sean is now fully involved in Epilepsy Action’s work and has big plans for a different future.

“I developed epilepsy when I was 18 months old, after being ill, and I ended up having up to six seizures a day. At 18, I had brain surgery but my seizures returned as I came off the anti-epileptic drugs. I developed type 1 diabetes a year later. My experience with epilepsy helps me manage my diabetes – being strict with my medication and looking after my health. I had a hard time for a few years balancing both conditions. But after adjusting my epilepsy medication I’ve been seizure free for a while.

I am now 29. Over the last 10 years since my surgery I have been involved with many charities, organising charity football matches, auctions and charity fun days. I decided to contact Epilepsy Action two years ago to become more involved as an Accredited Volunteer. I started off doing some fundraising and really enjoyed it. That gave me the push to get more involved and I started the Accredited Volunteer training. I’m also a member of Epilepsy Action’s Research Volunteer Network, so there’s a lot of different things I’m involved in.

I’ve done several presentations now, talking about epilepsy and sharing my own experiences. The audiences have included teachers and nurses, and they said that hearing me tell my story really made a difference to how they view epilepsy. I was really pleased to hear that – it’s great to know that I can make that kind of difference!

I’m also involved with Epilepsy Action’s local groups because I know the social aspect is so important. People can often feel anxious about having a seizure in public or meeting new people. I go to as many meetings as I can because I have gained so much from them. Now I want to help others by using my knowledge, improving the care people with epilepsy receive and removing the stigma.

I have had some great advice and support from the Epilepsy Action team. All of this has boosted my self-confidence and now I want to do more. I’m really passionate about working with people with epilepsy! I really want a career in that area, although I don’t think that will be easy. My life has changed and I hope there’s more exciting changes to come.”

“Epilepsy Action has really helped me as it allows me to socialise with people who understand my condition and give me support to cope in a non-judgmental manner. I really look forward to our meetings every month – I only wish we could have them more often.”

Member of a local group

“Thank you and your team for an amazing weekend. My family and I had a wonderful time. It was lovely meeting new people and gaining more information about epilepsy.”

Attendee at the ‘Weekend for all’ event

“It was a great afternoon, thank you. It was lovely to see some of the great people we met last year and to meet new people, living their lives to the full regardless of their epilepsy! Can’t wait to do it again. Thanks Epilepsy Action!”

Attendee at the beach event

Raising awareness in 2014

- 85 awareness and information days held around the UK
- 31 branches, 48 coffee and chat groups and four regional forums worked across the UK
- 2.7 million people had a chance to read about epilepsy in the press on Purple Day
- 62,460 hours were donated by our many volunteers – the equivalent of 35 full-time staff
- 5,000 people visited the Seize Control campaign section of the website
- 1,300 people on social media shared and commented on the Seize Control campaign
The next step on from raising awareness of epilepsy is making sure people understand the condition and what it means to live with it every day. Through education we can improve healthcare services and improve understanding in the workplace and education. For those with epilepsy, we can share understanding and greater confidence in adapting to life with a challenging long-term condition.

Epilepsy Action works with the NHS and champions the services provided by epilepsy specialist nurses. We helped fund nurse education through the Nicola Pickard Bursaries and supported nurses through our involvement with the Epilepsy Alliance.

Alongside this work, Epilepsy Action developed and piloted a new audit tool to monitor the impact of epilepsy specialist nurses. We hope to demonstrate the value that nurses bring to epilepsy care, leading to more nursing posts in 2015.

Our Accredited Volunteers deliver training to a broad range of audiences, including healthcare organisations, schools and colleges, employers and many more. In great demand, these presentations receive excellent feedback and help to ensure people with epilepsy are met with greater understanding and support.

Launched in 2013 our e-learning project gave people a new and exciting way to learn more about epilepsy. A range of very engaging videos supports the modules. The ‘Epilepsy and your wellbeing’ module was launched in July, while October saw our new resource for schools being warmly welcomed.

“I know a lot more about epilepsy than I did two hours ago. I can use what I’ve learned at work or when just out and about… I can also tell my co-workers what I’ve learned.”

Audience member at an Accredited Volunteer presentation

“I have used your really awesome videos to educate my colleagues in the office about all different kinds of seizures… They all found it really informative and I learned stuff as well about other types of epilepsy. Thank you.”

Online video service user

“I think that by using the audit tool commissioners and managers can actually visualise the impact epilepsy nurses have and how much money we can save.”

Epilepsy specialist nurse

“As a first-aider it will help me in assessing any situation… This should be mandatory for all workplaces.”

Audience member at an Accredited Volunteer presentation

**Educating people about epilepsy in 2014**

- 101 presentations delivered by Accredited Volunteers
- 16 local events provided epilepsy information – 99% of those attending rated the events as good or excellent
- 1,279 people registered for our e-learning modules
- 75,233 people watched our e-learning first aid videos
- 11 nurses attended Epilepsy Action induction days
Our members, supporters and service users are all a vital part of our work and provide the unique voice that is Epilepsy Action. As that voice, Epilepsy Action works hard to make sure it is heard. Influencing decision makers isn’t easy in a world of competing priorities but 2014 saw some significant successes.

As a direct result of our work, often in partnership with other like-minded organisations, we have seen a number of positive changes. For example, new guidance in schools placed a legal requirement on schools in England to support children with medical conditions. After nearly two years’ campaigning we were delighted to see this change.

We provided evidence as part of work to inform better processes around Employment and Support Allowance. We responded to 19 consultations, covering policy and legislation across Wales, Scotland, Northern Ireland and England. This sits alongside our work with your elected members of the UK’s parliaments and assemblies.

We sat on an expert committee looking at the safety of the anti-epileptic drug sodium valproate for women. Being able to share our experience and knowledge resulted in new guidance being issued.

Our work to improve and influence healthcare saw us research epilepsy service planning in England. Sadly we were able to demonstrate that the people who plan local health services simply aren’t properly considering people with epilepsy. Our report ‘Epilepsy in England: the local picture’ was launched in the autumn. Since then it has featured in a number of debates in parliament and will be the basis for further campaigning.

Epilepsy Action provides a voice for epilepsy

We worked with NHS trusts to deliver the appointment of five new epilepsy specialist nurses. These much-needed nurses are now working in Northumbria, County Durham, South Devon, Hywel Dda and Cumbria.

A voice for epilepsy in 2014

- 97% of England’s clinical commissioning groups and 93% of health and wellbeing boards responded to our requests for information
- 19 consultation responses were submitted
- 10 MPs took action after reading The local picture
- 14 MLAs attended our event at Stormont, Northern Ireland
- We sat on 10 strategic bodies in Wales and nine in Northern Ireland

“Thank you for your reply… I feel more confident now, knowing I am not alone.”
Email service user

“As duty manager I will feel more confident in dealing with any seizures… [the trainer] clearly had a lot of empathy for people with the condition – so useful to consider the impact on people’s lives.”
Attendee at epilepsy training
Raising money for Epilepsy Action

With virtually no government funding, we rely completely on the generosity and enthusiasm of our supporters. In 2014, thanks to your generosity, an amazing £2.53 million was raised, enabling us to be a lifeline for ever more people affected by epilepsy.

In 2014 most of the money raised came from legacies, fundraising events, membership subscriptions and donations from companies, trusts and individuals. From sending in £1 for a wristband, to taking part in major events, the range of activities our supporters take part in never fails to amaze us.

Thank you to the 38 riders in the Prudential RideLondon-Surrey 100 who cycled 3,268 miles and raised £28,437. That’s further than the width of the Sahara Desert!

We saw a record-breaking year for Epilepsy Action’s flagship event, the Epilepsy Action Bradford 10k. Thank you to the 1,714 people who took part, collectively running 17,140 km, and raising a staggering £40,425!

In 2014 many families celebrated the lives of loved ones who have died in donating in memory – ensuring that their special memories bring positive change to the lives of others. In 2014, a wonderful £140,642 was raised in memory through events, donations and collections. Thank you!

Thank you to everyone who spread festive cheer, and bought the 234,500 Epilepsy Action Christmas cards in 2014. And to the 4,243 supporters who raised awareness (and money) by buying an Epilepsy Action wristband!

Donations of time are just as important to us as donations of money. It wouldn’t be possible for us to deliver our wide range of events and activities without our fantastic, dedicated team of volunteers. In 2014 our fundraising volunteers gave over 35,972 hours of their time supporting fundraising activities. A huge ‘thank you’ to each and every one of you!

Big or small, every donation received helps provide hope, peace of mind and support to people affected by epilepsy. Our sincerest thanks go to all the individuals, groups, trust and companies who gave so generously. Thank you.

Funding our work in 2014

- £484,131 was left to Epilepsy Action in supporters’ wills
- £595,617 was raised by supporters taking part in events across the UK
- £365,782 came in from our valued members – the lifeblood of the charity
- £120,668 was donated by trusts and corporate partners

Grants over £10,000 received in 2014

- Cyberonics – Seize Control campaign £15,000
- Cyberonics – Treatment Options events £10,250
- Garfield Weston Foundation – advice and information £25,000
- Josephine Nunn Foundation – helpline £16,000
- Sanofi – e-learning projects for practice nurses £11,500
- Desitin Pharma – e-learning projects for practice nurses £8,000

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A company limited by guarantee (registered in England No. 797997)
Registered charity in England (No. 234343)