

The role of the voluntary organisations in epilepsy

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Epilepsy Society – a new name

Epilepsy Society, the new working name for the National Society for Epilepsy, has been delivering expert epilepsy care for almost 120 years. Our vision is for a full life for everyone affected by epilepsy. With the coalition government's vision of a 'Big Society' and the reorganisation of the National Health Service, voluntary organisations are really in the spotlight. Where charities once fought to be seen as professional and their work credible, they are now accepted as campaigners, supporters, the voice of the patient, and the voice of the expert and influencers.

Epilepsy Society is a member of the Joint Epilepsy Council of UK and Ireland (JEC), the united voice of the voluntary sector. Its 22 member organisations include health professionals, residential care providers and patient support groups. As an umbrella charity, JEC's vision is for a society where people with epilepsy receive the best possible care and support. It presents evidence-based views on the need for improved epilepsy services, as well as working to influence decision-makers in the health, social and education arenas. Central to the JEC's strategic direction is the need to present a consistent set of messages to government and increase epilepsy awareness among politicians, civil servants, service providers and the general public. It also aims to grow the list of supportive politicians in each country in which it operates.

JEC coordinates activity for the annual National Epilepsy Week in May and more recently has shown support for 'Purple Day' – a global awareness-raising day supported by around 25 countries.

The government health agenda

There is no doubt that epilepsy is moving up the government's health agenda. A report, *Wasted Money, Wasted Lives*, published in 2007 by the All-Party Parliamentary Group on Epilepsy, with the support of the JEC, highlighted a catalogue of failures in the care and treatment of people with epilepsy resulting in needless deaths and millions of pounds of wasted funds. The pressure was kept up on the government, with a JEC lobby at Westminster in 2009, which was attended by more than 50 MPs. Hundreds of supporters wrote to their local MPs urging them to make epilepsy count.

It took nearly three years for the Labour government to respond to that report, but finally in February last year the Department of Health engaged with the JEC to organise a conference focusing on commissioning epilepsy services.

Despite the change of government, epilepsy has remained in the political spotlight. In October 2010 Conservative MP Paul Maynard, the first MP to publicly announce his epilepsy, secured an adjournment debate on epilepsy and the NHS, at which the Parliamentary Undersecretary of State for Care, Paul Burstow MP, acknowledged failings

in the design and delivery of epilepsy services. In November 2010 Baroness Margaret Ford tabled a question in the House of Lords about increasing the provision of epilepsy services and MP Valerie Vaz's Ten-Minute Rule Bill on epilepsy received its first hearing.

Epilepsy has long been a target of the money-saving agenda. The epilepsy charities argue that cutting costs in epilepsy care is a false economy. Epilepsy Society led a campaign against government proposals for routine generic substitution of medication – cutting costs of all drugs as a means of cutting the NHS drugs bill. The charity hosted a round table debate, which included high street pharmacists and pharmaceutical companies, and submitted an influential report to the Department of Health explaining why the cost savings were not worth the potential harm and the cost of dealing with seizures. In October 2010 the Government announced it was shelving its plans.

The role of the voluntary sector

The voluntary sector is vital in ensuring that people with epilepsy receive adequate support at a time when they are ready to receive it. Just as epilepsy is not a single medical condition, so that support is offered by charities in many different ways, from information provision to vital emotional support provided by helplines and support networks.

A number of UK voluntary organisations provide helplines. Epilepsy Society's helpline is accredited by the Telephone Helpline Association for the quality of the service it provides. A translation service is also available. Epilepsy Society helpline staff are trained to a very high level. Many of the calls they receive begin as a seemingly straightforward request for information, and then develop into a more intense conversation in which the caller begins to explore areas of deeper concern. The helpline also answers calls from medical professionals. NCYPE offers a helpline service and Epilepsy Action's helpline is a freephone number.

Epilepsy Action also has a network of support groups across the country. Individual groups, such as Gravesend Epilepsy Network provide local support.

The Epilepsy Information Network (EIN), provided by Epilepsy Society, operates at a local level in hospital clinics and medical settings. Volunteers receive training in epilepsy and issues that arise from the condition to enable them to carry out their information-giving role alongside the work of neurologists and nurses. They are there to talk to patients while they are in the clinic waiting area, providing them with a range of literature about epilepsy, signposting people to local epilepsy support groups and other organisations with specialist knowledge.

Many Epilepsy Society volunteers have epilepsy themselves and have been recruited because they have dealt with their own issues around the condition and have time to help others. In some cases they are attracted to volunteering because the support and information they required was not there for them and they do not want others to have the same experience, while others had a good experience and want to give something back.

Thanks to the training they are given, volunteers appreciate the individual nature of the condition and that, even if they have epilepsy themselves, their experience will be very different to that of the patients they see. Many epilepsy nurse specialists appreciate the value volunteers can add to the patient experience in their clinics. The volunteers are valued as part of the team, providing an opportunity for people to talk through non-medical issues with someone who has empathy and lots of time to listen, time that may be in short supply for the nurse.

In a recent evaluation of the EIN service, 95% of neurologists said the service complemented what they offered and 95% said their patients benefited from speaking to an EIN volunteer during their hospital visit. More than 80% felt that their patients had a better understanding of epilepsy thanks to the EIN service. Support for the service was echoed by epilepsy specialist nurses, who all said that their patients benefited from speaking to information volunteers.

Raising awareness

Understanding and raising awareness of epilepsy among the general population and reducing stigma around the condition is key to improving the lives of people with epilepsy. The voluntary organisations have an important role to play here. Epilepsy Society, for example, has a Schools Awareness programme. Trained volunteers deliver the programme, which aims to dispel myths, reduce bullying and make young people better informed. To date more than 16,000 students are more epilepsy aware thanks to the programme.

Epilepsy can often be an isolating condition – but the internet is helping bring people together. Most epilepsy charities are using Facebook and Twitter to communicate and connect and Epilepsy Society and Epilepsy Action host popular online forums.

Making people more epilepsy aware is key to Epilepsy Society's training programme. The charity delivers a variety of training events to a wide range of clients, from carers, school escorts and postgraduate students, to commercial organisations, GP surgeries and drug company representatives.

Research

For the majority of people with epilepsy their greatest hope rests in finding a cure for the condition. Epilepsy research receives no government funding. Voluntary organisations such as Epilepsy Action and Epilepsy Research UK contribute financially to research programmes. Epilepsy Society is the only voluntary epilepsy organisation undertaking research. Its research programmes are world leading. Thanks to Epilepsy Society's MRI research programme, more people are undergoing surgery with successful outcomes. More recently Epilepsy Society has been looking at the role of genetics in the treatment of epilepsy. The results of that research could change the treatment of epilepsy forever. With its renowned Sir William Gowers assessment centre and outpatients clinic linked to the National Hospital for Neurology and Neurosurgery, Epilepsy Society is uniquely placed to translate research into clinical practice.

www.epilepsysociety.org.uk

Epilepsy Helpline 01494 601400 (Monday–Friday 10 am–4pm)