

## **The role of the voluntary organisations in epilepsy**

AMANDA CLEAVER

Communications Manager, Epilepsy Society, Chalfont St Peter, Buckinghamshire

---

### **Epilepsy Society and its aims**

Epilepsy Society has been delivering expert epilepsy care for almost 120 years. The charity's founding fathers were pioneers of their time – providing employment and a safe place to live for people with a much stigmatised condition. Today Epilepsy Society continues to be at the forefront of the epilepsy world, providing expert medical services and leading the world in epilepsy research. There are positive signs that epilepsy will disappear as a description of a disease and be replaced by the knowledge that it is a collection of rare diseases with a common feature: a predisposition to epileptic seizures.

### **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 Society, Epilepsy Action and Epilepsy Research UK contribute financially to research programmes.

Epilepsy Society's new research centre opened in March 2013 and is integrated with the charity's medical centre and magnetic resonance imaging (MRI) unit at the Chalfont Centre in Buckinghamshire. Its research programmes are world-leading, providing a major improvement in the understanding and treatment of epilepsy. For the first time there is a shift from a model of treatment based on experience and observation to one based on a fuller knowledge of the individual's genetic profile and on a better understanding of the way in which different anti-epileptic medications work.

Thanks to the charity'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.

A new research resource, the Epilepsy Society Brain and Tissue Bank, was established in 2014 – the UK's first dedicated brain and tissue bank for epilepsy. Based at the National Hospital for Neurology and Neurosurgery at Queen Square, London, it provides a vital research donation facility and central resource to support research into epilepsy.

### **Voluntary organisations and the NHS**

The NHS five-year 'forward view' calls for a new relationship with patients, citizens and communities, describing them as an 'untapped resource' for the NHS. It cites the voluntary sector as partners with whom they will invest significantly in evidence-based approaches such as group-based education for people with specific conditions and self-management educational courses.

Epilepsy Society has just come to the end of three years' funding by the Department of Health focusing on a community development project in six boroughs in north and east London. The project worked in communities where there was little understanding about epilepsy – primarily focusing on black, Asian and other minority ethnic groups. As a result of this work, Epilepsy Society has developed a tailor-made epilepsy self-management course for people living with epilepsy and their carers. The course has already been commissioned by Tower Hamlets Clinical Commissioning Group.

Charities have become major suppliers of commissioning support in the restructured NHS, supplying intelligence and helping redesign services. The first-ever national nurse consultant for epilepsy commissioning was created in 2013, funded in the first year by Epilepsy Action and subsequently by Epilepsy Society. Juliet Ashton is the first nurse in this post. Her role is to provide expert advice to clinical commissioning groups and strategic clinical networks in order to improve local services and outcomes for people with epilepsy. Her work involves analysing neurological conditions admission data, auditing neurology services, carrying out service mapping, designing an integrated care pathway, making a business case for extra resources, and developing training and increasing awareness among GPs and neurologists. This work has proved to be a 'win-win', with improved outcomes for patients and cost savings on inefficiencies.

### **Influencing policy**

Voluntary organisations have an important role to play in influencing policy. They are the patient representative and are able to bring the patient voice to the decision-making process. With the squeeze on NHS finances the move towards increased prescribing of generic drugs has been a hot topic for debate. For people with epilepsy, prescribing issues centre on consistency of supply rather than favouring a branded product over a generic product. Updated guidance from the Medicines and Healthcare Regulatory Agency (MHRA) explains how doctors can write prescriptions to ensure consistency of supply for individuals with epilepsy – but the epilepsy charities have expressed concerns at the way some drugs have been categorised in that guidance. Working with Epilepsy Action, Epilepsy Society has been collating evidence about the effect drug switching can have on patients and encouraging patients to share their experiences via the Yellow Card reporting scheme.

The united voice of the epilepsy charities has also resulted in new warnings about use of the epilepsy drug sodium valproate for women of child-bearing-age. Epilepsy charities have been campaigning for stronger warnings about risks associated with the drug and the effect on the unborn child. Earlier this year the MHRA issued new guidance stating that valproate should not be prescribed to female children, female adolescents, and women of child-bearing potential or pregnant women unless other treatments are ineffective or not tolerated.

### **Helplines and other support**

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. Young Epilepsy offers a helpline service and Epilepsy Action's helpline is a freephone number.

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

Epilepsy Society's regional information services operate 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 know that even if they have epilepsy themselves, their experience will be very different to that of the patients they see. Many epilepsy specialist nurses 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.

### **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, informing and educating.

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.

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

Epilepsy Helpline: 01494 601400 (Monday–Friday 9 am–4 pm)