

Epilepsy

Epilepsy is a serious neurological condition, affecting around 456,000, or one in 131, people in the UK. Around 27,400 new cases are diagnosed each year in the UK—that is equivalent to approximately 75 new cases each day. This article reviews the work of Epilepsy Action.

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Epilepsy can affect anyone, at any age and from any walk of life. At the moment, there is no cure for epilepsy. However, with the right type and dosage of anti-epileptic medication, nearly three quarters of people with the condition could have their seizures completely controlled.

Background

Epilepsy Action is a working name of British Epilepsy Association, which was established in 1950. The organisation will celebrate its 60th anniversary in 2010. Epilepsy Action is the largest member-led epilepsy organisation in the UK. The charity helps over 686,500 people every year through a range of services, including an advice and information centre, branch network and accredited volunteer scheme.

The charity acts as the voice of people with epilepsy in the UK and aims to:

- Raise and maintain awareness about epilepsy and about Epilepsy Action's work
- Bring about permanent change for the social and medical benefit of people with epilepsy
- Provide advice and information about epilepsy that is relevant to peoples' needs and that is accessible in terms of location, availability and cost

Epilepsy Action is currently working to encourage the government and healthcare commissioners to move epilepsy up the political agenda. This way services and care for people with epilepsy can be improved.

Campaigning for change

One of the main aims of Epilepsy Action is to bring about permanent change for the social and medical benefit of people with epilepsy. The charity campaigns

to improve epilepsy health services across the UK. We published our Epilepsy in England: time for change report earlier this year. The report identified considerable failings against national guidelines for epilepsy services set out by NICE.

The report, which draws on results from a survey of primary care trusts (PCTs) and acute trusts across England, exposed a bleak picture for people with epilepsy. It found that:

- Despite NICE stating that all people with suspected epilepsy should be seen by an epilepsy specialist, half (49 per cent) of acute trusts do not employ one
- Despite NICE stating that all people with suspected epilepsy should be seen urgently (within two weeks), most trusts (more than 90%) have waiting lists of longer than this.
- Despite NICE stating epilepsy specialist nurses (ESNs) should be an integral part of the medical team providing care to people with epilepsy, well over half of acute trusts (60 per cent) and of PCTs (64 per cent) do not have one.

The results also revealed that the majority of trusts lack even the most basic information to allow them to design adequate services. It was found that many trusts do not hold basic data on the prevalence and population of people with epilepsy in their region. Without this vital information, it is impossible to see how trusts are able to plan and provide services of an acceptable standard.

National Epilepsy Week

During National Epilepsy Week in May, Epilepsy Action, along with other members of the Joint Epilepsy Council (JEC), invited its members to attend lobbies of parliament in England, Wales and Northern

Ireland. The aim was to highlight inadequacies in services to MPs and encourage them to speak with health trusts in their constituencies to ensure NICE guidance on epilepsy care is properly implemented.

Consistency of supply

From January 2010 new dispensing regulations will be in place throughout the UK. Pharmacists will be expected to change the brand of drug named on a prescription and replace it with a different, generic version. These regulations may cause serious problems for people with epilepsy as even tiny changes in medication could potentially have a significant effect on seizures and side-effects.

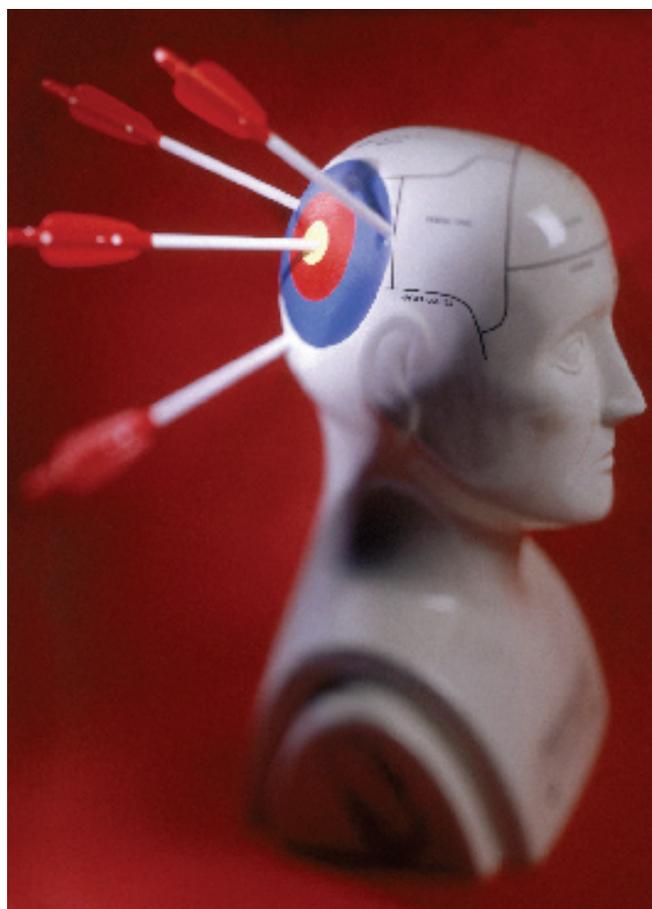
There is significant anecdotal evidence from clinicians and patients to indicate that a number of people may experience difficulties when switching between different versions of the same anti-epileptic drug. These include an unnecessary increase in seizures, breakthrough seizures or worsening of side-effects.

A single seizure can have a major impact on a person's life and can affect a person's employment, education and social life. Seizures can also bring with them the risk of injury from jerking or falling, as well as a loss of confidence.

Epilepsy Action strongly believes that people with epilepsy should receive the same version of anti-epileptic drug whenever they get a repeat prescription unless their clinician prescribes otherwise. We are therefore calling for anti-epileptic drugs to be exempt from the proposed new regulations. Along with members of the JEC, we have set up an e-petition. To sign the petition, visit <http://petitions.number10.gov.uk/epilepsygenerics>

Epilepsy in later life

Epilepsy can begin at any time in life, from birth to old age. It is only relatively recently, however, that doctors are realising just how frequently epilepsy begins in later life. As people are now living longer, epilepsy in older people is becoming increasingly common. Of the 456,000 people affected by epilepsy in the UK, almost a quarter are over the age of 65 years. About a third of new cases of epilepsy occur in people over 65 years. Epilepsy Action is planning



a campaign next year to highlight the issue and help support older people affected by the condition.

Further information

To find out more about our work or how you can help, please visit our website, www.epilepsy.org.uk. The website has all kinds of information about epilepsy and features an online advice and information service. We have an Epilepsy Helpline freephone 0808 800 5050, which is open Monday to Friday, 9.00am – 4.30pm (4.00pm on Fridays). You can also email the helpline at helpline@epilepsy.org.uk