

JOINT EPILEPSY COUNCIL PRESS RELEASE

Call to politicians for better epilepsy services

People from across the UK met with politicians this week to demand better epilepsy healthcare, as part of National Epilepsy Week. Lobbies were coordinated by the Joint Epilepsy Council of the UK and Ireland (JEC) – an umbrella organisation of 26 charities, working together to improve the standard and accessibility of health and support services for people with epilepsy.

Events took place at Westminster, Stormont, the Scottish Parliament and the National Assembly for Wales to highlight the problems with epilepsy services across the UK. Over 90 politicians from across the UK attended, with many meeting their constituents to hear about their experiences of current epilepsy services.

Epilepsy services can vary greatly across the country. In Scotland, Northern Ireland and Wales people living in bigger areas and cities currently receive a better service than others. Those in more rural areas tend to experience difficulties in accessing services, due to distances from major hospitals and specialist epilepsy clinics.

Every year in England, 990 people die of epilepsy-related causes. A 2005 report by the All Party Parliamentary Group on Epilepsy, *Wasted Money, Wasted Lives*, revealed that 400 of these deaths are avoidable. The report also found that 69,000 people live with unnecessary seizures and £189 million is needlessly spent each year.

A recent report by Epilepsy Action, *Epilepsy in England: Time for change*, also revealed a catalogue of failings in epilepsy care and services across the country. So far, more than 180 MPs have signed an Early Day Motion (EDM) tabled in support of *Time for change*.

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The lobby followed a meeting with Health Minister Ann Keen MP, in which she responded to both reports and outlined her plans for improving epilepsy services. In particular she promised to write to all Strategic Health Authorities, highlighting the reports and urging them to review their epilepsy services. She also promised to set up a meeting between the JEC and Director of Commissioning Mark Britnell, to discuss how World Class epilepsy services should be designed and commissioned.

Karen Deacon, chair of the JEC, said: "We are delighted that so many politicians attended the parliament and assembly events and met with their constituents. The meetings have given people affected by epilepsy a fantastic opportunity to highlight the need for improved services. We hope that politicians will put pressure on government and local health services to prioritise epilepsy and provide the standard of services that people with epilepsy so desperately need."

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Notes to editor:

1. For more information about the JEC and National Epilepsy Week please visit <http://www.jointepilepsycouncil.org.uk/>
2. For more information about Wasted Money, Wasted Lives, visit <http://www.jointepilepsycouncil.org.uk/Wasted-Money-Wasted-Lives.html>
3. For more information about the Time for Change report visit <http://www.epilepsy.org.uk/timeforchange>
4. For further information about anything in this release please contact Aimee Bowen at Epilepsy Action on 0113 210 8866, or email press@epilepsy.org.uk, or Amanda Cleaver at the National Society for Epilepsy on 01494 601404 or email amanda.cleaver@epilepsysociety.org.uk
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