



## ALL PARTY PARLIAMENTARY GROUP ON EPILEPSY

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*A FORUM FOR ENGAGEMENT BETWEEN PARLIAMENTARIANS, PROFESSIONALS AND THE PUBLIC*

### **APPg on Epilepsy Report 2016**



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28 October 2016

Dear Friends

## Re: APPG on Epilepsy Report 2016

I am delighted to present a Report from the APPG on Epilepsy which consists of the work undertaken this year.

If your constituents would like to raise any issues on Epilepsy, do forward their correspondence to me.

Yours ever  
Valerie

**Valerie Vaz MP**

**Chair: APPG on Epilepsy**

### **Vice Chairs:**

**Cheryl Gillan MP, Baroness Hussein-Ece, Paul Maynard MP,  
Andy McDonald MP, Greg Mulholland MP, Paula Sherriff MP**

### **Secretary:**

**Teresa Pearce MP**

## **Officers of the APPG on Epilepsy elected at the AGM on 11 July 2016**

### **Chair**

- Valerie Vaz MP                      Labour

### **Vice-Chairs**

- Cheryl Gillan MP                      Conservative
- Baroness Hussein-Ece              Liberal Democrat
- Paul Maynard MP                      Conservative
- Andy McDonald MP                      Labour
- Greg Mulholland MP                      Liberal Democrat
- Paula Sherriff MP                      Labour

### **Secretary**

- Teresa Pearce                      Labour

Secretariat provided by the Joint Epilepsy Council:

Dravet Syndrome UK • Epilepsy Connections • Epilepsy Ireland • Epilepsy Research UK • Epilepsy Wales • ESNA • ILAE • Matthew's Friends • Muir Maxwell Trust • Scottish Epilepsy Centre, Quarriers • The Daisy Garland • The Meath Epilepsy Trust • Young Epilepsy.

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## **IMPROVING PATIENT OUTCOMES:**

On Wednesday 2 March 2016, in Committee Room 17 in the House of Commons, the APPG held a meeting: Improving patient outcomes: Establishing a national epilepsy register.

The speakers were: Professor Helen Cross OBE, Prince of Wales' Chair of Childhood Epilepsy, Dr Amit Bali, Clinical Leadership Fellow, Young Epilepsy and Dr Colin Dunkley, Clinical lead for Epilepsy12.

**Professor Helen Cross** spoke about the multiple ways in which people are affected by epilepsy and the need to effectively identify and monitor needs and outcomes. Epilepsy is a common but hidden disease and represents multiple conditions. Its management is not always straightforward and there may be co-morbidities such as problems with learning and behaviour, as identified by Young Epilepsy's research on epilepsy in schools. Epilepsy can have an impact on under-achievement and employment, which has a cost to both the individual and society. At present, it is difficult to identify the epilepsy population. An epilepsy register would be a way of identifying who is affected, as well as monitoring their needs and outcomes. A register would enable audits of epilepsy services to be monitored more broadly and would help with cost analyses and the tailoring of individual care.

**Dr Amit Bali** spoke on the positive impact patient registers have already had for other groups. Registers are not a new concept and reports on their work go back to 1999. Research has shown that registers have played an active role in improving patient outcomes, as well as improving the quality and cost-effectiveness of services. It is estimated that investing £70 million in patient registers would bring about a cumulative return of £7 billion over a 10 year period. A patient register is not just a data collection system and can be used as an active process. A registry seeks to engage patients in order improve outcomes, with the system being used by individuals themselves.

**Dr Colin Dunkley** spoke about his frustration with the way data is currently recorded and used, and the importance of coordinating data collection in order to avoid duplication and maximise benefit. The Epilepsy12 clinical audit of paediatric epilepsy services shows a snapshot of epilepsy care at various points and there is a proposal to develop this work into a register. We need to join existing research databases together, such as the atlases of variation and the Neurology Intelligence Network, in order to produce a common dataset. A funded stakeholder group should be established to examine what a register would look like. Epilepsy monitoring is moving into wearable systems such as those on phones, although there can be problems in accessing this data for clinical notes. The next stage of the Epilepsy12 audit aims to include real-time monitoring, functioning more like a register. In order to take forward proposals in this area, a working group should be established to consider how a register might be funded. A register would need to be time-neutral or time-saving and would need to connect to the NHS systems. **Ω**



## **REPORT: EPILEPSY AND MARRIAGE – BUSTING THE MYTH:**

For many years there has been a myth circulating that there was a law forbidding people with epilepsy in the United Kingdom to marry, and that this law was not repealed until the 1970s. This was reported in many places, including by the World Health Organisation.

With the help of Valerie Vaz MP, chair of the All Party Parliamentary Group on epilepsy, I am pleased we have been finally able to debunk this myth.

Researchers for Valerie have confirmed that they have found no law in the UK that prohibited people with epilepsy from marrying.

It is likely that the myth arose from the fact that there was a law passed in 1937, The Matrimonial Causes Act 1937, where a marriage could be annulled if "either party to the marriage was at the time of the marriage ..... subject to recurrent fits of insanity or epilepsy".

To annul a marriage means that in effect the marriage never took place.

Interestingly, in 1937 when this act was debated, the then Archbishop of Canterbury spoke out against including epilepsy as grounds for annulity. He stated "It would not be suggested in such a case that that incurable disease [epilepsy] was a ground on which the man could get rid of his wife and send her to an institution and marry someone else."

It took 34 years before the rest of parliament caught up with the Archbishop.

In 1971 The Nullity of Marriage Act removed epilepsy as a ground upon which a marriage could be voidable. Lord Simon of Glaisdale said: "and it was certainly an anomaly that epilepsy should be a ground of nullity, even though existing at the time of the marriage, when no other physical ailment, and only to a very limited extent mental ailments, invalidated a marriage."

In the light of this research, for which we thank Valerie Vaz MP and her office, the World Health Organisation have amended their fact sheet to reflect the true story.

Simon Wigglesworth  
Deputy chief executive  
Epilepsy Action  
3 March 2016



## **EPILEPSY IN THE WORKPLACE:**

On Monday 13 June 2016 in the Attlee Suite Portcullis House, the APPG held a meeting to discuss Epilepsy in the workplace: Breaking down barriers.

The speakers were: Will Butterworth, Central England Local Services Manager, Epilepsy Action, Jamie Burton and Dawn Oliver, Transition Support Programme, Young Epilepsy.

**Will Butterworth** highlighted the findings of a TUC survey which showed that whilst the employment rate for the overall population was 74%, the rate for disabled people was 46% and for epilepsy it was only 28%. Entering employment can in itself be difficult for people with epilepsy. Workers can ask their employer to view epilepsy as a disability and they can also assist them by providing a care plan. Employers need to consider how they record epilepsy-related absence, for example distinguishing this as absence related to disability. There is also a need to consider whether any type of equipment might be needed such as tailored lighting. Epilepsy Action have been in contact with the Department for Work and Pensions (DWP) to ensure that they have the information they need in relation to how epilepsy affects a person's ability to work.

**Jamie Burton** shared his experience of dealing with epilepsy in the work place. Jamie had a job close to home for a year when he was experiencing seizures and his employer was supportive and knew what to do in case of a seizure. Later, Jamie joined the civil service and decided not to disclose his epilepsy as he did not want it to affect job offers. After moving roles within the civil service, Jamie felt able to disclose his epilepsy to his line manager. As a result, an occupational health assessment was carried out and reasonable adjustments were put in place, which included additional leave dates. Jamie's specialist epilepsy nursing support worked with Epilepsy Action and his line manager to put together a care plan which was presented to his colleagues. Individual care plans would be of benefit to many people.

**Dawn Oliver** spoke about her experience supporting young people with epilepsy as they make the transition into adulthood. There are around 112,000 children and young people with epilepsy in the UK, and approximately 1 in 200 under-18s have epilepsy. There is a lack of funding for projects offering early support and not enough support in education. Some institutions are unaware that they have students with epilepsy. There is a high prevalence of mental health issues and self-harm. Young people face challenges in tackling authority figures and may feel excluded because of the seizures they experience. Dawn works to raise awareness with schools, colleges and employers about how epilepsy affects young people and what to do in case of an emergency. Young Epilepsy's transition support programme is the first project of its kind. It is person-centred, holistic and led by young people. It has helped them develop independence through voluntary work, education and broadening their skills. Ω



## REPORT: DRIVING BANS FOLLOWING SEIZURES:

The issue of driving bans following seizures was raised by a member of the public via their MP and myself as Chair of the APPG on Epilepsy. A point of contention was the differing periods of driving bans following seizures between countries and states in the USA. I thought it was important to look into this, I asked the House of Commons Library to undertake research on differing driving bans, and the APPG published a report on 13 June 2016.

The European Union has unified member states under the singular policy of a 1 year ban specified for people diagnosed with epilepsy, after which a licence may be granted if there are no further seizures. In the USA alone, there is great discrepancy in legislation in the different states, ranging from no set seizure-free period to an 18 month ban following seizure.

China, India and Singapore impose a total ban on driving following diagnosis of epilepsy, not seizures. This severe legislation is an outlier amongst global policy towards driving and epilepsy. A total ban on driving following diagnosis discriminates and unjustly restricts the freedom of those who have the condition.

A next step identified in the report is to raise this issue with the World Health Organisation and the International Bureau for Epilepsy. The aim would be to ensure that a singular policy would apply internationally making it simple, transparent, and equitable.

Table 1 outlines the varying driving restrictions following seizures in the countries identified.

Country/State	Driving ban
Australia (1)	Default standard is a 12 month ban following a seizure, after which a conditional licence may be granted, but this period may be reduced in certain circumstances
Canada (2)	6 months ban after seizure
China	Total ban after diagnosis
European Union (3)	1 year ban specified for people diagnosed with epilepsy, after which a licence may be granted if there are no further seizures
India (4)	Total ban after diagnosis
Japan (5)	2 years ban after seizure
New Zealand (6)	1 year ban after seizure - this period may be reduced in certain circumstances
Norway (7)	1 year ban after seizure
Singapore (8)	Total ban after diagnosis
USA (9)	Varies from state to state. There is a trend towards shorter bans following seizures. Some states have no set seizure free period and in these cases the doctor's recommendation is key.
Alabama	6 months with exceptions
Alaska	6 months
Arizona	3 months, with exceptions
Arkansas	1 year, with exceptions



California	3 or 6 months, with exceptions
Colorado	No set seizure-free period
Connecticut	No set seizure-free period
Delaware	No set seizure-free period
Florida	6 months, with doctor's recommendation
Georgia	6 months
Hawaii	6 months with exceptions
Idaho	No set seizure-free period
Illinois	No set seizure-free period
Indiana	No set seizure-free period
Iowa	6 months, with doctor's statement
Kansas	6 months with exceptions
Kentucky	3 months or longer
Louisiana	No set seizure-free period, Doctor's recommendation
Maine	3 months or 2 years depending on medical prognosis
Maryland	3 months, with exceptions
Massachusetts	6 months with exceptions
Michigan	6 months with exceptions
Minnesota	3 months, with doctor's recommendation
Mississippi	6 months
Missouri	6 months, with doctor's recommendation
Montana	No set seizure-free period, Doctor's recommendation
Nebraska	No set seizure-free period
Nevada	3 months, with exceptions
New Hampshire	1 year, less at discretion of DMV
New Jersey	6 months
New Mexico	6 months
New York	1 year, with exceptions
North Carolina	6 to 12 months, with exceptions
North Dakota	6 months; restricted license available after 3 months
Ohio	No set seizure-free period
Oklahoma	6 months with exceptions
Oregon	3 months or longer
Pennsylvania	6 months with exceptions
Rhode Island	18 months; less at discretion of DMV
South Carolina	6 months
South Dakota	6-12 months, less with doctor's recommendation
Tennessee	6 to 12 months, with exceptions
Texas	3 months, with exceptions
Utah	3 months, with exceptions
Vermont	No set seizure-free period
Virginia	6 months with exceptions
Washington	6 months with exceptions
West Virginia	6 months
Wisconsin	3 months, with doctor's recommendation
Wyoming	3 months, with exceptions

## **Information and Support Services:**

At one of our APPG meetings, a participant asked what information and support services existed. These are the organisations that are available to help.

- **Epilepsy Action**

Monday to Friday (8.30am to 5.30pm)

Phone: 0808 800 5050

Text: 0753 741 0044

Email: [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk)

- **Epilepsy Scotland**

Monday to Friday (10am to 4.30pm)

Phone: 0808 800 2200

Text: 07786 209 501

Email: [enquiries@epilepsyscotland.org.uk](mailto:enquiries@epilepsyscotland.org.uk)

- **Epilepsy Society**

Monday and Tuesday (9am to 4pm), and Wednesday (9am to 7.30pm)

Phone: 01494 601 400

Email: [fromthehelpline@epilepsysociety.org.uk](mailto:fromthehelpline@epilepsysociety.org.uk)

- **Epilepsy Wales**

Phone: 0800 22809016

- **Young Epilepsy**

Monday to Friday (9am to 1pm)

Phone: 01342 831342

Text: 07860 023 789

Email: [helpline@youngepilepsy.org.uk](mailto:helpline@youngepilepsy.org.uk)





