

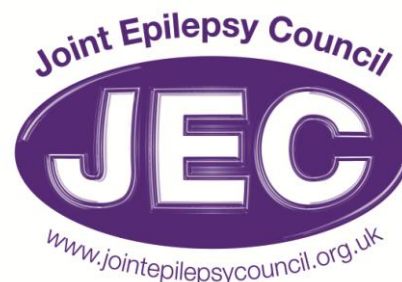
A brief from the Joint Epilepsy Council (JEC) - November 2010

The JEC is the umbrella body for 23 organisations operating throughout the UK and Ireland. The JEC provides the secretariat to the All-Party Parliamentary Group on Epilepsy.

Epilepsy: The consequences of inadequate health and education services

For references and further detail, see “Wasted Money, Wasted Lives” (WMWL) available at www.jointepilepsycouncil.org.uk/inquiry.asp and “Epilepsy in England: time for change” (T4C) available at <http://www.epilepsy.org.uk/campaigns/timeforchange> or by request to Sharon Wood at sharon.jec@btconnect.com

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Executive summary

Epilepsy is currently defined as a tendency to have recurrent seizures (sometimes called fits). A seizure is caused by a sudden burst of excess electrical activity in the brain, causing a temporary disruption in the normal message passing between brain cells.

- Epilepsy affects almost half a million people in the UK - that is one in every 131 people, or 705 in an average Parliamentary constituency.
- 990 people in England die every year of epilepsy-related causes. About 400 deaths each year are considered potentially avoidable.
- 69,000 more people with epilepsy in England could have their seizures controlled with good treatment.
- 74,000 people in England are taking aggressive drugs unnecessarily, owing to misdiagnosis.

Epilepsy can have a profound effect on a person's quality of life.

- The avoidable cost of providing the current poor service is estimated at £189 million each year as delays, misdiagnosis and mistreatment all lead to further calls upon NHS resources.
- The risk of maternal death is 7-10 times higher in women with epilepsy than for the general population. The risk of malformations including autism and spina bifida in babies born to women with epilepsy is 2-3 times higher than for the general population. About 5,000 women with epilepsy become pregnant in the UK each year, but only 21 per cent received counselling.
- Roughly a quarter of those known to learning disability services have epilepsy.
- In education, half of the 60,000 young people with epilepsy are estimated to be under-achieving academically in relation to their intellectual level.
- People with epilepsy have been shown to be up to twice as likely as those without it to be at risk of unemployment.

1 HEALTH ISSUES

1.1 Health issues - the scale of the problem

Epilepsy affects almost half a million people in the UK - that is one in every 131 people, or 705 in an average Parliamentary constituency. Health outcomes for people with epilepsy are demonstrably poor.

- 990 people in England die every year of epilepsy-related causes
- About 365 deaths are of children and young adults
- About 400 deaths each year are considered avoidable
- 59% of all childhood deaths are considered avoidable
- 69,000 more people with epilepsy could have their seizures controlled with good treatment
- 74,000 are taking aggressive drugs unnecessarily, owing to a misdiagnosis rate of 20-31%

1.2 Health issues - Sudden Unexpected Death in Epilepsy

The term SUDEP is used when there is no clear explanation for the death of a person with epilepsy. SUDEP accounts for at least 500 deaths per year, greater than the total of cot deaths and AIDS-related deaths combined. Patients commonly receive no information at all about the possibility of SUDEP. In Wales and Scotland, an information resource on the risks and the prevention of SUDEP has been produced. No such resource has yet been produced in England.

1.3 Health issues - the benefits of improving services

Given the outcomes above, the case for urgent improvement to NHS epilepsy services on behalf of patients is compelling and arguably unique.

Inevitably, a question arises: can we afford the necessary improvements given the current financial environment? The answer is that the current dysfunctional service is extremely wasteful. Improving services will lead to very significant cost savings.

- The avoidable cost of providing the current poor service is estimated at £189 million each year as delays, misdiagnosis and mistreatment all lead to extra calls upon NHS resources
- Over 70,000 people with epilepsy in the UK currently claim Disability Living Allowance at a cost of over £244m per year
- The medical costs alone of misdiagnosis are estimated at £22m per year

About 50% of people with epilepsy in the UK make a full contribution to society because their condition is controlled. A further 20% could join them with good treatment, making significant reductions in both NHS costs and the welfare budget.

The benefits to society of improving health services for epilepsy are therefore clear.

1.4 Health issues – key reports

“Wasted Money, Wasted Lives” (WMWL)

The APPG on epilepsy published WMWL in June 2007, following its inquiry into epilepsy services. The report contained 30 recommendations and is available at www.jointepilepsycouncil.org.uk/inquiry.asp

WMWL examined in detail the poor delivery of epilepsy services in England and showed how improvements would save lives and money.

“Epilepsy in England: time for change” (T4C)

In January 2009, the T4C survey conducted by Epilepsy Action collated evidence provided by the NHS that showed how poorly the NICE guidelines are being delivered. The report is available in full at <http://www.epilepsy.org.uk/campaigns/timeforchange>

There have been other Reports over many years detailing the failings in NHS services for epilepsy. See, for example, the Chief Medical Officer’s Annual Report of 2001.

1.5 Health issues – Government response

Former Health Minister Ann Keen MP accepted the findings of both WMWL and T4C. With her support the Department and the JEC jointly organised a conference specifically on epilepsy for NHS Commissioners. This took place in January 2010.

The Minister also proposed a study to provide further evidence of the clinical and cost effectiveness of epilepsy specialist nurses.

Although there is reason to believe that the new Government also accepts the two key reports, the Department now advises that it does not have the resources to undertake the specialist nurse study.

A Westminster Hall debate was held recently led by Paul Maynard MP, the first MP ever to publicly declare his epilepsy, with a contribution from Laura Sandys MP, chair of the All Party Parliamentary Group on epilepsy, who also has epilepsy.

Responding the Minister, Paul Burstow MP, acknowledged “we must do better for the 450,000 people with epilepsy in the UK” and he agreed to meet with the MPs and the voluntary sector.

1.6 Health issues – what an efficient service should look like

In 2004, NICE published clinical guidelines for the treatment of epilepsy. The standards set out by NICE are widely accepted as good by both clinicians and patient groups. Improvements in treatment were confidently expected to follow. However, in January 2009, a survey of Trusts showed how poorly the NICE guidelines are being delivered.

- The headline figure from the survey of Trusts showed that over 90% were failing to meet the two week deadline for a first specialist appointment, many by a very wide margin
- Many Trusts do not employ even one epilepsy specialist neurologist, a key post according to NICE
- Well over half of the Trusts do not employ even one epilepsy specialist nurse, a key post according to NICE

NICE considers that the first specialist appointment should take place urgently as no treatment is made available until diagnosis. Between first seizure and first specialist appointment many people experience continued seizures, loss of driving licence and the consequences of that, unnecessary emergency hospital admissions, and some people die.

Trusts are not obliged to commission services as set out by NICE clinical guidelines and consequently the guidelines have no teeth. The services have largely not been commissioned; the waste of lives and money continues.

The serious failure to commission services some five years after the guidelines were introduced has led to those guidelines falling into disrepute.

Service users ask: what is the point of the NICE clinical guidelines?

There is a serious lack of tertiary referrals driven by short-term cost considerations. There is no clearer case of a false economy. Tertiary referrals are required to resolve misdiagnosis (currently at 20-31% of all cases) and to establish patient suitability for surgery. In both cases, the initial outlay is soon recouped by the savings in treatment costs that follow. Added to this clear economic case is the obvious and life-changing benefit to the patient. Sensible drivers to prevent blocks on tertiary referrals need to be found.

1.7 Health issues – will the White Paper reforms help?

Although the proposed reorganisation may lead to better commissioning of service for people with epilepsy through greater clinical involvement in the process, there is no certainty that it will.

The reforms are unlikely to be completed before 2013/4 and evidence of improvement or otherwise is unlikely to be available for a further year or two after that.

Given the scale of the human cost and the wasted resources, neither patients nor NHS budgets can afford to wait before sensible steps are taken.

2 EDUCATION

2.1 Education issues – underperformance in mainstream schools

There is a long history of children with epilepsy not realising their potential in mainstream schools. In the past, epilepsy was poorly understood but we now have the knowledge to support many of these children much more successfully and without major resource implications.

It is remarkable that the following extract from the key Warnock Report into special education of 1978 remains as valid today as it was at the time. The actions proposed by Warnock still need implementation.

“11.43 We consider that every effort should be made to inform staff in schools and colleges about the facts of epilepsy, how it may be controlled by drugs, what the side effects of these drugs may be and how to manage seizures should they occur, in order to create the right attitudes to children with epilepsy. Lack of full knowledge may cause a child’s activities to be unduly restricted and if the school does not know about the existence of the condition the child may run unnecessary risks. This is an instance where mutual confidence and understanding between parents, doctors and teachers is particularly important.

11.44 Even where satisfactory control of seizures by anticonvulsants is achieved, many children with epilepsy may have serious problems in concentration and behaviour, which affect their learning....Their particular difficulties are not always recognised by schools and colleges, and better arrangements for reviewing their progress are needed....if these children are to be helped to develop their potential to the full.”

The problem has been in translating our modern knowledge into practice in our schools. This could change with appropriate support from the Department. Training and information for education staff is readily available from the voluntary sector.

Apart from the benefits to the child, improved support will assist, in concert with the improvements required in NHS services, in driving down the high unemployment rate and consequent benefit dependency of people with epilepsy.

About 60,000 young people under 18 in the UK have epilepsy in the UK

Half of these children are estimated to be under-achieving academically in relation to their intellectual level

Approximately 40,000 children with epilepsy are in mainstream schools

2.2 Education issues – the impact of epilepsy on performance

The effects of epilepsy on education and the problems experienced by teachers in understanding the challenges faced by the affected pupil are authoritatively described:

“As well as the potential for seizures to make the child miss lessons, epilepsy can cause short- and long-term memory problems, difficulties with concentration and information retention. Often teachers don’t fully understand why a child may appear to lack effort or attention and achieve poorly. Variable behaviour can be misinterpreted as being wilful.” Professor Brian Neville (former Prince of Wales’s Chair of Childhood Epilepsy)

In addition, for those children whose epilepsy is well-controlled, the effects of the powerful drugs they are taking affect their educational attainment and include impaired memory and attention. These effects apply equally to children with recognised special educational needs as well as to children with higher than average intellectual ability, who may only be achieving at a comparatively lower level. Without an individual assessment, it is not possible to know how best to support a child with epilepsy.

2.3 Education issues – the position of the Department

Epilepsy is defined by the Department as a purely medical condition, in the same category as asthma or diabetes. The comparison with asthma and diabetes is badly flawed. With the proper management of medication, a large majority of children with asthma and diabetes have little or no educational or behavioural challenges arising from their condition. That is simply not the case for children with epilepsy.

There is no reference to epilepsy in the Department's key SEN documents, *The Special Educational Needs Code of Practice* and *Removing Barriers to Achievement*. The latter states that every child has the right to a good education and the opportunity to fulfil their potential. This is not currently the case for children with epilepsy.

This lack of recognition actively hampers the teacher by failing to provide advice. There is a serious gap in the advice provided by the Department to the teacher.

Epilepsy is a medical condition that frequently has an impact on learning, well-being and behaviour. In this, it is more like autism than it is like asthma or diabetes.

The Department needs to provide advice on epilepsy in the same way that it provides advice on autism or to make clear that it is not proposing anything additional to assist this large cohort of underperforming children.

2.4 Education issues – “duty to take reasonable steps”

There is a legal duty “for schools...to take ‘reasonable steps’ to ensure that disabled pupils are not placed at a substantial disadvantage in relation to the education and other services they provide. This means that they must anticipate where barriers to learning lie and take action to remove them as far as they are able.” All too often, those barriers remain in place for pupils with epilepsy.

2.5 Education issues – Government response

We are encouraged that Minister Sarah Teather has met with us to discuss these issues and by a considered response from the Department. However no change in the Departmental position has been signalled and no proposals to improve support for children with epilepsy have been forthcoming. We hope that the proposed new Green Paper on SEN will propose improvements in support for children with epilepsy. However, as the Department does not currently define epilepsy as a condition that may give rise to SEN, a significant change in approach will be required.