



The human and economic cost of epilepsy in England

- 400 avoidable deaths per year
- 69,000 people living with unnecessary seizures
- 74,000 people taking drugs they do not need
- £189 million needlessly spent each year

wasted money
wasted lives

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The All Party Parliamentary Group on Epilepsy

The All Party Parliamentary Group (APPG) on Epilepsy, chaired by Baroness Gould of Potternewton, was launched to spread awareness of the nature of epilepsy amongst Parliamentarians and to raise the political profile of epilepsy and related problems. The secretariat is provided by the Joint Epilepsy Council (JEC), an umbrella group of 21 epilepsy organisations, operating across the UK and Ireland. Officers of the group are: Chair: Baroness Gould of Potternewton; Vice-chairs: Cheryl Gillan MP, Norman Lamb MP, Lord Smith of Leigh; Treasurer: John Battle MP; Secretary: David Cameron MP.

Acknowledgements

The Group would like to thank the Joint Epilepsy Council for their assistance in organising and facilitating the evidence sessions and with the production of this Report. The Parliamentarians who received oral evidence were Baroness Gould, Christine McCafferty MP, Nick Hurd MP and Evan Harris MP.

Witnesses

The Group would like to thank the witnesses, the service users, clinicians, and the voluntary sector representatives who took part in the oral evidence sessions as well as providing written evidence, and who were able to provide the wealth of real-life experience that forms the substance of this report. The APPG would particularly like to thank the many individuals who contributed to the findings of the Inquiry by submitting evidence on their personal, often very difficult, experiences.

Below is a list of witnesses who gave oral evidence to the Inquiry:

Naomi James – service user
Bernadette Howarth – service user
Emma & John Steele – service users
Liz Hallett & Bob Hollingdale – service users
Roger Scrivens – service user
Sue & Ti Parks – service users
Dr Henry Smithson – General Practitioner, Escrick Surgery, Yorkshire
Dr Helen Cross – Paediatric Neurologist, Great Ormond Street Hospital, London
Dr Hannah Cock – Senior Lecturer and Honorary Consultant, St. George's Hospital, London
Professor John Duncan – Neurologist, National Hospital for Neurology and Neurosurgery, London
Ms Vicky Rimmer – Roald Dahl Sapphire Epilepsy Specialist Nurse, the Royal Surrey County Hospital
Jane Hanna – Epilepsy Bereaved
Monica Cooper & Ingrid Burns – Epilepsy Action
David Ford & Nick Byford – National Centre For Young People with Epilepsy (NCYPE)
Graham Faulkner & Karen Lane – National Centre for Epilepsy (NSE)
Lynn and Fred Savill – Gravesend Epilepsy Network

What is epilepsy?

Epilepsy is the most common serious neurological condition affecting 382,000 people in England, one in every 131. Epilepsy is 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 messages passing between brain cells.

Epilepsy is not a single condition. There are about 30 different epileptic syndromes and over 38 different types of seizure and a person may have more than one type. Epilepsy can affect anyone, at any age and from any walk of life.

Every year 990 people in England die of epilepsy related causes¹. About 365 of those deaths are young adults and children.² Of the total number of deaths about 400 per year are avoidable.³

Introduction

During the course of this Inquiry, it has become clear that the National Health Service (NHS) is failing people with epilepsy and that a much improved service can be delivered at the same time as making significant cost savings.

The All Party Parliamentary Group on Epilepsy therefore calls upon the Government to recognise the benefits of change, accept the political, administrative and ethical duty to implement these changes, and to take positive action for the benefit of both the patient and the taxpayer.

Government has devolved much decision making to local Primary Care Trusts. It was not the purpose of this Inquiry to examine that policy. It does, however, sometimes give rise to a gap between stated Government policy and actual delivery. It can also lead to a postcode lottery, abhorrent to Government, where patients in one part of the country receive a significantly worse service than elsewhere. Again, this will be clearly shown to exist in the case of epilepsy.

Government must take care to avoid the criticism that admirable policy developments on paper without targets for implementation or powers to roll out the policy are seen as no more than Government “wish-lists”, and of little use to patients facing critical service failures on the ground.

Epilepsy is not a new condition. It has always been with us. Traditionally, it has been poorly understood. People with epilepsy have had to contend with every kind of mistreatment and social stigma. Our knowledge of the condition has much increased in recent decades and effective treatments have been developed yet the provision of services and access to them has never been adequate and is clearly not adequate now.

People with epilepsy are obliged to live with fears unknown to the rest of the population. Will I be bullied at school? Will my teachers understand my special needs? Will I be able to reach my educational potential? Can I get a job? Will I lose my job if I have a seizure? Will I lose my driving licence? What might happen to me when I have a seizure? Will I be robbed whilst out of control? How will my peers react? How about boyfriends or girlfriends? Must I keep it a secret? How can the NHS help me? Can I be cured or at least seizure-free? Does my doctor know what he or she is doing?

¹ Mortality Statistics: Cause (series DH2 no 32) Office of National Statistics, adjusted for the population of England

² The National Sentinel Audit of Epilepsy Related Death, The Stationary Office, London, 2002, adjusted for the 2005 number of reported deaths

³ Ibid

The All Party Parliamentary Group would like to thank the more than 200 MPs who showed their support for epilepsy specialist nurses facing threats to their posts during the current difficult financial circumstances within the NHS by signing EDM 541 and those MPs and Lords who have asked Parliamentary Questions.

The written and oral evidence we received from patients and their families helped us to understand the challenges of a life with this condition and, sadly, in some cases a death from this condition. The level of avoidable deaths at about 400 each year in England alone is shocking. In addition, the numbers experiencing seizures unnecessarily and the numbers taking anti-epileptic drugs for which they have no need is a national scandal.

It is about time that people with epilepsy received for the first time ever a health service that meets their needs, at least to the standard available to patients with other conditions. There is no doubt that this has not been the case to date.

The Joint Epilepsy Council, in its recently published manifesto for epilepsy, has shown how improvements in epilepsy care in England could realise savings estimated at around £134 million a year, the annual cost of epilepsy misdiagnosis based on figures from the National Institute for Clinical Excellence (NICE). In addition, around £55 million a year could be saved in England through reduced payments of the Disability Living Allowance. Together this is more than enough to fund the improvements being called for.

When faced with the widespread suffering and mortality directly attributable to the demonstrably poor level of service, plans with no deadlines and no targets offer little comfort to service users. It is important for Government to recognise its duty to take action and to introduce a step change in progress towards reaching the worthy policies that look so good on paper. We look forward to a Government response to this Report that does more than place responsibility firmly on the providers of local services. Guidance notes in an environment of no targets and no sanctions will achieve little. Our recommendations are designed to demonstrate how much can be done to improve the service, whilst saving costs.

We commend this Report to you and give grateful thanks to the many witnesses who gave up their time and shared their often painful experiences in order to educate us in the realities of the uncertain world that is life with epilepsy.

During the course of our Inquiry, it has become clear that even in this world of competing health interests, the case for improving epilepsy services is overwhelming.

A vicious circle of social stigma, secrecy and widespread medical ignorance has led to a poor service, from which patients cannot confidently expect good treatment at primary or secondary level.

The waste of money in delivering this inadequate service is almost as appalling as the unnecessary deaths and damage to quality of life experienced by people with epilepsy.

We hope we have identified ways forward in some detail but further momentum for change will have to be created. We believe that the Health Select Committee could make a vital contribution by focussing attention on the service failures and driving progress. We call upon the Select Committee to consider including epilepsy issues in its next programme of work.

Recommendations

1 Existing guidelines and Government action:

1.1 Review of epilepsy action plan – p9

The APPG believes that a review of the 2003 Action Plan is necessary and calls for an urgent assessment as to its progress towards implementation.

1.2 Early review of NICE guidelines – p10

That the Healthcare Commission conduct an early review of progress towards implementation of the NICE guidelines on the epilepsies and considers further action if that review reveals a lack of progress.

1.3 National Service Framework for Long-Term (Neurological) Conditions (NSF) – p11

Full implementation of the NSF is due by 2015. Progress towards success must be monitored or risk catastrophic failure. The APPG recommends that the Department for Health also consider the case for a stand-alone National Service Framework for Epilepsy.

2 Misdiagnosis and seizure freedom

2.1 Implementation of NICE guidelines – p13

The APPG recommends that PCTs unable to conform to NICE guidelines be required to produce a timed and costed Action Plan to meet this standard

2.2 Urgent review of equipment and staff – p15

The shortage of appropriate equipment and trained staff to operate it is a clear pinch point in the progress of treatment which will need to be addressed if NICE Guidelines and Government policy are ever to be delivered. A full review is urgently required.

2.3 Funding for expanding MRI & EEG services – p15

The APPG recommends that funding be made available to PCTs to expand referral access to MRI and EEG facilities.

2.4 Availability of surgery – p16

Surgery is the only known cure for epilepsy. All those who could benefit from surgery should have access to it as the cost savings of a lifetime of medical support are far greater than the costs of surgery.

2.5 Sudden Unexpected Death in Epilepsy (SUDEP) – p17

There is an urgent need to ensure improved communications of the risk of SUDEP and the management of that risk.

There is a need for a national protocol for the investigation of SUDEP cases and for the support of families.

Government criteria for funding and practice of bereaved services should recognise the needs of families affected by sudden medical deaths.

3 Workforce issues

3.1 The Quality and Outcomes Framework (QOF) – p18

The APPG recommends that the maximum number of points which GP surgeries can earn under QOF for Epilepsy be increased from the current 15 out of a possible 1,000 and that the quality criteria under QOF be revised so that they reflect optimal care as opposed to basic care.

The APPG recommends that a new QOF indicator be introduced which states the percentage of women with epilepsy of child-bearing potential who have been given information and counselling about contraception, conception and pregnancy.

The APPG recommends that a new QOF indicator be introduced which states the percentage of adult patients who are not seizure-free in the last twelve months who have been referred to tertiary services when circumstances require.

3.2 Neurologists and specialists – p19

The APPG believes that the Government should put in place a programme to increase the number of:

- 3.2.1 adult neurologists from 455 to 781;
- 3.2.2 paediatric neurologists from 75 to 150;
- 3.2.3 learning disability specialists from 340 to 500;
- 3.2.4 neuro-radiologists from 110 to 160, all within five to ten years.

Progress towards filling these posts must start now given the eight years it takes to train and gain the relevant experience to manage this complex and difficult to diagnose neurological condition.

3.3 GPs with a special interest (GPwSIs) – p19

The APPG welcomes the important contribution made by GPwSIs and urges the Government to make their development a key policy in the way they deliver services to people with epilepsy.

The APPG recommends that a national database of GPwSIs in epilepsy be compiled and that formal qualification for GPwSIs in epilepsy is put in place as early as possible.

GPwSIs should have a key role in performing the formal annual review of people with epilepsy, as recommended by the NICE guidelines.

3.4 Access to tertiary services – p20

Access to tertiary centres needs to be reviewed to enable all people with epilepsy who would benefit to have equal access. Consideration should be given to increasing the number of tertiary care centres.

3.5 Epilepsy specialist nurses – p22

The Department of Health should develop a national plan to increase the number of ESNs from the current 152 to 600 and, in the longer term, to 920 across all epilepsy disciplines (adult, paediatric, learning difficulties).

3.6 Implementation of NSF – p23

The Government should commit to providing guidance to local NHS organisations to ensure implementation of the 11 quality requirements within the National Service Framework for Long-Term (Neurological) Conditions.

3.7 National plan of epilepsy training – p23

There is a vital need for a national plan of epilepsy training for GPs, A&E doctors, paediatricians and other clinicians in order to increase their epilepsy knowledge base to the appropriate level

required for them to fulfil their respective roles.

3.8 Nurses trained to ESN level – p23

The APPG recommends that the health service makes better use of the pool of nursing staff trained to ESN level, yet not employed in that capacity.

4 Funding

4.1 Including epilepsy in national health targets – p25

That the Healthcare Commission carries out as a matter of urgency an Improvement Review into the state of epilepsy services.

4.2 Increasing funding for epilepsy – p25

Government urgently needs to increase funding for epilepsy services by the equivalent of £340 per person with epilepsy. This investment will help to address years of under investment and will quantifiably reduce the current costs of delivering a poor service.

5 Employment

5.1 Education for employers – p26

The APPG recommends that further efforts to educate employers and their first aid staff to build confidence in their ability to employ people with epilepsy are required.

6 Stigma

6.1 Tackling stigma – p27

The APPG recommends that the government do more to tackle stigma amongst employers, educational institutions and the general public by embarking on a programme of education amongst schools and employers to dispel some of the common myths.

7 Other vulnerable groups

7.1 Individual Education Plans (IEPs) – p29

The APPG recommends that each student with epilepsy has an Individual Education Plan which allows them to fully access learning.

7.2 Training for schools – p29

The APPG recommends that all schools receive training regarding the impact of epilepsy on learning.

7.3 National Centre for Young People with Epilepsy (NCYPE) – p29

The APPG fully endorses the NCYPE Code of Practice for Children with Epilepsy.

7.4 Improving care for elderly people with epilepsy – p30

The APPG recommends that awareness is increased amongst clinicians of the elderly regarding advances and developments in epilepsy.

7.5 Tackling misconceptions associated with epilepsy in minority ethnic groups – p30

The Department of Health needs to undertake research into misconceptions about epilepsy amongst ethnic minority groups, building on the Bradford study, and to take active steps to reduce misconceptions and improve epilepsy services for minority ethnic groups.

7.6 Risk of taking AEDs during pregnancy and interaction with the contraceptive pill – p31

All women with epilepsy should be provided with the information they need by epilepsy health professionals about the risk of taking AEDs during pregnancy, the risk of congenital anomalies

and potential interaction with the contraceptive pill, to meet the recommendations in the NICE guideline.

7.7 Review of NICE guidance in relation to learning disabilities – p32

The APPG recommends that the Department of Health and the Department for Education and Skills should take steps to deliver the NICE guidance on the treatment of people with epilepsy with learning disabilities and issue a guidance note to epilepsy health professionals on how to meet the NICE guidance.

7.8 Treatment for prisoners – p32

The APPG calls on the Department of Health to take steps to ensure that the NICE guidelines on the treatment of prisoners with epilepsy are fully implemented.

8 Residential care

8.1 Supported housing – p34

The APPG calls on the Government to bridge the gap between policy and practice by developing guidance to local authorities to ensure resources follow the individual when moving from residential care into supported housing.

8.2 Specialist commissioning of residential care services – p34

The APPG further calls on the Government to develop a national plan for specialist residential care.

1. Overview of existing guidelines and Government action

Between 1953 and 2000 there have been five Government reports concerning the provision of epilepsy care. All drew much the same conclusions about the fragmented and poorly co-ordinated service provision. But the provision of services for people with epilepsy in England has not substantially improved over the years.

The Chief Medical Officer's Annual Report of 2001

The Chief Medical Officer's report included an overview of the scale of epilepsy in the UK and called for a genuine commitment to put right serious and long-standing weaknesses in the standard of care.

National Sentinel Audit of Epilepsy-Related Death 2002

The National Audit of Epilepsy-Related Deaths which was published in 2002 showed that overall 39 per cent of adult deaths and 59 per cent of deaths in children were considered to have been potentially or probably avoidable⁴. In 2005 the number of epilepsy related deaths in England had increased to about 990⁵, of which about 400 per year are avoidable.

Action Plan for Epilepsy 2003

As a result of the Sentinel Audit, the Department for Health published the Government Action Plan for Epilepsy in February 2003. The plan included provisions to:

- Increase spending by £1.2 million over the next two years to improve access to neurology services.
- Modernise pathology and post mortem services to address shortfalls in current practice, and help to improve support and information for bereaved families of people with epilepsy;
- Introduce medicines management programmes, improving partnership between patients and professionals in relation to medicine taking, and looking at the effective use of medicines;
- Help to develop more general practitioners with a special interest in neurology;
- Improve care and support for pregnant women with epilepsy.

The Action Plan was generally welcomed but received criticism from epilepsy groups for the lack of targets for reducing the number of epilepsy-related deaths and for failing to propose any way of monitoring the effectiveness of the plan.

Recommendation: The APPG believes that a review of the 2003 Action Plan is necessary and calls for an urgent assessment as to its progress towards implementation.

NICE clinical guidelines on the epilepsies 2004

NICE published its clinical guidelines on the 'Diagnosis and Management of the Epilepsies in Adults and Children in Primary and Secondary Care', in October 2004. The guidance makes recommendations for the treatment and care provided by GPs and by specialists, the use of specialist centres (a clinic or unit with specialist skills in epilepsy that is difficult to diagnose or treat – a tertiary centre).

The document contained clear guidelines on diagnosis, investigation, classification and treatment of epilepsy, as well as guidelines for women, children, young people and older people with epilepsy.

⁴ National Sentinel Clinical Audit of Epilepsy-related Deaths, 2002, p15.

⁵ Mortality Statistics: Cause (series DH2 no 32)' Office of National Statistics, adjusted for the population of England

Selected summary of the NICE guidelines:

***Diagnosis:** Any person who has had a possible seizure should be seen within two weeks by a specialist medical practitioner with training and expertise in epilepsy. This specialist should make a diagnosis, using tests such as EEG (electroencephalogram) and MRI (magnetic resonance imaging) where appropriate. The tests should be available within four weeks of a specialist asking for them.*

***Treatment:** Anti-epileptic drugs (AEDs) should be started under the guidance of the specialist. Patients should be fully involved in all discussions about the benefits and risks of their treatment. After two years without seizures patients should have the opportunity to discuss with the specialist the benefits and risks of withdrawing or continuing AED treatment. The withdrawal of AEDs must be managed by, or under the guidance of, the specialist.*

***Information:** Patients should be empowered to manage their condition as well as possible, and be fully involved with their specialist and GP as a partner in all decisions about their health care and lifestyle. Information should be available on a range of issues such as: epilepsy as a condition; diagnosis and treatment options; risk management; first aid; driving; employment and education.*

***Review:** Adults with epilepsy should have a review at least once a year by their GP or specialist. If patients continue to have seizures or side effects or need particular advice (for example women planning a pregnancy), they should be referred to a specialist by their GP. Children should be reviewed by a specialist at least once a year, but more often if necessary.*

People with epilepsy welcomed the work of NICE. The National Audit of Epilepsy Deaths 2002 and these NICE Guidelines represented the first serious attempt by policy makers to address the historically low standards of care for people with epilepsy and to respond to the significant loss of life. The NICE Guidelines on epilepsy provide a clear framework by which standards of treatment and care for people with epilepsy can be measured

Non-implementation of the guidelines

The APPG is very concerned by the evidence of non-implementation of the NICE Guidelines, which was presented to us in oral and written evidence time and again.

The main reasons given by witnesses for non-implementation of the Guidelines was the absence of any plan (national, regional or local) to address poor levels of knowledge in the clinicians managing the care of many people with epilepsy. There is also a critical shortfall in clinicians and nurses specialising in epilepsy, nor has this treatment gap been addressed by the development of clinical networks to make the best use of such expertise as is currently available.

Recommendation: That the Healthcare Commission conduct an early review of progress towards implementation of the NICE guidelines on the epilepsies and considers further action if that review reveals a lack of progress.

National Service Framework on Long-term (Neurological) Conditions 2005

The Long-term (Neurological) Conditions National Service Framework (NSF) was launched in March 2005. The NSF aims to transform the way health and social care services support people to live with long-term neurological conditions. Key themes are:

- Independent living;
- Care planned around the needs and choices of the individual;
- Easier, timely access to services;
- Joint working across all agencies and disciplines involved

At the heart of the NSF there are 11 quality requirements which are drawn from and mapped against the core and developmental standards in National Standards, Local Action, and are to be fully implemented by 2015. The NSF also explains how these quality requirements can be achieved and how they will contribute to a number of Public Service Agreement targets.

Although the NSF was generally welcomed by people who have long-term conditions, the Government has been criticised for the lack of funding which will delay the implementation of the NSF. There is a 10 year implementation period for the NSF, with pace of delivery determined by local priorities. However, the APPG is disappointed that in response to a recent Parliamentary Question, the Minister responsible for Long-term Conditions replied:

No assessment has been made of the effectiveness of the “Long-term Conditions National Service Framework”. There is a 10-year implementation programme for this NSF. The overall pace of change will be according to local priorities and there are no targets.⁶

This is in stark contrast to NSFs for specified conditions such as diabetes, cancer and coronary heart disease which all have had progress reports on their implementation three to four years after their introduction.

Recommendation: Full implementation of the NSF is due by 2015. Progress towards success must be monitored or risk catastrophic failure. The APPG recommends that the Department for Health also consider the case for a stand-alone National Service Framework for Epilepsy.

White Paper - Our Health, Our Care, Our Say 2006

This White Paper, launched in January 2006, aims to set out a new direction for the whole health and social care system and confirms the vision set out in the Department of Health Green Paper, Independence, Well-being and Choice. It aims to start a radical and sustained shift in the way in which services are delivered, ensuring that they are more personalised and that they fit into people's busy lives and seeks to give people a stronger voice so that they are the major drivers of service improvement.

The White Paper states there will be more support for people with long-term conditions, who will be supported to manage their conditions themselves with the right help from health and social services. GPs will issue 'information prescriptions' to all patients with long-term conditions. These will detail the steps patients should take to improve their own circumstances and the support services they can access locally. In addition, the White Paper provides for all patients with long-term conditions to be offered integrated personal health and social care plans, as part of a wider combined health and social care records system.

It also seeks to support people with long-term conditions by trebling investment in the Expert Patient Programme which trains patients with long-term conditions to support themselves better, so that by 2012 100,000 people will be enrolled on the programme each year. To support a more integrated approach with regards to social as well as health care, the White Paper seeks to develop Personal Health and Social Care Plans and integrated social and health care records.

Conclusion

The APPG recognises the initiatives which the Department for Health has taken regarding the care of people with epilepsy. The NICE guidelines have been seen as groundbreaking in setting the standards

⁶ Rosie Winterton in Answer to a Written Parliamentary Question (135909) by Nicholas Brown

for optimal care. However, effective implementation of the Guidelines and Action Plan remains in question.

2. The treatment gap

“It is not only the misdiagnosis of whether it is epilepsy or not, it is the misdiagnosis of the type of epilepsy. In paediatrics particularly that is so important, because the multitude of syndromes start in childhood and if you do not make an accurate diagnosis of the type of syndrome you can get the drug treatment wrong and actually make it worse.”⁷ Dr. Helen Cross

“If somebody is not well trained for taking a good history and dissecting out the points, they are likely to get the diagnosis wrong.”⁸ Professor John Duncan

“...that consecutive letters about the same patient coming into those practices will talk about different sorts of epilepsy, different sorts of seizures, depending on which registrar that patient sees for their review”⁹ Dr Henry Smithson GP

“Because of my misdiagnosis I have lost chunks of my daughter growing up. Doctors should get their heads together, listen to their patients and not dismiss us when we say we need an MRI or an EEG.”¹⁰ Anonymous witness

Misdiagnosis, seizure freedom and its cost

Many people are wrongly diagnosed with epilepsy or have been diagnosed with the wrong type of epilepsy. Misdiagnosis rates in England are shocking, standing at between 20 – 31 per cent. An unknown number of people also have a missed diagnosis, where they have got epilepsy but it has been diagnosed as something else.

Assuming a misdiagnosis figure of 23 per cent, this means that 74,000 people without the condition in England alone have a diagnosis of epilepsy and are receiving treatment for it.

The Joint Epilepsy Council, in its recently published manifesto for epilepsy, has shown how improvements in epilepsy care in England could realise savings estimated at around £134 million a year, the annual cost of epilepsy misdiagnosis based on figures from NICE.¹¹ The medical cost alone of the unnecessary treatment of people who do not have epilepsy and the wrong treatment of people who have been diagnosed with the wrong kind of epilepsy in England alone is estimated to be around £22.68million per annum.¹² This does not include the economic cost or the cost in opportunities for people who could be in work but are not due to misdiagnosis or mistreatment. When those costs are included, the estimated total cost of misdiagnosis in England rises to £134 million a year.

Seventy per cent of the population with epilepsy in the UK could be seizure-free with optimal treatment. Currently this is achieved for only 52 per cent, meaning 69,000 of those experiencing seizures in England could be seizure-free. The human cost of these failings is huge for the individuals concerned, their families, and to society. Not only are they receiving treatment for a condition they do not have – their true condition is not being treated.

⁷ Dr Helen Cross, oral evidence, medical practitioners, p12

⁸ Prof John Duncan, oral evidence, medical practitioners, p33

⁹ Dr Henry Smithson GP, oral evidence, medical practitioners, p6

¹⁰ Anonymous witness, transcripts, p7

¹¹ The Joint Epilepsy Council, Epilepsy the Case for Investment, 2005, p2

¹² The Joint Epilepsy Council, Epilepsy Prevalence, Incidence and Other statistics, August 2005

In many submissions the APPG received, misdiagnosis was a recurrent theme which had a profound impact on the quality of life of people with epilepsy or those who were wrongly identified as having epilepsy.

Naomi James, who was diagnosed in 2003 with temporal lobe epilepsy said: *“Not knowing what has been wrong with me has been very distressing and has had a profoundly negative impact on my life. I was withdrawn, frightened, confused and at times suicidal, which caused a long history of absences disrupting both my student and working life. Since diagnosis and taking anti-epileptic medication, my quality of life has greatly improved. I am now more confident, stable and in control, however, I am still not seizure-free.”*¹³

The APPG took written evidence from one witness who wished to remain anonymous and who spent a lot of her adult life in psychiatric care because her epilepsy had for years been diagnosed as schizophrenia.

Commenting on her misdiagnosis, she said: *“If someone had only diagnosed me correctly 27 years ago (I am now 52), perhaps my life would have been a bit different. The devastation this has created for me throughout my life is enormous. I have not been able to lead a normal life and in doing so my family has suffered. They have lost me for great chunks of my life three months at a time and I have just been pumped full of drugs none of which worked.”*¹⁴

Many people have their seizures successfully controlled with AEDs. This is the most common way that epilepsy is treated. AEDs do not cure epilepsy. Their aim is to prevent seizures by acting in some way to control the excitability of the brain. How they do this is not yet fully understood. Nevertheless, for a large proportion of people, their effectiveness in treating epilepsy is beyond dispute. AEDs should be effective for around 70 per cent of people with epilepsy. There are several different AEDs available, some of which are more suitable for different seizure types than others.

The side effects of some AEDs should not be underestimated. The most common involve the central nervous system (CNS), and include dizziness, problems with coordination, sleep disturbance, and cognitive dysfunction. In addition to these quite common side effects, AEDs may have clinically relevant side effects that involve other organ systems. **Studies have also shown that major malformations in the offspring of mothers with epilepsy can be associated with use of AEDs during early pregnancy.**¹⁵

Given the high number of misdiagnosed epilepsy cases in England, the APPG can only conclude that as a result tens of thousands of people are enduring these side-effects from drugs they should not be taking in the first place.

One of the main reasons for the high level of misdiagnosis is the lack of training amongst medical practitioners and the limited access for people with epilepsy to epilepsy specialists. Many of the world’s leading epilepsy specialists work in the UK but very few healthcare professionals understand epilepsy sufficiently; there are too few healthcare professionals specialising in epilepsy in both adult and paediatric care; for many people it takes far too long to gain access to equipment used to diagnose and treat epilepsy accurately.

Recommendation: The APPG recommends that PCTs unable to conform to NICE guidelines be required to produce a timed and costed Action Plan to meet this standard

¹³ Naomi James, written evidence, service users, p3

¹⁴ Anonymous witness, transcripts p5

¹⁵ K Wide, B Winbladh, B Källén (2004), Major malformations in infants exposed to antiepileptic drugs *in utero*, with emphasis on carbamazepine and valproic acid: a nation-wide, population-based register study, *Acta Paediatrica* 93 (2), 174–176.

Investigations

NICE clinical guidelines on the epilepsies state that any person who has had a possible seizure should be seen within two weeks by a specialist medical practitioner with training and expertise in epilepsy. This specialist should make a diagnosis, using tests such as EEG (electroencephalogram) and MRI (magnetic resonance imaging) where appropriate. The tests should be available within four weeks of a specialist asking for them.

The APPG recognises the under-provision of MRI and EEG scanners and staff trained to operate such equipment in many NHS trusts. Dr Hannah Cock told the Inquiry that many of her colleagues had reported waiting lists for EEG scans of up to several months, and for video-telemetry waits of up to 9-12 months had been accepted as the norm for some years. She said this reflected inadequate numbers of consultant neurophysiology staff and technicians.

There have been suggestions that referrals for EEG, video-telemetry, and MRI scans should be limited to specialists to reduce the large number of unnecessary referrals for these limited resources. This will reduce waiting times for those who do require scans.

The NICE guidelines on epilepsy recommend that “individuals requiring MRI should have the test performed soon”. The Guideline Development Group subsequently considered that ‘soon’ meant being seen within four weeks.

From a recent survey by Epilepsy Action only 26 per cent of 185 respondents who had had an MRI scan within the last two years said that they had had the scan within four weeks.¹⁶

This was illustrated during the inquiry by the evidence of Bernadette Howarth¹⁷, whose 17-year old son Josh had his first seizure at the age of 9. He was diagnosed with partial seizures and was put on various medications which he was either allergic to or did not work. When Josh was 11 years old it became doubtful that he had epilepsy and further tests were necessary to establish the cause of his seizures. However, he had to wait 18 months for video telemetry. Afterwards, the hospital told them that they had lost the tapes.

Subsequently, Josh went for another appointment for a video telemetry test. However, there was no bed for him and no neurophysiologist available to perform the test. When the test was eventually done, he was finally diagnosed with generalised seizures from the right frontal lobe. He was put on a waiting list to go to Kings College in London with a view to having surgery as the medication he was on did not work. It was more than a year later before he was told there was only a 60 per cent chance that surgery would work in his case. The family have not heard anything about the operation since then.

The APPG also took evidence from Emma Steele whose parents decided that she should go private for her EEG after being on an NHS waiting list for two years. She has just come out of hospital having had the EEG scan done privately and is due to have another test (pre-operative), which she will again have done privately for the same reasons¹⁸.

Experiences such as Joshua’s and Emma’s show that waiting times for vital MRI and EEG tests are still far too long in many NHS Trusts.

¹⁶ Epilepsy Action, Epilepsy Services Survey, January 2007.

¹⁷ Bernadette Howarth, oral evidence service users

¹⁸ Emma Steele, oral evidence session, service users

Recommendation: The shortage of appropriate equipment and trained staff to operate it is a clear pinch point in the progress of treatment which will need to be addressed if NICE Guidelines and Government policy are ever to be delivered. A full review is urgently required.

The APPG was informed by Epilepsy Action¹⁹ that a number of PCTs are using referral and funding panels to decide which epilepsy patients can be referred to a specialist and whether surgery can be provided. It is clearly inappropriate for these decisions to be taken out of clinical hands.

Recommendation: The APPG recommends that funding be made available to PCTs to expand referral access to MRI and EEG facilities.

Surgery

“Many adults coming to surgery have had epilepsy since early or mid-childhood, so they have already had epilepsy for 15 years before they come to surgery, which offers a 75 per cent to 80 per cent chance of getting rid of their seizures. In many cases, this could have been done 10 years before.”²⁰
Dr Helen Cross

Surgery remains the only curative treatment for epilepsy. It is considered effective for reducing or eliminating seizures in people with medically intractable epilepsy.

Ingrid Burns from Epilepsy Action states: *“A large number of patients who could benefit from surgery remain untreated because, due to insufficient funding, many patients are not referred for specialist care.”²¹*

Surgery is only appropriate for people for whom drugs have failed, and whose seizures come from one part of the brain – and where that part is fairly small and the individual can live without it. This amounts to about three per cent of those who develop epilepsy. About 70 per cent of all people who have surgery become completely seizure-free. Many more experience a reduction in frequency of seizures.

According to Professor Duncan, Head of the Department of Clinical and Experimental Neurology at University College London’s Institute of Neurology, there is a need for about 1,000 epilepsy operations a year in the UK²². It has been estimated by Lhatoo et al that in 2003 around 4,500 patients in the UK required epilepsy surgery. Each subsequent year, 450 people with newly diagnosed epilepsy are added to this surgical pool. However, the Lhatoo study showed 211 operations carried out in six months surveyed.²³ At that rate, the backlog will never be cleared.

Surgery should be made available to all people with epilepsy for whom it is indicated. There is a clear net saving when taking into account the alternative of expensive lifetime medication and occasional hospitalizations, as well as the health benefit to the individual.

Patients who are successfully treated will also have better employment prospects and be less dependent. The high initial expenditure involved in epilepsy surgery would result in long-term cost savings.

¹⁹ Epilepsy Action, written evidence voluntary organisations

²⁰ Dr Helen Cross, oral evidence, medical practitioners, p18

²¹ Ingrid Burns, Voluntary organisations oral evidence, p9

²² Prof John Duncan, oral evidence, medical practitioners

²³ Lhatoo et al, A Prospective Study of the Requirement for and the Provision of Epilepsy Surgery in the United Kingdom. *Epilepsia* 2003; 44 (5):673-676.

Recommendation: Surgery is the only known cure for epilepsy. All those who could benefit from surgery should have access to it as the cost savings of a lifetime of medical support are far greater than the costs of surgery.

Sudden Unexpected Death in Epilepsy (SUDEP)

“...what we experienced was a total lack of awareness. There was just no knowledge, it appears, of how serious the situation could potentially be.” Roger Scrivens, father of Becky Scrivens who died of SUDEP²⁴

In recent years, there has been an increase in reported epilepsy deaths, the majority of which are SUDEP.

It may be that the National Audit of Epilepsy Deaths which was published in 2002 has led to an increased awareness of SUDEP, but this has not been translated into action in the majority of PCTs.

In addition, it is clear that a number of NICE guidelines which would not require significant funding to implement are currently not put into practice. NICE guidelines recognise the importance of seizure freedom and being aware of the dangers of night seizures and recommend that SUDEP should be part of essential information to patients following diagnosis.

The Inquiry took evidence from service users such as the parents of Becky Scrivens²⁵, who died in 2004 having never had access to a specialist. As a result, Becky was diagnosed with epilepsy at a very late stage and never received appropriate treatment even though her type of epilepsy was known to respond well to medication.

Furthermore the inquiry heard of Katie Hallett, who died from SUDEP aged 20 years. Her parents said: *“SUDEP was something that we were totally unaware of, we had never been told about. Katie had heard of SUDEP, which she had stumbled across by chance because she was training to be a children’s nurse at Bristol University, but she was never told about SUDEP as a patient and was never told how to minimise the risks or what to avoid. We were not contacted and we still have not been contacted to this day by the health team. We were never given any information on Epilepsy Bereaved and it was simply through a family friend whose daughter is a severe epileptic that we were able to contact the charity who have been very supportive to us since.”*²⁶

The APPG also heard evidence from Epilepsy Bereaved with regards to the specialist investigation required in cases of SUDEP. The current lack of standardisation and quality assurance in post-mortem investigation and certification of these deaths is a key barrier to implementation of recognised prevention strategies. We agree with Epilepsy Bereaved that an urgent re-audit of epilepsy deaths is necessary to determine whether lessons from the previous audit have been learnt.

Epilepsy Bereaved made the point that, although it is the only SUDEP support service in the UK, in their experience most of the referrals of bereaved families to them are from the internet and other epilepsy organisations rather than from clinicians or coroners.

The APPG welcomes the Government’s acknowledgement of the need for improved support for the bereaved following a sudden death and that coroners should have powers to ensure lessons are learnt from sudden deaths, as part of its proposed coroner’s reforms.

²⁴ Roger Scrivens, oral evidence service users, p35

²⁵ Roger Scrivens, oral evidence service users

²⁶ Liz Hallett, oral evidence service users, p27

Recommendations:

There is an urgent need to ensure improved communications of the risk of SUDEP and the management of that risk.

There is a need for a national protocol for the investigation of SUDEP cases and for the support of families.

Government criteria for funding and practice of bereaved services should recognise the needs of families affected by sudden medical deaths.

3. Workforce issues

Primary care

The Quality and Outcomes Framework (QOF) is part of the new General Medical Services (GMS) contract that resources and rewards GPs for how well they care for patients rather than simply how many they treat.

Under the QOF, practices score points for achievement against a range of indicators and are paid according to points achieved. The more points the practice achieves the more money they earn. A GP practice can currently get a maximum of 15 points out of a possible 1,000 for the treatment of people with epilepsy. It is a voluntary part of the new contractual arrangements and came into effect in April 2004.

Witnesses to the Inquiry have stated that the QOF indicator performance does not necessarily correlate with adherence to government guidelines. In addition, as Dr Henry Smithson stated in his evidence: *"We have found that the QOF for a number of conditions, including epilepsy, measures the basic, not the best care."*²⁷

Whilst agreeing that the QOF has made a difference to patient care in some practices, Dr Smithson added that: *"Some of the best care for people with epilepsy cannot be measured, because it is about information, it is about support, and it is about making correct decisions about self-management of the condition."*²⁸

The Inquiry received further evidence that GPs are vital in carrying out the annual epilepsy review. However, often the review was simply done over the telephone by a practice nurse with no experience or training in epilepsy. We understand that some pharmacists are now saying they can do an epilepsy medicines review in a chemist's shop. That proposition would reduce, not improve, the standard of annual reviews.

In addition, the Inquiry was informed of the need to introduce a new category into the QOF which would ensure that patients would receive appropriate care and information when deciding to start a family and during pregnancy.

The APPG also believes there is a need to include a new category in the QOF with a specific inducement to GPs to consider referral of patients whose seizures continue. The introduction of this category needs to be a priority because a reduction in the frequency of epileptic seizures will only be achievable once a patient not responding well to AEDs has been referred to tertiary services.

²⁷ Dr Henry Smithson, oral evidence, medical practitioners, p5

²⁸ Ibid, p6

Recommendations:

The APPG recommends that the number of maximum points which GP surgeries can earn under QOF for Epilepsy be increased from the current 15 out of a possible 1,000 and that the quality criteria under QOF be revised so that they reflect optimal care as opposed to basic care.

The APPG recommends that a new QOF indicator be introduced which states the percentage of women with epilepsy of child-bearing potential who have been given information and counselling about contraception, conception and pregnancy.

The APPG recommends that a new QOF indicator be introduced which states the percentage of adult patients who are not seizure-free in the last 12 months who have been referred to tertiary services when circumstances require.

Specialists

“We are way behind the rest of Europe, the western world, in terms of the number of neurologists per head of population – we are a long, long way behind.”²⁹

The NICE clinical guidelines note that all adults and children with a recent-onset suspected seizure should be seen within 2 weeks by a specialist. Generally these specialists are neurologists (adult and paediatric), but they may also include neuropsychiatrists, learning disability specialists and occasionally General Practitioners and other specialities.

The results of an Epilepsy Services Survey by Epilepsy Action in 2007 suggested however that only 14 per cent of people with a recent-onset suspected seizure who were referred to a specialist saw one within two weeks.³⁰

Access to specialist neurologists is currently too limited and there is a postcode lottery in access to neurological services.

According to Dr Hannah Cock, Senior Lecturer and Honorary Consultant at St George’s Hospital: *“Unless patients with long-term epilepsy at general practice level are in crisis, they do not get referred. There are a lot of people out there still getting sub-standard care who could be on better drugs, who could have better control, who certainly need better information provision and support, and they are just not getting it, because they only get referred when a crisis happens.”³¹*

In comparison with most European countries there is significant under provision of a skilled medical workforce to provide both acute and long-term care for people with long-term neurological conditions³². England has one of the lowest numbers of neurologists in Europe. Countries comparable in population size to England such as France and Italy respectively have three times and 14 times the number of neurologists.

The Royal College of Physicians publication “Consultant Physicians Working with Patients”³³ estimates that *“to provide comprehensive neurological care, including the care of the acutely ill neurological patient, one whole time equivalent consultant neurologist is required for 40,000*

²⁹ Dr Hannah Cock, oral evidence medical practitioners, p31

³⁰ Epilepsy Action, Epilepsy Services Survey, (January 2007). Epilepsy Action mailed a questionnaire to a random sample of 1,000 members and clients and posted the survey on www.epilepsy.org.uk.

³¹ Dr Hannah Cock, oral evidence medical practitioners, p24

³² Workforce Issues Discussion Paper, Department of Health, Neuro Advisory Panel

³³ Consultant Physicians Working with Patients, Royal College of Physicians,, January 2005

population. This model demands 1,250 NHS neurologists, 175 centre-based neurologists and 78 academic neurologists, which gives a total of approximately 1,400 nationally."

The Royal College has conceded that this target is perhaps unrealistic in the short term and goes on to call for a target of 909 whole time equivalent across the UK by 2012. For England alone, this equates to 781 neurologists by 2012, compared to the current 436.

Similar shortfalls in clinical specialists occur in Paediatric Neurology, Learning Disability (more than one in five people with epilepsy have a learning or intellectual disability) and Neuroradiologists.

The White Paper "Our health, our care, our say"³⁴, reinforced the view that general practitioners with special interests (GPwSIs), have a key role in delivering services closer to patients' homes. The APPG recognises the role these practitioners can play in the care for people with epilepsy and the vital link they provide between primary care and secondary care. It is clear that these professionals, who are easier for the patient to access and who do not have long waiting lists, can play an important role specifically regarding accurate diagnoses and effective annual reviews as recommended in the NICE guidelines. Also, given the shortage in the number of neurologists in England, more GPwSIs would have a considerable impact in taking the pressure off secondary neurological services.

The APPG believes that GPwSIs would be more appropriate to carry out annual reviews than non-specialist GPs, who often do not have the required specialist knowledge. However, as pointed out by Dr Henry Smithson in his evidence to the Inquiry, many PCTs do not necessarily have the funding to appoint such GPwSIs.³⁵

Although the Department of Health has issued guidelines, there are no formal, accredited qualifications for becoming a GPwSI in Epilepsy at present, nor is there currently a formal course that GPs can attend to become a GPwSI in Epilepsy. It is therefore still up to individual PCTs to say whether a GP can call themselves a GPwSI.

The APPG has been informed that a formal course is planned, which will be run by a University in the South East. It is hoped that this course will be accredited by the Royal College of General Practitioners and the Association of British Neurologists and will become the standard training that has to be undertaken to become a GPwSI in Epilepsy.

Recommendation: The APPG believes that the Government should put in place a programme to increase the number of:

- adult neurologists from 455 to 781;
- paediatric neurologists from 75 to 150;
- learning disability specialists from 340 to 500;
- neuro-radiologists from 110 to 160, all within five to 10 years.

Progress towards filling these posts must start now given the eight years it takes to train and gain the relevant experience to manage this most complex and difficult to diagnose neurological condition.

Recommendation: The APPG welcomes the important contribution made by GPwSIs and urges Government to make their development a key policy in the way they deliver services to people with epilepsy.

Recommendation: The APPG recommends that a national database of GPwSIs in epilepsy be compiled and that formal qualification for GPwSIs in epilepsy is put in place as early as possible

³⁴ "Our Health, Our Care, Our Say", Department of Health, October 2006

³⁵ See Dr Smithson oral evidence, medical practitioners, p3

Recommendation: GPwSIs should have a key role in performing the formal annual review of people with epilepsy, as recommended by the NICE guidelines.

Tertiary care

Ready access to high quality, responsive primary and secondary care is crucial for those with epilepsy and this will meet the needs of the majority of those with epilepsy. However, only 52 per cent of people with epilepsy have their seizures successfully controlled. The 48 per cent who have seizures that are not controlled with AEDs should be referred to tertiary care clinics.³⁶ It is estimated that 70 per cent of people with epilepsy could be seizure-free with optimal treatment.

Tertiary referrals will usually take place in a bigger hospital or neuroscience centre where there are neurologists who specialize in epilepsy and who have in their teams psychologists, psychiatrists, neurosurgeons, an EEG specialist, etc.

The APPG was informed that many of those seen in tertiary care indicated that they had to battle with their local Primary Care Trusts over a protracted period to get the referral approved. Professor John Duncan who gave evidence to the inquiry stated: *“It is evident that these individuals and their families are commonly well-educated, assertive and articulate. We only see those who succeeded. The concern is that there are many who are dissuaded, turned down or give up the struggle with the system and who are then denied the opportunity for optimal advice and care.”*³⁷

According to Professor Duncan tertiary referrals can be vital for a number of reasons such as diagnostic uncertainty, specialised advice on drugs, surgery, epilepsy combined with other complicated medical conditions or psychological problems, or situations where people just need advice on difficult issues such as how to combine their condition with their employment situation.

Recommendation: Access to tertiary centres needs to be reviewed to enable all people with epilepsy who would benefit to have equal access. Consideration should be given to increasing the number of tertiary care centres.

Epilepsy specialist nurses

*“The impact that epilepsy has on people’s lives can be huge. The more we can support children, adults, people with learning disability and all carers who are coping with this condition, the greater the chance of encouraging them to actively participate and contribute to society.” Vicky Rimmer, Children’s epilepsy specialist nurse*³⁸

*“Epilepsy nurse specialists are being made redundant. That is happening, and it is such a silly cost containment because, of course, it means that then people will have to go to more expensive professionals or more expensive services.” Dr Henry Smithson GP*³⁹

*“Epilepsy specialist nurses are absolutely vital to the running of most services countrywide... providing education, on the spot advice, alterations in medication, monitoring, etc. Most of all they are accessible and any reduction in numbers of specialist nurses would lead to a poorer quality of treatment for people with epilepsy.” Jon Sutcliffe*⁴⁰

³⁶ Prof John Duncan, written evidence medical practitioners, p17

³⁷ Prof John Duncan, written evidence medical practitioners, p17

³⁸ Vicky Rimmer, written evidence, medical practitioners, p20

³⁹ Dr Henry Smithson, oral evidence, medical practitioners, p3

⁴⁰ Jon Sutcliffe, Protection of Epilepsy Services, Joint Epilepsy Council, p5

It is clear that epilepsy specialist nurses (ESNs) are a crucial source of support and advice to patients with epilepsy, and enable many patients to manage their epilepsy effectively and to remain independent in the community. Epilepsy Action has calculated that in England alone, at least 60 per cent of people with epilepsy, or 230,000 people, should have regular access to an ESN and all should have occasional access.⁴¹

There are approximately 152 epilepsy specialist nurses in England and the epilepsy organisations have been campaigning for this number to increase to 920 in England. Epilepsy Action also recommends that epilepsy specialist nurses have a caseload of no more than 250 patients with active epilepsy.

Guidelines have been produced in recent years which state the importance of having epilepsy specialist nurses. NICE epilepsy guidelines state that “epilepsy specialist nurses should be an integral part of the network of care of individuals with epilepsy” whilst SIGN Guideline No. 70 on the Diagnosis and management of epilepsy in adults⁴² states that: “All epilepsy care teams should include an epilepsy specialist nurse”

However, a number of witnesses to the inquiry gave evidence which suggests that many ESNs across the UK are currently threatened with redundancy, reduced hours or assignment to non-specialist duties.

There is no dispute regarding the efficacy of ESNs. ESNs save the NHS money by:

- releasing consultants’ time,
- reducing accident and emergency admissions,
- enhancing patients’ adherence to anti-epileptic treatment, and
- reducing the use of hospital beds.

Clear evidence displays high levels of patient satisfaction, reduced psychosocial trauma, less time off work, less medical input and fewer readmissions. In addition, ESNs enable people with epilepsy to better self-manage their condition and therefore reduce waiting times to see a neurologist.

However, from our evidence it became clear that access to ESNs is still patchy. The Hallett family told the APPG that *“Doctor X recommended that maybe Katie should see a nurse in the first instance and that was in 2001. She never saw anybody or received an appointment at that time. Doctor Y then recommended she should see an ESN again in 2005 and that appointment came through mid-January 2006, a few days after Katie passed away”*⁴³.

In her evidence to the inquiry, Jane Hanna, from Epilepsy Bereaved⁴⁴, also made the point that ESNs play an essential role in raising awareness of SUDEP.

Despite the already chronic shortage of ESNs across Britain, patients and epilepsy organisations are currently forced to defend the status quo, rather than seeking an expansion of the excellent service provided by ESNs. The APPG is concerned that local NHS organisations facing severe financial pressures are making short-term cuts which will seriously impact upon the quality of life for those with epilepsy.

Sapphire Nurses

Seventy two of the current ESN posts within the UK were pump prime funded through Epilepsy Action with agreements with the NHS trust concerned that these posts (Sapphire Nurses) would continue once the pump prime funding had expired. Through the scheme, Epilepsy Action provides

⁴¹ Epilepsy Action, written evidence, voluntary organisations, p13

⁴² SIGN Guideline No. 70 on the Diagnosis and management of epilepsy in adults, NICE, April 2003

⁴³ Hallett family, oral evidence, service users, p30

⁴⁴ Jane Hanna, Oral evidence, voluntary organisations

£30,000 - £55,000 of financial support to NHS trusts for them to employ an epilepsy specialist nurse. **Since the scheme was set up in 1995, there has been over £2.5 million invested creating 83 nurse posts within the NHS. Seven NHS trusts have not honoured their agreement to continue funding the posts once the pump priming funding ceased. This is likely to have an effect on the future of this valuable funding provided to the NHS by charities.**

Evidence from the International League Against Epilepsy, UK Chapter, suggests that as a result of recent Government NHS reforms such as Payment By Result (PBR), some local PCTs have been reported to be barring consultant to consultant referrals which will have a negative impact on the number of referrals from secondary care to tertiary level care and may even stop direct handover referrals from paediatric to adult neurology services⁴⁵

Government's involvement

The Department of Health has repeatedly acknowledged the vital contribution that specialist nurses make to the treatment and care of patients with epilepsy. Minister for Care Services, Ivan Lewis MP, recently stated in a Written Answer that "specialist epilepsy nurses provide an additional clinical resource and have spearheaded the development of nurse led and fast access clinics, monitoring treatment regimes and seizure control, support and information on aspects of medication and side effects and lifestyle precautions."⁴⁶

However, Government also makes it clear that decisions which affect ESN services are made by the local NHS trusts and it cannot intervene. However, the APPG believes that it should do more to prevent local health trusts from seeing ESNs as 'soft targets' when seeking to balance budgets.

We very much welcome the recent dialogue between Ivan Lewis MP, as the Minister responsible for long-term conditions, and voluntary organisations on the issue of specialist nursing. We look forward to the draft guidance on specialist nurses which his Department will be publishing early in 2008 and the conference at which it will be launched.

Dr Ruby Schwartz, Consultant Paediatrician at the Royal Middlesex Hospital, summarises the APPG's view that: *"ESNs provide continuity within the clinic setting. It is ironic that when the Government wants services to be led by nurses and GPs, the one group of nurses whose value has been shown to be effective, are under threat. Without specialist epilepsy services patients will get a poor deal."*⁴⁷

ESNs and specialist nurses which deal with other neurological conditions ought to be an integral part of the Government's strategy to provide more care in the community, including enabling and facilitating self-management of patients' conditions, as well as being vital to delivering the Quality Requirements of the National Service Framework for Long-term (Neurological) Conditions (NSF).

The NSF aims to transform the way in which health and social care services support people who live with long-term neurological conditions. In addition, Government needs to take urgent steps to ensure that the commitment in NICE Clinical Guidance 20 (see above) is fully implemented across all NHS trusts so that the current cuts in specialist epilepsy nursing teams do not result in any more of a postcode lottery than already exists for the 382,000 people in England with epilepsy.

Recommendation: The Department of Health should develop a national plan to increase the number of ESNs from the current 152 to 600 and, in the longer term, 920 across all epilepsy disciplines (adult, paediatric, learning difficulties).

⁴⁵ International League Against Epilepsy, written evidence, p 2

⁴⁶ PQ 101247 (Nick Hurd MP), 21 November 2006

⁴⁷ International League Against Epilepsy, written evidence, p2

Recommendation: The Government should commit to providing guidance to local NHS organisations to ensure implementation of the 11 quality requirements within the National Service Framework for Long-term (Neurological) Conditions.

Training

According to the Department of Health Workforce Issues Discussion paper of 2006, there is a shortage of medical care staff with training and expertise in epilepsy and many patients travel long distances to regional neuroscience centres for tests and treatment. As a result, acutely ill neurology patients are often not under the care of a neurologist and either have to wait for a long time for expert advice or may not receive this at all.

The Association of British Neurologists (ABN) states that neurologically trained nurses and GPs with special interests should play an increasing role in the interface between the different levels of patient care. The National Statement of Good Practice recommends that epilepsy care staff should have a recognised qualification in epilepsy.

A survey by the Neurological Alliance in 2000 recommended that GPs needed training about neurological conditions and to be kept up to date with developments in diagnosis, treatment and rehabilitation. A survey of geriatricians, carried out by Epilepsy Action in 2005⁴⁸, found that 84 per cent of geriatricians that see between one and 20 patients aged 60 and over with epilepsy each month, have never been on an epilepsy-related course.

The APPG received evidence that despite a number of good epilepsy courses available, nurses are often not getting the funding from their trusts to pay for the courses. According to Epilepsy Action, a further 770 ESNs are needed in England. There are approximately 250 - 300 nurses who have undertaken sufficient training in epilepsy and which could be classed as ESNs but are currently not working in that role due to a shortage of posts.

In addition, there are on average about 70 nurses per year who train to be a professional epilepsy nurse. In five years time there may therefore be a total of approximately 600 - 650 nurses trained to be ESNs. Whilst this is still short of the necessary 770 ESNs needed, this is a positive development. However, in reality it will be impossible to create that many posts in five years because of a lack of interest from PCTs in funding this type of post.

Recommendation: There is a vital need for a national plan of epilepsy training for GPs, A&E doctors, paediatricians, care of the elderly physicians and other clinicians in order to increase their epilepsy knowledge base to the appropriate level required for them to fulfil their respective roles.

Recommendation: The APPG recommends that the health service makes better use of the pool of nursing staff trained to ESN level, yet not employed in that capacity.

4. Funding

“Numerous reports and guidelines have made excellent recommendations about how the lives of people with epilepsy could be improved through better health care. However, a blatant lack of funding means that these recommendations have not been implemented, leading to people with epilepsy, firstly, not having access to health care staff with training and expertise in epilepsy;

⁴⁸ Epilepsy Action. Survey of UK geriatricians (April 2005). Source: Market & Opinion Research International (MORI). www.epilepsy.org.uk

*secondly, waiting for a long time to even see a neurologist; and thirdly, waiting for referrals for tests such as CT and MRI scans for an unacceptable length of time.”*⁴⁹ Ingrid Burns, Epilepsy Action

*“I had to fight tooth and nail to keep my role going when the funding ran out last time.”*⁵⁰ Vicky Rimmer, Children’s ESN

*“Because funding for epilepsy is at such a low level, extra investment can make a big difference. You could see a considerable added value and hopefully quite a dramatic falling off of these deaths if an investment was made.”*⁵¹ Jane Hannah, Epilepsy Bereaved

The APPG believes that a significant reason for the serious gaps in service provision for people with epilepsy is lack of funding. Despite similar numbers of people being affected, funding for epilepsy is very low in comparison with that for other conditions that impact on similar numbers such as insulin-dependent diabetes. There needs to be an urgent rethink on funding to address the gap in service provision.

The Chief Medical Officer (CMO) confirmed that epilepsy care and services have suffered from a historic neglect and lack of investment compared with other long-term conditions in his 2001 report. The report stated that “services for people with epilepsy fall short of what might be expected in modern chronic disease management.”⁵² The APPG has received no evidence during its Inquiry that suggests significant improvement from the state of epilepsy services as described by the CMO in 2001.

The lack of funding for epilepsy services has serious consequences on a number of areas which are crucial in the treatment of epilepsy, such as workforce numbers, access to training, the provision of essential equipment, and the other resources required to implement NICE Guidance and Government policy.

In November 2004, expert clinical epileptologists and representatives of the epilepsy voluntary sector (the Consensus Group) met to review various survey findings characterising the current state of epilepsy care and to compare them against standards outlined in the NICE guideline on epilepsy.

The expert consensus was that “the experts welcome the NICE guideline on epilepsy, as well as earlier initiatives such as the Department of Health action plan on epilepsy and the new GMS (GP) Contract; however without appropriate levels of Government funding implementation remains a major concern.”⁵³

The APPG acknowledges that many of the above concerns have been highlighted by the Government as areas which need to be addressed. As epilepsy organisations are keen to point out: “Primary Care Trusts (PCTs) often seem powerless, or unwilling, to implement improvements”⁵⁴.

In 2004 Epilepsy Action surveyed 160 PCTs, of which only 26 per cent indicated that it was likely that epilepsy would be included in their Local Delivery Plan for 2005-8 (although a further 46 per cent suggested it was possible), compared with the 19 per cent that include it currently. In 75 per cent of

⁴⁹ Ingrid Burns, oral evidence voluntary organisations, p10

⁵⁰ Vicky Rimmer, Oral Evidence, medical practitioners, p41

⁵¹ Jane Hannah, Oral evidence voluntary organisations, p5

⁵² The Annual Report of the Chief Medical Officer of the Department of Health 2001, Department of Health 2001

⁵³ <http://www.epilepsy.org.uk/campaigns/lobbying/consensus/index.html>, November 2004

⁵⁴ Epilepsy Action, written evidence, voluntary organisations, p25

cases, reasons given for non-inclusion were that ‘national targets take priority’ and that ‘national targets leave insufficient funding’⁵⁵.

Recommendation: That the Healthcare Commission carries out as a matter of urgency an Improvement Review into the state of epilepsy services

The APPG mirrors the conclusions of the Consensus Group which stated that to put in place the necessary resources to enable health trusts and GP surgeries to implement the NICE guidelines: **“It will require serious investment – as much as £150 million per year, equivalent to only £340 per person with epilepsy. We want the government to commit to this investment. Investment now will help address years of under investment, as money spent on increasing numbers of qualified health care professionals, diagnostic equipment and improving education will reduce the costs of misdiagnosis, both direct and indirect costs, not to mention improve the lives of people with epilepsy.”** However, this funding has not been made available.

Making surgery for epilepsy available for more people would benefit the individual person and society as a whole. Patients who are successfully treated require fewer medical services and AEDs⁵⁶. They will also have better employment prospects and be less dependent⁵⁷. The initial expenditure involved in epilepsy surgery would result in long-term cost savings.

The APPG would conclude by saying that it has been widely recognised that NICE guidelines and Government policy have not been fully implemented, mainly due to funding difficulties. Health Trusts and GPs have found it difficult to put in place the necessary resources to implement the recommendations. These excellent quality requirements lack the support of specified funding to put them in place.

Recommendation: Government urgently needs to increase funding for epilepsy services by the equivalent of £340 per person with epilepsy. This investment will help to address years of under investment and will quantifiably reduce the current costs of delivering a poor service.

5. Employment

“I suffer more with my epilepsy when out of work because if I had a job, I would be concentrating on the job, rather than the epilepsy.” Terry Stevens⁵⁸

“On a more common basis, many large superstores are very reluctant to accept people with epilepsy. Sufferers will only be accepted after extensive reassurances about the control of their condition.” Fred Savill, Gravesend Epilepsy Network⁵⁹

The rate of unemployment continues to be disproportionately high for people with epilepsy. According to Epilepsy Action, underemployment also contributes very significantly to the economic burden of epilepsy. For many people with epilepsy, employment is a major quality of life issue, with significant impacts on their financial status and psychological wellbeing.⁶⁰

⁵⁵ Epilepsy Action. Improving Services for People with Epilepsy Survey, 2004

⁵⁶ Economic Evaluation of Epilepsy Treatment: A Review of the Literature, Heaney et al, *Epilepsia*, 43(Suppl. 4)10-17, 2002

⁵⁷ Epilepsy surgery: patient-perceived long-term costs and benefits, Reid et al, *Epilepsy & Behaviour* 5 (2004) 81 - 87

⁵⁸ Terry Stevens, written evidence misc – p18

⁵⁹ Gravesend oral evidence p34

⁶⁰ Epilepsy Action, written evidence, voluntary organisations

The Disability Discrimination Act (DDA) applies to epilepsy. Employers must therefore not discriminate unfairly in job advertisements, interviews or when offering a job. Once in employment, the DDA also covers duties and opportunities for training and promotion.

A recent Epilepsy Action survey⁶¹ found that 14 per cent of respondents were unemployed but actively looking for work, significantly higher than the overall International Labour Organisation unemployment rate of 8.8 per cent for disabled people. It also revealed that 47 per cent of respondents felt they had been discriminated against when applying for employment. In addition, 30 per cent of respondents did not feel that the Disability Discrimination Act had helped them to find and keep a suitable job. A further investigation found that 32 per cent of respondents to an online survey believed that they had been discriminated against by their employer because of their epilepsy within the last two and a half years.

Furthermore, the APPG was informed of a study by A Jacoby et al in 2004⁶² which found that epilepsy ranked as second in a range of conditions which would cause people the greatest concern if they had to work with someone so affected.

Some of these figures have been explained by the fact that a lot of employers and their employees still seem to fear the consequences of someone having a seizure at work, even though many people with epilepsy are completely seizure-free on medication, while others have their seizures well controlled.

The APPG was told of one particular story which illustrates the need for better information being supplied to employers:

“Another group member whose husband has epilepsy is a disability employment adviser...and she states that a client with epilepsy is one of the most difficult of conditions to place...Case one was a third year law student who had the meningitis vaccination and started having seizures a few hours afterwards. She was diagnosed with epilepsy, but doctors found it difficult to control her seizures, and the university would not let her return to complete her studies. The DEA officer tried to place her in many solicitors’ offices, but all refused to take her. After 18 months trying, yet another solicitor was approached but said that he could not accept someone that could be “writhing around on the floor”, he would not know what to do. When the officer asked what he would do if someone had a heart attack he replied simply, “I would call an ambulance.” So the DEA officer replied, “You’ve answered your own question.” So on the basis of that, this young lady was accepted by the solicitors and she has worked for them for the past four years now without any problems. But again, it is overcoming the original stigma.”⁶³

The APPG believes that employers could take a number of sensible steps, such as allowing an employee time to recover after seizures; allowing an employee to start and finish later if seizures occur a short time after waking; allowing an employee to work regular hours rather than shifts if seizures are aggravated by disrupted sleep patterns; and ensuring that all first aid staff have a basic knowledge of epilepsy.

Recommendation: The group recommends that further efforts to educate employers and their first aid staff to build confidence in their ability to employ people with epilepsy are required.

The APPG welcomes the recently-published explanatory booklets produced by Epilepsy Action and commends them to Government for circulation to employers or to be used as a basis for their own guidance to employers.

⁶¹ Epilepsy Action. Epilepsy and Employment Survey – National Epilepsy Week 2007, see www.epilepsy.org.uk

⁶² Jacoby A et al, Public Knowledge, Private Grief: A Study of Public Attitudes to Epilepsy in the United Kingdom and Implications for Stigma. *Epilepsia* 2004; 45 (11): 1405.

⁶³ Gravesend Epilepsy Network, oral evidence, voluntary organisations, p34

6. Stigma

“Whilst he had a seizure he had his wallet stolen. Nobody had stopped it happening, and when Paul questioned a crowd around him when he did come round and said, “Why didn’t you?” somebody replied that, “We didn’t want to get involved because we didn’t want to catch anything.” Lynn Savill, Gravesend Epilepsy Network⁶⁴

“As a general practitioner with a significant interest in the condition for 10 or 15 years, I still find that some people with epilepsy have trouble telling me a lot about the impact of that condition in my consulting room, and these are people I know well. There is a barrier to discussing the condition, and there is still that stigma around the condition⁶⁵, Dr Henry Smithson

Although social attitudes towards people with epilepsy have gradually improved in the developed world over the last decade, there are still a number of persistent misconceptions and social stigma attached to the condition. Many people who have the condition are reluctant to reveal this. The APPG received evidence that there is an established correlation between the level of stigma experienced and problems such as anxiety, depression, self esteem and life satisfaction. Relatively few well-known personalities have declared that they have epilepsy. Epilepsy has remained a hidden condition and has not received much attention, despite its prevalence.

Epilepsy groups around the UK have made concerted efforts to tackle some of these misconceptions and to raise awareness about epilepsy. These efforts have focussed on raising awareness of the condition with people who have epilepsy, parents and in the school environment, particularly in the classroom and with regards to school activities.

Involving patients in their own care and encouraging them to make informed decisions about their treatment is one of the most important steps in tackling epilepsy-related stigma. In other words helping people to manage their condition better is likely to improve control of seizures which will have a knock-on positive effect and make epilepsy – and the stigma attached to it – less of a problem.

The APPG agrees that: *“education of the public and employers is crucial to reducing the stigma attached to epilepsy. We feel there is an urgent need to get more into schools to educate the young people. This is so that they can grow up to adulthood with a basic knowledge of the condition, and to hopefully improve the attitudes in the longer term. We have found that children with epilepsy have experienced persecution from both peers and teachers.”⁶⁶*

Recommendation: The APPG recommends that the government do more to tackle stigma amongst employers, educational institutions and the general public by embarking on a programme of education amongst schools and employers to dispel some of the common myths.

⁶⁴ Gravesend Epilepsy Network, oral evidence, voluntary organisations, p35

⁶⁵ Dr Henry Smithson GP, oral evidence health practitioners, p 2

⁶⁶ Ibid, p2

7. Vulnerable groups

Young people

“I think we must reiterate the fact that it is the multi-disciplinary working where all the professionals come together that actually make the education of youngsters with epilepsy and associated neurological disorders effective. We need speech and language input, we need physio input, and we need a holistic programme that reflects needs and provides beyond the school day.”⁶⁷ Nick Byford, NCYPE

“In one instance, my own son’s experience, he was placed in a room alone to take his GCSE examination because the teacher thought he could be too distracting if he had a seizure during the open examination. He was left in a side room unsupervised for the whole duration of the examination, and when the teacher returned to collect his paper at the end found him slumped against the radiator after having a seizure, with major burns to his face. That is the sort of problems that we are experiencing.”⁶⁸ Lynn Savill, Gravesend Epilepsy Network

“When I went to school it was actually not recognised as being epilepsy, it was just me basically staring into space and the teachers never sort of picked up on it, they just used to comment, or I got bullied at school by other kids who said, “Oh, she’s staring at me. Why?”⁶⁹ Emma Steele

One in 242 young people in the UK aged under 18 years of age have epilepsy. The APPG is concerned that many children and young people who have epilepsy are currently prevented from having an education that is suitable and appropriate for them.

According to the National Centre for Young People with Epilepsy (NCYPE), around two-thirds of children and young people with epilepsy who attend mainstream schools are believed to underachieve academically in relation to their intellectual level.

In its oral evidence to the Inquiry, the NCYPE stated that: *“The neglect of childhood epilepsy has been particularly due to a lack of understanding of the major importance of other impairments which are secondary to the seizure disorder. Thus epilepsy has been categorised as a medical disorder, which it is, but therefore not as an educational disorder, which it also clearly is.”*

Around 7,500 young people can suffer serious regression in their learning as well as having other difficulties⁷⁰. For children and young people with epilepsy, gaining an education particularly in a non-specialised school, can be an additional challenge to overcome.

In addition, there is a lack of appropriate staff training. The APPG sees enormous benefit in increasing the level of awareness of epilepsy which will aid staff in dealing with the learning, behavioural and health impacts on the child or young person’s education. The Inquiry shares the sentiment of one of the witnesses, Bernadette Howarth, who in answer to our question as to whether the school should have coped better in dealing with her son’s condition, stated that it was all down to *“education, education, education.”⁷¹*

“Quite a lot of the children who we see at St. Piers have actually been excluded from school because of their behaviour, because there just was not the understanding...the behaviour problems had been

⁶⁷ Nick Byford, NCYPE, oral evidence voluntary organisations, p19 -20

⁶⁸ Gravesend Epilepsy Network, Oral Evidence, voluntary organisations, p39

⁶⁹ Emma Steele, Oral evidence service users, p17

⁷⁰ David Ford, NCYPE, oral evidence voluntary organisations, p17

⁷¹ Bernadette Howarth, Oral evidence, service users p13

taken at face value, there was no understanding of what was causing them. So, yes, we certainly feel that a programme for teachers would be very helpful."⁷²

The DfES should take seriously its commitments embedded in the *Removing Barriers to Achievement: The Government's Strategy for Special Educational Needs (2004)*, which seeks to ensure that all teachers should expect to teach children with special education needs, as well as *Every Child Matters* which outlines the Government's work towards improving the achievements and well-being of children in England and Wales. One way of doing so is by ensuring that all teachers and teaching assistants are trained to deal with the learning, behavioural and health impacts on the child or young person's education.

The APPG wishes to commend the efforts of St Piers schools, part of the NCYPE, in dedicating itself to educating and supporting the needs of children with epilepsy.

Recommendation: The APPG recommends that each student with epilepsy has an Individual Education Plan which allows them to fully access learning.

Recommendation: The APPG recommends that all schools receive training regarding the impact of epilepsy on learning.

Recommendation: The APPG fully endorses the NCYPE Code of Practice for Children with Epilepsy.

Elderly

Whilst epilepsy is diagnosed more commonly in those over 60 years of age than any other age group, diagnosis of epilepsy in the elderly is often harder than in the general population and the consequences may be more marked.

The APPG is alarmed by the figures which suggest that a lot of elderly people do not appear to find their way to specialists. Hannah Cock, Senior Lecturer and Honorary Consultant at St George's Hospital states: *"We are certainly not seeing the expected number of new epilepsy cases in our clinics, although we know they are out there."*⁷³

Following the evidence received by the APPG it would seem that the reasons for this are complex, but include:

- that elderly patients are more likely to be admitted after presentation to A&E with collapse and are usually under the care of geriatric or general physicians, and are not being referred to a neurologist;
- GPs often "don't think" of referral to neurologist, more likely to refer to care of elderly team given additional/complex comorbidities;
- unconscious perception that specialist care is less important than "holistic" approach for elderly with complex needs (and that neurologists/epileptologists won't provide this);
- lack of awareness amongst care of the elderly physicians about current issues in epilepsy care and thus lack of perceived advantage in specialist referral, e.g. that newer AEDs may be better tolerated;
- issues relating to bone-health in epilepsy, thus lack of perceived advantage from specialist referral;
- many care of the elderly physicians are routinely seeing epilepsy patients (new and follow up) in their clinics, without neurology/epilepsy specialist input, and were unaware of published information and support available for epilepsy patients.

⁷² David Ford, NCYPE, oral evidence voluntary organisations p 20

⁷³ Dr Hannah Cock, written evidence, medical practitioners, p12

The APPG was told of studies which also suggest that elderly patients are also more likely to be on older (and often inappropriate, with more side effects and drug interactions) AEDs.⁷⁴

Thus even assuming correct diagnoses (although the error rate is likely to be considerable), patients seen in care of the elderly clinics without epilepsy specialist input were often not receiving optimal medical treatment, support or information. Evidence shows that elderly patients with epilepsy are referred significantly less often to epilepsy specialists.

Recommendation: the APPG recommends that awareness is increased amongst clinicians of the elderly regarding advances and developments in epilepsy.

Minority ethnic groups

The APPG was provided with evidence which showed that there are still many myths and misconceptions about epilepsy among some minority ethnic groups and that access to adequate advice and information about epilepsy for these groups remains limited.

Research has highlighted a high degree of stigma associated with epilepsy within the South Asian communities, lack of appropriate advice and language and communication barriers, all of which lead to a high degree of under-reporting.

The APPG was provided with the example of an epidemiological study on the health care needs of people with epilepsy that was carried out in Bradford in 2000⁷⁵. This study identified underreporting of epilepsy amongst the South Asian population in Bradford (prevalence figures reported at 3.6/1000 compared to 7.8/1000 in the rest of the population). It was believed that the underreporting could be due to cultural and religious beliefs about epilepsy as well as barriers to health services and lack of appropriate advice and information.

Other work^{76 77 78} following the Bradford study confirmed that there are many misconceptions about epilepsy within minority ethnic groups. People with epilepsy are receiving inadequate support and understanding from friends and families. The perceived need to keep the condition secret also means that people are less likely to seek necessary medical help.

Recommendation: The Department of Health needs to undertake research into misconceptions about epilepsy amongst ethnic minority groups, building on the Bradford study, and take active steps to reduce misconceptions and improve services for minority ethnic groups.

Women

There are approximately 194,000 women with epilepsy in the UK, of which an estimated 110,000 are of child bearing age (12-50 years). Epilepsy in women requires careful management, with full consideration given to the potential implications of epilepsy and its treatment on reproductive health and quality of life.

In women of child bearing age, there are several issues that increase the complexity of managing the condition, such as the potential effect of taking anti-epileptic drugs (AEDs) in pregnancy on foetal and child development, the increased potential of contraceptive failure and interaction when hormone-

⁷⁴ Dr Hannah Cock, oral evidence, medical practitioners, p29

⁷⁵ Wright et al Seizure 2000, 9 (5):309-13.

⁷⁶ South Asians and Epilepsy, Epilepsy Action, December 2003.

⁷⁷ Epilepsy Culture and Religion: Attitudes in Black Minority Ethnic Groups in Glasgow, Epilepsy Connections, May 2006.

⁷⁸ Ethnibus survey, Ethnic Focus 2006.

based contraceptives are prescribed with certain AEDs and the potential effect of seizures increasing in some women during pregnancy and other issues.

Women in the general population have a one to two per cent chance of having a baby with a Major Congenital Malformation (MCM). Women with epilepsy, who do not take AEDs, have a three and a half per cent chance of having a baby with a MCM. Women who take AEDs have a four per cent chance of having a baby with a MCM.⁷⁹

One witness, Leoni McDonagh, said: *“My husband and I would like to have children, but as an epileptic pregnancy becomes even more complicated than it is for other ladies, one also worries whether it would be safe for me to be left alone with a baby.”⁸⁰*

A large proportion of women with epilepsy are not receiving vital information to enable them to make important decisions about pregnancy and contraception. The consequences of this are that more children than necessary are being born with malformations caused by anti-epileptic drugs, and that women are having unwanted pregnancies due to failed contraception.

Epilepsy Action gave the example of one its members who had said: *“Unfortunately, three years ago I was on Keppra and Epilim. I got pregnant and was advised to terminate the pregnancy, as I was on lots of medication and they were worried about the effects on the unborn child.”⁸¹*

Recommendation: All women with epilepsy should be provided with the information they need by epilepsy health professionals about the risk of taking AEDs during pregnancy, the risk of congenital anomalies and potential interaction with the contraceptive pill, to meet the recommendations in the NICE guideline.

Learning disabilities

Evidence suggests there is quite a strong relationship between difficult-to-control epilepsy and learning disabilities. According to Professor Duncan, around 15 per cent of people with epilepsy have a learning disability, whilst around 30 per cent of people with learning disabilities have epilepsy. The more severe the learning disability, the more likely you are to have epilepsy. People with learning disabilities who have epilepsy have extensive needs and the APPG has been informed that often they are not very well served.⁸²

NICE guidelines on epilepsy include very specific statements that people with learning disabilities should receive the same support and care for their epilepsy as the general population, which should be undertaken by an epilepsy specialist, within a multidisciplinary learning disability team.

However, studies show that the mean proportion of people with epilepsy with learning disabilities who achieved seizure-control was between 22 per cent and 32.8 per cent, which is significantly below the proportion of the general population with epilepsy. The author of the study, Markus Reuber says: *“The poor outcome in terms of seizure-control, the lack of access to the epilepsy specialist service, and the apparent underutilisation of investigations indicate that there are grounds for serious concern about this community model of medical epilepsy care for people with learning disabilities.”⁸³*

⁷⁹ Malformation risks of anti-epileptic drugs in pregnancy: A prospective study from the UK Epilepsy and Pregnancy. J Neurol Neurosurg Psychiatry. 2005 Sep 12, sourced from <http://jnnp.bmjournals.com/cgi/rapidpdf/jnnp.2005.074203v1>, 28 September 2005

⁸⁰ Leoni McDonagh, misc written evidence, p21

⁸¹ Epilepsy Action, written evidence, voluntary organisations, p 7

⁸² Prof Duncan, oral evidence, medical practitioners, p35

⁸³ Dr Markus Reuber, Senior Clinical Lecturer and Honorary Consultant in Neurology written evidence, misc written evidence, p5

Following oral evidence presented by Dr. Hannah Cock, the APPG was made aware that often only selected patients with learning disabilities have contact with the epilepsy group, the majority with epilepsy being cared for exclusively by learning disability psychiatrists.

Other than where a specific epilepsy clinic/service (within learning disability services) has been established, the benefits of a dedicated epilepsy service (information provision; links to other support/training; better diagnostic accuracy; appropriate treatment informed by up to date evidence) are not necessarily available to patients with learning disabilities.

Dr Cock specified: *“There is a kind of low expectation or sub-conscious feeling that they do not need more specialist input; whereas actually they are the epilepsy clinical group that if anything need even more specialist input than the middle class, educated person who has had a couple of fits, who actually is quite able to get a lot of the information they need themselves, pointed in the right direction, whereas the vulnerable groups are not and do not get referred.”*⁸⁴

Recommendation: The APPG recommends that the Department of Health and the Department for Education and Skills should take steps to deliver the NICE guidance on the treatment of people with epilepsy with learning disabilities and issue a guidance note to epilepsy health professionals on how to meet the NICE guidance.

Prisoners

NICE guidelines stipulate that healthcare for prisoners should meet the standards developed for the general population. However, the APPG was informed that in a recent audit of healthcare provision for UK prisoners with suspected epilepsy⁸⁵, there were significant differences between the healthcare services and access to information offered to prisoners and the recommendations in these guidelines.

A person who has had a first seizure should be seen within two weeks by a specialist in the management of the epilepsies⁸⁶. In a recent audit of healthcare provision for UK prisoners with suspected epilepsy, 62 per cent of diagnoses had not been made by epilepsy specialists. Of those prisoners considered to have epilepsy by prison primary healthcare services, the diagnosis of epilepsy was confirmed in only 58 per cent. In addition, 53.8 per cent of those prisoners diagnosed as having epilepsy had not had a medical review in the past 12 months; 63.2 per cent required a change in their antiepileptic drugs (AEDs), whilst none of the prisoners with epilepsy had received adequate information concerning their condition.

The APPG deplores the significant discrepancies between the quality and range of services offered to prisoners and the NICE guidelines. Government is invited to recognise that better care will result in financial savings, given the extreme rate of misdiagnosis in prison, as well as improving the potential for the successful re-integration into society of the prisoners affected.

Recommendation: The APPG calls on the Department of Health to takes steps to ensure that the NICE guidelines on the treatment of prisoners with epilepsy are fully implemented.

⁸⁴ Dr Hannah Cock, oral evidence, medical practitioners, p25

⁸⁵ Reuber, M et al. Audit of healthcare provision for UK prisoners with suspected epilepsy. Unpublished – due to be published 2007

⁸⁶ Stokes T, Shaw EJ, Juarez-Garcia A, Camosso-Stepinovic J, Baker R. Clinical Guidelines and Evidence Review for the Epilepsies: diagnosis and management in adults and children in primary and secondary care. London: Royal College of General Practitioners 2004.

8. Residential care

*“Epilepsy is clearly a medical condition, but it has many, many psychosocial effects. Local authorities will say, “We fund social care; we don’t fund health care.” We say however that you can’t separate out the two; we have to look after the whole person.”*⁸⁷ Karen Lane, National Society for Epilepsy

“Local authorities are not wanting to spend money out of county in a specialist provision, it is becoming more and more difficult for parents to actually persuade local authorities that that is the way their child needs to go and certainly the National Centre is having difficulty.” Mrs Parks, mother of Molly Parks who is currently waiting for a long-term residential place at Canterbury Oast Trust in Kent⁸⁸

In the course of its Inquiry, the APPG has been presented with two important issues relating to residential care for people with epilepsy. Firstly, practice-based commissioning and specialist residential care placements, secondly ordinary residence and the obstacles to moving from residential care.

The APPG agrees with the evidence provided by the National Society for Epilepsy (NSE) that, given the complexities around the diagnosis and treatment of epilepsy, it is not necessarily reasonable to expect GPs to be able to commission and purchase the specialist residential and nursing care services which those patients with complex epilepsy need. In addition, it is unlikely that such services will exist locally.

Pressures on local authority and health authority budgets also make the funding of specialist residential care difficult, with local authorities continually querying increases in fees. Below inflation fee increases are regularly offered which would fail to meet the cost of providing the care that is needed for the safety of the service users. In some cases the local authorities have even demanded a reduction in fees, despite the fact there has been no change in the care needs of the service user, and have threatened to remove the service user to an alternative, less specialist care setting.

A particular telling example was provided by the NSE: *“one authority recently removed a service user with complex epilepsy from the NSE to an alternative non-specialist care provider, even though they acknowledged that the care that would be provided was less than optimal. This was in response to a request for an increase in fees to meet an increase in need following an assessment by that local authority’s own social worker. The local authority determined that the fees we asked for were excessive, and the service user was moved to a non-specialist nursing home, causing him to live apart from a female service user with whom he had formed a long-term relationship.”*⁸⁹

Often the only sanction that the service provider has is to threaten and eventually implement the cancelling of the contract with the local authority, leading to the eviction of the service user.

Bureaucratic rules can impede the move to more independent accommodation. The *rules of ordinary residence* state that a person remains ordinarily resident in the area of a placing authority while they remain in residential care even if the home in which they are placed is out of county and they remain there for a lengthy period. On moving out of residential care, they become ordinarily resident in, and hence the financial responsibility of, the area into which they move. This creates significant difficulties for people moving out of residential care, especially if they have been placed out of county into a specialist residential setting or nursing care setting, and wish to move to supported housing in that area. This is a situation the NSE is faced with.

⁸⁷ Karen Lane, National Society for Epilepsy, oral evidence, voluntary organisations, p31

⁸⁸ Mrs Sue Parks, oral evidence, service users, p 38

⁸⁹ NSE, oral evidence voluntary organisations, p26

The APPG recognises that, whilst this may not necessarily be an under funding issue, it is an issue of bureaucratic obstacles preventing the efficient use of resources, preventing people with epilepsy and other younger disabled people making the choices that Government policy suggests is their right, such as enabling people to live independently and self manage their condition.

The APPG has set out two specific recommendations below which, rather than requiring additional resources, at worst would be cost neutral. There is even the potential of quite significant savings to the public purse enabling the money that is saved to be diverted into other much needed services.

Recommendation: The APPG calls on the Government to bridge the gap between policy and practice by developing guidance to local authorities to ensure resources follow the individual when moving from residential care into supported housing.

Recommendation: The APPG further calls on the Government to develop a National Plan for specialist residential care.

[illegible]

[illegible]



The All Party Parliamentary Group on Epilepsy exists to spread awareness of the nature of epilepsy amongst parliamentarians and to raise the political profile of epilepsy and related problems

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