Epilepsy in England:

Time for change

A study of epilepsy service provision in England by Epilepsy Action

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Editorial control rests with Epilepsy Action

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Epilepsy affects nearly 400,000 people in England and can be a disabling condition. This critically important report highlights how far away some parts of the health service are from providing the type of services that people with epilepsy have every right to expect in 2009.

It is nearly seven years since the groundbreaking National Sentinel Clinical Audit of Epilepsy-Related Death was published, which highlighted how poor care and management of epilepsy has led to over 400 unnecessary deaths in England each year. In response, the government launched its Epilepsy Action Plan in 2003, closely followed by the NICE epilepsies guidelines in 2004.

Despite these plans and guidelines, this report exposes that epilepsy services still fall far short of the standards needed to help address avoidable deaths, misdiagnosis (estimated to cost the NHS £22m a year) and unnecessary seizures. These issues were highlighted by the All Party Parliamentary Group (APG) on Epilepsy in their 2007 report ‘Wasted Money, Wasted Lives’. An estimated 2,000 lives have been needlessly lost since the government’s Action Plan was launched.

Today’s report has revealed a concerning lack of epilepsy specialists, waiting lists that often exceed the recommended two week guidelines, and shows that too few patients have access to a care plan to define and support their needs. The majority of trusts still lack a basic understanding of epilepsy, making it impossible to design adequate services for patients. Epilepsy Action is now calling for the government to show leadership and recognise the importance of urgently driving improvement in these services.

We have been much encouraged by the commitments made by Ann Keen MP, the Parliamentary Under Secretary of State at the Department of Health, at a meeting with the APG on Epilepsy in October 2008. She acknowledged the need for improved epilepsy services was critical and undertook to find a way of giving a lead to raising the profile of epilepsy and the importance of implementing guidelines within primary care trusts.

It is time for change for people with epilepsy. It is time that NICE guidance was fully implemented.

Baroness Ford of Cunninghame
President, Epilepsy Action
executive summary

Epilepsy affects over 382,000 in England and is the most common serious neurological condition.\(^1\) It affects people of all ages and from all walks of life. One in every 131 people in England has epilepsy including 48,000 children under the age of 18. There are currently 69,000 people with epilepsy experiencing recurrent seizures due to poor management and treatment of their epilepsy.\(^2\)

Epilepsy is defined as a tendency to have recurrent seizures caused by a sudden burst of excess electrical activity in the brain. This causes temporary disruption in the normal messages passing between brain cells. Epilepsy is not a single condition; it is currently thought that there are over 30 different epileptic syndromes and 38 different types of seizure, and an individual may have more than one type\(^1\).

In recent years, there have been a number of reports, including the All Party Parliamentary Group on Epilepsy Report ‘Wasted money, wasted lives’ and the National Sentinel Clinical Audit of Epilepsy-Related Death. They have repeatedly highlighted the urgent need for better epilepsy service provision in England.

More recently, the National Institute for Health and Clinical Excellence (NICE) launched a commissioning guide for the accurate diagnosis of the epilepsies in adults (October 2008). This followed on from the 2004 NICE guidance on the diagnosis, treatment and management of epilepsy in children, young people, adults and older people. Despite this, concerns remain about the quality and suitability of epilepsy care in England.

This study, carried out by Epilepsy Action and sponsored by UCB Pharma Ltd, set out to understand more about the current state of local provision for people with epilepsy in England. The aim was to understand whether the care guidelines set by NICE have led to any improvements in provision and/or delivery of services. All primary
care trusts (PCTs) and acute trusts (ATs) in England were surveyed to assess current service provision. Alongside this, Epilepsy Action received 260 responses to their survey of people living with epilepsy to understand their own personal experiences of the health service over the last couple of years.

This report shows that the key clinical priorities for providing an effective epilepsy service, as highlighted in the 2008 NICE commissioning guide, are unlikely to be available in many PCTs and ATs. This is mainly due to key shortfalls in the availability of epilepsy specialist clinicians and epilepsy specialist nurses. The survey also highlighted that average waiting times across PCTs and ATs are well over the two weeks specified by the 2004 NICE guidelines, leading to delays in diagnosis and treatment.

**Headline findings**

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

In addition, the low level of information available within PCTs and ATs indicates that provision of epilepsy services is still not a high priority. In particular, a significant proportion of PCTs and ATs did not hold basic data on prevalence and population, particularly in relation to children. This makes it extremely difficult to build a true picture of national service provision, and raises an important question. What information are trusts using to plan and commission their epilepsy services?

It is clear that most trusts still fall far short of the recommendations made by NICE. This is possibly because the Department of Health does not appear to be treating it as a priority. If standards of care do not meet the levels recommended in the NICE guidelines, people with epilepsy will continue to have a poorer quality of life through misdiagnosis and unnecessary seizures and face a greater risk of dying.
To address the shortfalls in service provision for people with epilepsy in England, Epilepsy Action calls on the government and policy makers to take a lead in driving improvements in epilepsy service provision and to:

1. Appoint a National Clinical Director for epilepsy to review service provision in England and lead change.

2. Define in the NHS constitution a patient right to health care to the standards outlined in NICE clinical guidelines.

3. Ensure local commissioners carry out a formal review of their implementation of the NICE epilepsy guidelines and develop plans to ensure these are met.

4. Ensure that NHS workforce planning focuses on the recruitment and training of sufficient epilepsy specialist consultants and epilepsy specialist nurses to allow PCTs and ATs to deliver the NICE guidelines.

5. Ensure that PCTs build a clearer picture of the epilepsy population in their area, especially the under 18s, and factor this into their review.

6. Commit to ensuring that all patients with suspected epilepsy see an epilepsy specialist consultant within two weeks.

7. Ensure all ATs have adequate diagnostic equipment in line with the patient population they serve.

8. Ensure all patients receive an annual review of their epilepsy.

9. Ensure transition services for children moving in to adult epilepsy services are in place and effective.

10. Ensure all patients with epilepsy who want a comprehensive care plan have one.
Although I started having seizures around four and a half years ago, it took two years after this for doctors to diagnose my epilepsy. I wasn’t put forward for any tests in the first 18 months of my having seizures and I only had an MRI scan a few months ago. At one point, my husband and I were so disappointed with the services I’d received that we discussed going private. However, my consultant at the time then wrote a letter, notifying me I was being referred to a different consultant. I now have a good consultant and an epilepsy specialist nurse.

Anonymous, patient with epilepsy
Only half (51 per cent) of ATs confirmed they have a consultant neurologist with a special interest in epilepsy and 24 per cent did not even have a consultant neurologist.

Figure 1: Consultant staff in ATs

Current NICE guidelines for the treatment of epilepsy state that all individuals with a recent first suspected seizure should be seen urgently by a specialist. An epilepsy specialist is defined by NICE as a medical practitioner with training and expertise in the epilepsies. The survey results show that this aim is far from the reality.

From Epilepsy Action’s survey less than a third (30 per cent) of patients who were diagnosed with epilepsy within the last two years, reported seeing an epilepsy specialist after their first suspected seizure.

Only 12 per cent of PCTs employ a GP with a Special Interest (GPwSI) in epilepsy – defined as a practising GP who, in addition to their generalist role, provides specialist services to meet the needs of patients with epilepsy in primary and secondary care organisations.
The Department of Health acknowledged the vital contribution that specialist nurses make to the treatment and care of patients with epilepsy in their recent good practice guide to the development of the multidisciplinary team and the value of the specialist nurse\(^4\).

Despite this, only the minority of ATs employed a specialist epilepsy nurse for either adults (40 per cent) or children (28 per cent). This low number is also reflected in the low percentage (36 per cent) of PCTs which employ a specialist nurse. The number of patients in the Epilepsy Action survey who reported that they have been referred to a specialist nurse for support is only 40 per cent.

**Figure 2: Epilepsy specialist nurses in PCTs**

Collectively, these figures suggest that epilepsy services in England are failing to meet the standards of care set out by NICE. This lack of epilepsy specialists contributes to misdiagnosis rates of 21-30 per cent and the wrong treatment for the wrong kind of epilepsy, which is estimated to have cost the NHS over £22 million a year\(^5\). In addition to the financial implications, this results in prolonged difficulties for people with epilepsy and their carers.


Epilepsy comprises a complex and varied range of conditions. Those with epilepsy need high quality clinical care delivered by specialist clinicians and nurses who have a thorough understanding of the condition, its many manifestations and the impact it has on people’s lives. It is essential that a robust, comprehensive and effective network of NHS care for epilepsy patients is implemented across the whole country.

Professor John Duncan
Professor of Neurology, UCL Institute of Neurology
Medical Director, National Society for Epilepsy

I work at two hospitals – one with an epilepsy specialist nurse, one without. The difference in the quality of patient care is spectacular.

Dr Jane Thompson, Associate Specialist in Neurology and Epilepsy, Frimley Park Hospital
A third (32 per cent) of ATs do not run epilepsy clinics

Low numbers of specialists with a particular interest in epilepsy seems to be contributing to the low levels of available epilepsy clinics thus reducing access to optimal care. The survey found that a third (32 per cent) of ATs do not run epilepsy clinics, which provide patients with an essential support network of education, therapy and condition management.

Everywhere I go as an Accredited Volunteer, and everyone I speak to has the same problem – basically the shortage of neurologists and epilepsy specialists. People are saying they can’t get to their neurologist and, that their GP doesn’t specialise in epilepsy, and they don’t have access to an epilepsy nurse.

Roy Carey, Accredited Volunteer, Epilepsy Action

On the basis of these findings we therefore recommend that the government and trusts do the following:

Ensure that NHS workforce planning focuses on the recruitment and training of sufficient epilepsy specialist consultants and epilepsy specialist nurses to allow PCTs and ATs to deliver the NICE guidelines.

Ensure all patients receive an annual review of their epilepsy.
Nearly all people with suspected epilepsy have to wait more than the guideline two weeks for an appointment. In some cases this can mean a wait of between 17 and 24 weeks.

The current NICE clinical guidelines for epilepsy recommend that “all individuals with a recent onset suspected seizure should be seen urgently by a specialist”\(^6\) and that, for NICE, urgent equates to within two weeks. Despite this, over 90 per cent of ATs and PCTs reported waiting times longer than the guidelines. Of the 86 patients in the Epilepsy Action survey who were diagnosed with epilepsy in the last two years, only 18 percent had their first appointment within two weeks.

\textbf{Figure 3: Waiting times for epilepsy specialist consultants in ATs and PCTs}

Long wait times mean delayed treatment and a wasted opportunity to help patients quickly gain control of their epilepsy. Uncontrolled epilepsy can have a devastating impact on the quality of life of people with epilepsy. Every seizure brings the risk of injury and even death and early treatment means that risk, worry and seizures can be reduced.

Dr Jonathan Bird, Consultant Neuropsychiatrist and Clinical Electroencephalographer, The Burden Centre, Frenchay Hospital Bristol

The impact of these delays is then made worse by the fact that many patients have to wait more than the guideline four weeks for diagnostic imaging or electroencephalography (EEGs). The results from the survey demonstrate that over a third of patients who require an MRI (magnetic resonance imaging) and/or an EEG have to wait five weeks or more. These waiting-times are mirrored by the Epilepsy Action survey, which found that a half (51 per cent) of patients diagnosed in the last two years who had an MRI scan waited more than four weeks and a further half (50 per cent) of people reported a waiting-time for an EEG of over four weeks.

The survey found that only 41 per cent of ATs had access to ambulatory EEGs.

I would expect all acute hospital trusts to have access to EEG investigations including ambulatory EEG (and videotelemetry) as an essential part of investigating people with seizures.

Professor Pam Crawford, Consultant Neurologist, York Hospital
Collectively these tests are key to making an accurate diagnosis. This is vital because some types of epilepsy respond well to specific anti-epileptic drugs, and treatment should always be tailored to the individual. Also, the sooner that a correct diagnosis of epilepsy is made, the sooner tailored therapy can be initiated. Delays through insufficient diagnostic equipment cause distress and impact negatively on the everyday lives of patients.

**On the basis of these findings we therefore recommend that all trusts do the following:**

- **Commit to ensuring that all patients with suspected epilepsy see an epilepsy specialist consultant within two weeks.**
- **Ensure all ATs have adequate diagnostic equipment in line with the patient population they serve.**

Becky became a victim of sudden unexpected death in epilepsy (SUDEP) on a wet spring morning in May 2004, exactly three months short of her 12th birthday.

She had her first ever seizure in September 2001. She was promptly seen by a registrar at the local hospital but, despite all the clues (so obvious in hindsight) we were sent on our way with a “nothing to worry about, it’s probably migraine, we can’t do anything more unless the seizures become regular and frequent” message.

After a further two years of sporadic night time fits, those words of comfort converted to concern when seizures appeared during the first weeks of January, February and March 2004. We pushed for a referral to a paediatrician who did think that Becky might be suffering from epileptic seizures in addition to migraine. He arranged for her to undergo EEG and MRI scans. But seizure control medication was “out of the question for a child of this age” (we have subsequently found this statement to be totally unfounded) and no mention was made of SUDEP.

She died three days before we were due to visit the hospital to discuss the MRI results. Three days after her death we heard about “sudden unexpected death in epilepsy” for the first time. Even then it was in the form of a passing reference from the Coroner’s Office. Then some web searching uncovered the Epilepsy Bereaved site and our first viewing of the acronym SUDEP... and the horror associated with it.

Sandie and Roger Scrivens, parents of Becky, who died from sudden unexpected death in epilepsy (SUDEP) in May 2004.

http://www.sudep.org/in_mem_002.asp
Care plans and transition services are not routine for people with epilepsy. Only a low number of ATs and PCTs currently use care plans for epilepsy patients.

A patient care plan is an important tool in the overall long-term management of people with epilepsy. A care plan can help improve communication between different groups involved in the care of people with epilepsy, both in the hospital and in the community. This in turn helps to integrate care and empower the patient to improve their own circumstances and access local support services.

A care plan can help to improve epilepsy services – it is designed to be shared, it is easily accessible and straightforward to use. It is a step towards effective patient involvement and, I feel, helps to improve communications.

It is always useful when a patient brings a care plan to clinic appointments, as an up-to-date health record is immediately available.

Lesley North, epilepsy specialist nurse, Royal Preston Hospital

Despite the publication of important government guidance in the last four years recommending care plans – the Long-term (Neurological) Conditions National Service Framework (NSF) in 2005 and “Our health, our care, our say” in 2006 – and their inclusion as a key recommendation in the NICE guidelines, very few PCTs and ATs were able to provide any information about their use. This finding was mirrored by the Epilepsy Action survey which showed that only 13 per cent of the respondents had a care plan.

7 Of the 105 responses only 20 (19 per cent) PCTs provided an answer to the question of whether care plans were in place for people with epilepsy and of the 92 returned questionnaires from ATs only 54 (59 per cent) were able to provide some information on this, with some trusts only providing a figure for adults and some only for children.
I've never been offered a review to discuss my epilepsy or the medication I'm taking to control it. I also don't currently have a written care plan. I feel let down by this. Just because my epilepsy is controlled doesn't mean I can just forget about it. I want to be in a position where I know about my condition and know that the medication I'm receiving is the best for my circumstances.

Stephen Lythgoe, Matlock

NICE guidelines recommend that: "Multidisciplinary services provided jointly by adult and paediatric specialists have a key role in the care of the young person with epilepsy. They can facilitate the transition from paediatric to adult services and aid in the dissemination of information.” However the survey found that transition services are not properly mapped out, leading to poor services for young adults as they move out of paediatric care into adult care. Only 36 per cent of ATs and 33 per cent of PCTs had transition services for children already in place. The lack of transition services, together with the lack of paediatric specialist nurses and lack of data regarding children’s epilepsy services paint a poor picture of care for children with epilepsy.

Currently the structure of adult services in the UK hinders the development of transition services, meaning the care of adolescents and young adults with epilepsy may be compromised.

Professor Helen Cross, Consultant in Paediatric Neurology, Great Ormond Street Hospital

On the basis of these findings we therefore recommend that all trusts commit to the following:

Ensure transition services for children moving in to adult epilepsy services are in place and effective.

Ensure all patients with epilepsy who want a comprehensive care plan have one.
filling the information void

Many PCTs do not collect or hold basic population data for people with epilepsy

There is limited information collated at a local level on the prevalence of epilepsy amongst adults and children in England. PCTs were asked to provide figures for the number of adults (age 18 and over), and the number of children, with epilepsy. Despite epilepsy being one of the conditions included in the Quality and Outcomes Framework (QOF), not all PCTs answered these basic questions.

Most PCTs (64 per cent) provided data for the adult epilepsy population (generally as reported for the QOF).

Only 18 per cent of PCTs knew how many children had epilepsy in their catchment area. This was frequently explained as due to the fact it is not a requirement of the QOF to collate data on children with epilepsy.

The lack of data about the number of children with epilepsy raises a fundamental question. How do PCTs plan adequate levels of service for children with epilepsy when a proper understanding of prevalence is not available?

**On the basis of these findings we therefore recommend that all trusts commit to the following:**

Ensure local commissioners undertake a formal review of their implementation of the NICE epilepsy guidelines and develop plans to ensure these are met.

Ensure that PCTs build a clearer picture of the epilepsy population in their area, especially the under 18s, and factor this into their review.
The results of the study revealed a worrying variation in service provision, data collection, evaluation and quality of care in England. Planning epilepsy provision will be extremely difficult due to the lack of basic information. If trusts do not collect or hold basic data on the prevalence of epilepsy within their population, it is difficult to see how can they plan and commission appropriate epilepsy services.

It is readily apparent that many of the recommendations set out by NICE are still not being met, particularly access to specialists in epilepsy (consultants and/or specialist nurses), waiting times for a first appointment and diagnostic tests, the lack of care plans and transition services.

Taken together, the facts from the surveys paint a picture of poor service provision. Epilepsy appears to be a forgotten condition, where patients are falling through the cracks in the system. The surveys of PCTs and ATs highlighted a disturbingly low level of knowledge about the epilepsy services they are currently providing and should be providing.

This study concludes that most trusts in England still fall far short of some of the key recommendations made by NICE in 2004 and subsequently reinforced in the 2008 epilepsy commissioning guide.

This shortfall in service provision has a profound impact on the quality of life of people with epilepsy and requires immediate attention. **Epilepsy Action is therefore calling on the government and policy makers to take a lead in driving improvements in epilepsy service provision.**
Acute trust and primary care trust survey

This report represents an overview of the key findings from our survey of all acute trusts and primary care trusts in England. The final response rate to the questionnaires was strong for both ATs (92/170; 54 per cent) and PCTs (105/152; 69 per cent), but there was considerable variation in the response rate for each question. The full report of the survey, including responses to every individual question, can be accessed at www.epilepsy.org.uk/timeforchange.

Epilepsy Action patient survey

An additional survey was developed by Epilepsy Action for people with epilepsy located in the UK to provide the patient’s perspective on the trust responses. A total of 260 responses to the patient questionnaire were collected and the full results are available at www.epilepsy.org.uk/timeforchange. It must be noted however that 70 per cent of the respondents experienced seizures, which is not in accordance with the expected prevalence in the epilepsy population, where up to 50-70 per cent of people with epilepsy are expected to be seizure free. We therefore accept that the responses could be skewed to those with more severe problems.
Epilepsy Action aims to improve the quality of life and promote the interests of people living with epilepsy.

Our work includes:
• providing information to anyone with an interest in epilepsy
• improving the understanding of epilepsy in schools and raising educational standards
• working to give people with epilepsy a fair chance of finding and keeping a job
• raising standards of care through contact with doctors, nurses, social workers, government and other organisations
• promoting equality of access to quality care

Epilepsy Action has a network of local branches in most parts of the UK. Each branch offers support to local people and raises money to help ensure our work can continue.

Join us...
You can help us in our vital work by becoming a member. All members receive our magazine Epilepsy Today, free cover under our unique personal accident insurance scheme and access to our services and conferences.

Getting more information

Call our Epilepsy Helpline:
freephone 0808 800 5050  text 07797 805 390
Email helpline@epilepsy.org.uk

www.epilepsy.org.uk