A Critical Time for epilepsy in England

A study of epilepsy service provision in England by Epilepsy Action
January 2013

This report has been produced as part of the 'A Critical Time' campaign. More information about the campaign and its other resources (including interactive data maps) can be found by visiting www.epilepsy.org.uk/acriticaltime
We would like to thank all those who helped compile responses to our questions, in particular any clinicians who took time out to contribute data. We would also like to thank all those service planners and providers for the good practice examples that illustrate this report.

This report was made possible thanks to a grant from UCB Pharma.
We're proud to launch the *A Critical Time for epilepsy in England* report. Unfortunately we regret that this set of surveys has uncovered a familiar picture of inequitable and uneven services, findings supported by the *National Audit of Seizure Management in Hospitals and Epilepsy12* reports published in 2012. Some providers are delivering good services, and patients recognise this. But in many areas, specialist services are next to non-existent and there have only been marginal improvements since 2009. Some patients with epilepsy are being left in a system where their needs are never identified, or addressed, and unscheduled care is commonplace.

Improvements can be made to integrate services and knit together the patchwork of services to achieve a decent minimum level of care available to all, regardless of where they live. We know, from personal experience and through our work, the difference that reliable and quality epilepsy services can make to patients and their families. Even small changes regarding information provision can have a profound effect on a patient’s outlook and the health outcomes they experience.

Service improvement would herald benefits for clinical staff too, as speedier processes and better opportunities for successful interventions will help make every contact count. There is added financial incentive in tackling misdiagnosis and reducing unplanned and unnecessary health expenses; and in doing so halting inadequate care and freeing-up capacity in the health service.

Throughout this report Epilepsy Action shows why this is needed, and provides advice on how better outcomes can be achieved. The overall message is simple: better planning will lead to better provision.

The new NHS reconfiguration presents a new opportunity to act on epilepsy; new organisations can approach epilepsy provision with a clean slate. But addressing current shortfalls requires a small but concerted effort, and clinical leadership. Sadly this report shows this is lacking with two thirds of Clinical Commissioning Groups not planning to do a written needs assessment of the health and social care needs for people with epilepsy.

We urge all those in positions to positively effect change for the 495,000 people with epilepsy in England to read this report and act now.
Epilepsy Action surveyed Clinical Commissioning Groups (Primary Care Trusts and Primary Care Trust clusters), acute trusts, local authorities and people with epilepsy, in England, between April and September 2012. With the exception of those questions pertaining to care planning, statistics derived from acute trust data refer to the 89% of respondents that stated they provide either a diagnostic, an outpatient or a surgical treatment for epilepsy.

These surveys showed:

**Planning**
- Two thirds (66%, 104/158) of Clinical Commissioning Groups (CCGs) do not have, or even intend to produce, a written needs assessment of the health and social care needs for people with epilepsy.
- Of the local authority responses, only 27% (27/102) of their Joint Strategic Needs Assessments (JSNAs) include a section that mentions the care of people with epilepsy.
- Only 17% (27/158) of CCGs or CCG confederations have appointed a clinical lead for epilepsy.

**Provision**
- Only 20% (8/40) of acute trusts stated that their average waiting time for an adult with suspected epilepsy to see an epilepsy specialist consultant was two weeks or less.
- Of those acute trusts that provide an epilepsy service, only 66% (52/79) offer their patients access to an adult epilepsy specialist clinician.
- Only half (52%, 475/905) of people with epilepsy told us that they have seen an epilepsy specialist nurse.
- Only 14% (128/947) of people with epilepsy report having a written care plan.
- Over a third (37%, 305/827) of patients (adults and children) were not offered an epilepsy review in the last twelve months. Of the adults, 68% (206/305) were still having seizures.
- Nearly three quarters (73%, 495/682) of patients (adults and children) who are still having seizures have never been referred to a specialist tertiary epilepsy centre.
recommendations

Epilepsy Action calls upon:

**Clinical Commissioning Groups**

1) Each Clinical Commissioning Group (CCG) to carry out an epilepsy needs assessment, with reference to the NICE Clinical Guideline, the Quality Standards for the epilepsies and the NHS Outcomes Framework by April 2014.

2) CCGs and the NHS Commissioning Board to commission services based on specifications informed by discussions with people with epilepsy, that are aligned with NICE Clinical Guidelines and the Quality Standards for the epilepsies.

**Acute trusts**

3) Acute trusts to provide a service compliant with NICE Clinical Guideline and Quality Standards that affords people with epilepsy adequate and timely access to epilepsy specialists and epilepsy specialist nurses.

**The NHS Commissioning Board**

4) The NHS Commissioning Board to adequately plan and provide tertiary epilepsy services, including guaranteeing fair and ample access to non-drug interventions.

**Local authorities**

5) Each local authority’s Health and Wellbeing Board to include a section on epilepsy in their Joint Strategic Needs Assessment, to demonstrate their understanding of the needs of people with epilepsy.

**Clinicians**

6) Primary care clinicians to review and refer their adult patients with epilepsy, who continue to have seizures, to a specialist in epilepsy. If this does not lead to an improvement in care, these patients should be referred to tertiary services for further management.

7) All clinicians to ensure that their patients with epilepsy are offered a personalised care plan, shared with all professionals involved in their care and produced in conjunction with an epilepsy specialist.
The National Audit Office

8) The National Audit Office, in light of our findings, to investigate the provision of epilepsy services, with special reference to the costs and spend of these services and patient outcomes.

Members of Parliament and local councillors

9) Members of Parliament to pursue this report with their local commissioners and providers to ensure this report is acted upon. Local councillors should ensure that this report is raised with and responded to by their Health and Wellbeing Boards.

The Health Select Committee

10) The Health Select Committee to conduct its first ever enquiry into the availability and quality of healthcare services available to people with epilepsy.

the findings

The findings have been presented in chapters under the following themes:

1. Assessing local needs
2. Access to specialists
3. Epilepsy specialist nurses
4. Tertiary services
5. Investigations
6. Care planning…
7. …and annual reviews
8. Women’s health
9. Transition
10. Advice and information
11. The patient experience

Case studies relating to each theme are included to illustrate examples of effective practice.

In 2009, Epilepsy Action published its Epilepsy in England: time for change report. This was based on a study of epilepsy health services, provided by primary care trusts (PCTs) and acute trusts in England. Throughout this report, comparisons have been made, where relevant and appropriate, to similar data discovered in 2009. This is intended the show the improvements (or lack of) in the previous four years. You can view this report by visiting www.epilepsy.org.uk/timeforchange
"To date my father has not seen an epilepsy specialist, he has not been referred to a ‘First Fit’ clinic. He has no appointment to see an epilepsy specialist. He has no care plan and has no point of contact. This is appalling treatment and I am concerned that it may be to do with his age – he is 77."

Patient Survey respondent 153
1. Assessing local needs

From April 2013, Clinical Commissioning Groups (CCGs) will assume responsibility for designing and commissioning local health services in England. This will include services in the community and secondary care that are received by people with epilepsy.

Our surveys have found that many of the organisations that will be responsible for planning and providing this care are not considering epilepsy in its own right.

Recognising that the CCGs (PCTs and PCT clusters) were surveyed early in the commissioning reform cycle, during their authorisation stage, we asked them about their intentions to plan for commissioning epilepsy services.

Our CCG survey found that two thirds (66%, 104/158) of CCGs do not intend to produce a written needs assessment of the health and social care needs for people with epilepsy. Over half (53%, 84/158) do not intend to produce a written needs assessment of the health and social care needs for people with neurological conditions in general.

A written needs assessment would collect local data about people with epilepsy and the current services, analyse these and compare them to the services that should be delivered. It would be a step on the way to producing an action plan to move and improve services towards better practice. Without this, clinical commissioners cannot determine the needs of the local population, or the most effective use of their budgets, and therefore cannot meet these needs.

Only 15% (24/158) of responding CCGs had a written needs assessment of the health and social care needs for people with epilepsy (21%, 33/158, for those with neurological conditions in general.)

Often the services that provide the best integrated, patient-centred care have been established because of the strong clinical leadership from a band of dedicated staff. Often the drive for establishing a service or improving care rests with the clinicians who specialise or are responsible for the clinical area.
Good practice requires good clinical leadership. However our CCG survey found:

- Only 17% (27/158) of CCGs or CCG federations have appointed a clinical lead for epilepsy.
- Only 21% (33/158) of CCGs or CCG federations have appointed a clinical lead for neurology.

We also asked CCGs about the services they intend to commission for epilepsy. They said:

<table>
<thead>
<tr>
<th>CCG commissioning intentions (%)</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>A GP with a Specialist Interest (GPwSI) led service</td>
<td>9%</td>
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<tr>
<td>A transition service</td>
<td>21%</td>
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<tr>
<td>A surgical pathway</td>
<td>23%</td>
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<td>A first seizure clinic</td>
<td>30%</td>
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<tr>
<td>A care planning service</td>
<td>32%</td>
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<tr>
<td>A diagnostic pathway</td>
<td>46%</td>
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<tr>
<td>An epilepsy specialist nurse service</td>
<td>46%</td>
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<tr>
<td>An outpatient clinic service</td>
<td>56%</td>
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This data show a lack of analysis of the needs of people with epilepsy, and a dearth of comprehensive planning.

**Case study – The Greater Manchester Strategy**

The Greater Manchester Neurosciences Network Board has agreed a programme of work that includes developing a strategy for the management of seizure disorders. The project team includes clinicians, patient representatives and commissioners and is supported by the development of a pathway of care, a model for service delivery and the strategy itself. For more information about the Greater Manchester Strategy and related work, please visit www.epilepsy.org.uk/acriticaltime.
Joint Strategic Needs Assessments (JSNAs)

A JSNA is the main mechanism that CCGs and local authorities will use to work together to understand the future health, care and wellbeing needs of their community. Every local authority should undertake a JSNA, and produce a document to guide the priorities of local health and social care commissioning over the next 12 months. Of those responding, 79% (102/113) have a Joint Strategic Needs Assessment (JSNA) for 2012/2013. This means 21% (27/113) of responding local authorities do not yet have a framework, and are unprepared for a role designating health and social care priorities. Of those with a JSNA, our data shows:

- Nearly three quarters (74%, 75/113) of the JSNAs include a section that includes long-term conditions.
- Only 28% (29/113) include a section that includes neurology.
- Only 27% (27/113) include a section that includes epilepsy.

An internal Epilepsy Action audit of those JSNAs with a section on epilepsy found that many include only a small amount of information about epilepsy, rather than a statement of the needs of people with epilepsy or recommended actions for improvement. A small number of local authorities did not know about JSNAs, in spite of an existing statutory responsibility to produce one residing with the local authorities (since 2007), and the growing importance of these assessments.

Recommendations

- Each CCG to carry out an epilepsy needs assessment, with reference to the NICE Clinical Guideline, the Quality Standards for the epilepsies and the NHS Outcomes Framework by April 2014.

- CCGs and the NHS Commissioning Board to commission services based on specifications informed by discussions with people with epilepsy, that are aligned with NICE Clinical Guidelines and the Quality Standards for the epilepsies.

- Each local authority’s Health and Wellbeing Board to include a section on epilepsy in their Joint Strategic Needs Assessment, to demonstrate their understanding of the needs of people with epilepsy.

- Members of Parliament to pursue this report with their local commissioners and providers to ensure this report is acted upon. Local councillors should ensure that this report is raised with and responded to by their Health and Wellbeing Boards.

- The Health Select Committee to conduct its first ever enquiry into the availability and quality of healthcare services available to people with epilepsy.
2. Access to specialists

NICE recommends that both adults and children with suspected epilepsy are diagnosed by a specialist in the condition. With over 40 different types of epilepsy and as many as 50 types of seizure, accurate diagnosis and determining the most appropriate course of treatment is not easy, even for dedicated epilepsy specialists.

A fifth (20%, 35/174) of adults diagnosed in the last two years reported being diagnosed by an epilepsy specialist clinician.

Of those people diagnosed with epilepsy in the last two years (adults and children), only 7% (12/177) were seen by the appropriate specialist within the NICE guideline waiting time of two weeks. At the other end of the scale 7% (13/177) had to wait more than 32 weeks before being seen by any specialist.

Where patients are seeing an epilepsy specialist, we found:

- One fifth (20%, 8/40) said their average waiting time for an adult with suspected epilepsy to see an epilepsy specialist consultant meets the guideline. While still not acceptable, this is an improvement from 2009 when we found this figure to be 6%.

- Only 13% (6/48) said their average waiting time for a child with suspected epilepsy to see an epilepsy specialist consultant or paediatrician with a special interest in epilepsy meets the guideline.

A third (34%, 27/79) of acute trusts who provide an epilepsy service do not offer their patients access to a clinician with a specialist interest in epilepsy.

This means many people are diagnosed by non-specialists, and they also are waiting far too long.

- A third (33%, 14/42) said their average waiting time for an adult with suspected epilepsy to see a non-epilepsy specialist neurologist meets the guideline.

- Three in ten (29%, 10/35) said their average waiting time for a child with suspected epilepsy to see a paediatrician (non-epilepsy specialist) meets the guideline.

“I am happy with my epilepsy treatment…since my GP put me in touch with a specialist epilepsy neurologist, who was the person who took the time to listen and investigate and… got my epilepsy under control.

Prior to that, no-one was listening, no-one took the time to really make an adequate diagnosis. I was left in a limbo of three or four seizures a week and living alone. Now I live a normal life and have done for over one year now.”

Patient Survey respondent 140
Epilepsy management
Of our surveyed adults with epilepsy, who are continuing to have seizures (662 people):

- 48% are managed by epilepsy specialists
- 33% are managed by non-epilepsy specialist neurologists
- 18% have their epilepsy managed by a GP in primary care
- 1% other

This means, including children, 49% (374/771) of those who continue to have seizures have their epilepsy managed primarily by a non-epilepsy specialist.

With a treatment gap of around 20% (people with epilepsy who have seizures, but would not with more appropriate treatment)\(^1\) there is a proven need for review and specialist advice on optimal management carried out by specialists.

Neuropsychological services
Access to neuropsychological services is particularly important for those people with the most severe medical and developmental needs. They aid the evaluation of learning disabilities and cognitive dysfunction, particularly in regard to language, speech and memory, and assessment to support a decision around surgical intervention. They also help people to manage and deal with the consequences of non-epileptic attack disorder. NICE recommends that:

“Neuropsychological assessment should be considered in children, young people and adults in whom it is important to evaluate learning disabilities and cognitive dysfunction” (1.6.32).

But of the responding trusts:

- Only 44% (35/80) offer their patients access to a neuropsychologist.
- Only 23% (18/79) offer their patients access to a neuropsychiatrist.

Four in ten (40%, 37/92) did not offer their patients access to any specialist neuropsychological services.


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Case study – Cardiff’s diagnostic strategy

Following the development of a multi-agency epilepsy steering group, Cardiff and Vale University Health Board developed an action plan for service improvement for patients experiencing a first seizure. This included a nurse-led emergency unit assessment service for patients experiencing a first seizure and nurse-led first seizure clinics. For more information about the Cardiff Chronic Conditions Management Demonstrator, including key patient outcomes, please visit www.epilepsy.org.uk/acriticaltime
Almost **500,000** people in England live with epilepsy. That’s around **one** person.

Epilepsy Action believes that all people with epilepsy should have access to specialist healthcare and treatment for their condition.

Current health services for people with epilepsy are not good enough.

The guideline waiting time for someone with suspected epilepsy to see an epilepsy specialist consultant is two weeks. Trusts told us:

- **20%** more than 2 weeks
- **80%** 2 weeks

**34%** of trusts do not offer adults access to epilepsy specialist doctors

**46%** of trusts do not offer adults access to epilepsy specialist nurses

**73%** of people who still have seizures have never been referred to a specialist centre

It’s **A Critical Time** for epilepsy in England. Now is the time to act and improve healthcare services for people with epilepsy.

[www.epilepsy.org.uk/acriticaltime](http://www.epilepsy.org.uk/acriticaltime)
Almost 500,000 people in England live with epilepsy. That's around 1 in 105.

Epilepsy Action believes that all people with epilepsy should have access to specialist healthcare and treatment for their condition.

1 Current health services for people with epilepsy are not good enough.

The NHS structure is changing and not enough is being done to plan good epilepsy services for the future.

27% of local authorities have assessed the needs of people with epilepsy.

17% of clinical commissioning groups have appointed someone to lead on epilepsy.

34% of clinical commissioning groups have a plan, or intend to produce a plan, for epilepsy.

Now is the time to act and improve healthcare services for people with epilepsy.

www.epilepsy.org.uk/acriticaltime
3. Epilepsy specialist nurses

Epilepsy Action believes that all people with epilepsy should have the opportunity to see an epilepsy specialist nurse (ESN). We estimate that 60% of people with epilepsy will require access to a nurse at any one time. Therefore universal coverage of nursing services is vital.

ESNs are an expert and essential part of a multi-disciplinary team, providing clinical and psychosocial information and support. They can act as key workers/care plan coordinators and a central cog for epilepsy services, often linking other valuable services and ensuring the patient receives integrated and joined-up care. They are a specialist in the clinical management of epilepsy, independent living and personal goal setting and adherence. (For more info, see the Adult ESN Competency Framework referenced in Further Reading). To a person with epilepsy, they are often the human face of health services.

Adults

Only half (52%, 475/905) of people with epilepsy told us that they have ever seen an epilepsy specialist nurse. This is not surprising as only 54% (43/79) of acute trusts offer their patients access to adult epilepsy specialist nurses. However this is up from 2009, when 41% (102/252) had seen a nurse.

Over a third (38%, 233/622) of adults who still have seizures have never seen an epilepsy specialist nurse.
Children
Over half (57%, 28/49) of acute and foundation trusts that provide a paediatric epilepsy service, do not offer their patients access to a paediatric epilepsy specialist nurse. The Epilepsy12 audit of paediatric epilepsy (2012) uncovered similar findings, with no evidence of access to a nurse in over half of children’s care (54%).

From our patient survey, 42% (63/149) of children who are still having seizures have never seen an epilepsy specialist nurse.

People with learning disabilities
Around 120,000 people (a fifth of all people) with epilepsy also have recognised learning disabilities, which present a different set of health and social challenges and needs. However 49% (40/79) of acute and foundation trusts do not offer their patients access to learning disability epilepsy specialist nurses.

Only 14% (13/88) of responding trusts with epilepsy services had the full complement of ESN roles (adult, paediatric and learning disability), allowing them to cater for all needs of people with epilepsy.

**Recommendation**

- Acute trusts to provide a service compliant with the NICE Clinical Guideline and the Quality Standards that affords people with epilepsy adequate and timely access to epilepsy specialists and epilepsy specialist nurses.

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Case study – ESNs and paediatric epilepsy admissions

The new post of a Children’s Epilepsy Nurse Specialist at Kings Mill Hospital was created in April 2007. Between 2007 and 2011, ward visits reduced, outpatient interventions increased and epilepsy-related admissions reduced. The number of telephone contacts more than doubled between Year One and Year Two. Educational and supportive visits to homes and schools have also increased. The appointment of an ESN has also been associated with an approximate halving of epilepsy-related admission rates. **For more information about the Sherwood Forest Hospitals review of nurse-led clinical activity, please visit www.epilepsy.org.uk/acriticaltime**
4. Investigations

For many people with epilepsy, an accurate diagnosis cannot be made at a first appointment with an epilepsy specialist. Because epilepsy is a broad spectrum of syndromes and seizure types (with different origins), determining appropriate treatment is not always easy.

To aid with accurate diagnosis, many people with epilepsy will undergo medical investigations to help determine the aetiology, focus or type of seizure.

MRI
Magnetic resonance imaging (MRI) is the most common type of investigation for epilepsy.

Of those newly diagnosed (within the last two years), 50% (83/165) of those who received an MRI scan did so within the four week recommended time (guideline recommendation 1.6.22). This is supported by the acute trust data, with 50% also stating that they were within the four week time (31/62).

Of those with a prior diagnosis of epilepsy, who have had an MRI scan for their epilepsy in the last two years, 42% (214/504) had it within four weeks. In 2009, this was 45% (48/107).

EEG
Our surveys found that, of all those referred for investigations in the last two years, 41% (177/436 responders) have average waiting times of under four weeks for a standard EEG referral.

5. Tertiary services

Some world-leading centres for epilepsy exist in England, but we have found that often it is difficult to get a referral. This may be because of limited capacity, or more simply that the referring clinician doesn’t consider a referral as an option. Either way, it is not acceptable to assume that some people ‘just have seizures’ without exhausting the possible tests and investigations that could determine aetiology for the epilepsy.
Nearly all (95%, 76/80) of all acute trusts surveyed told us that they do refer to tertiary epilepsy centres. However only around one fifth (22%, 210/947) of people with epilepsy have ever been referred to a specialist tertiary epilepsy centre.

Nearly three quarters (73%, 495/682) of patients (adults and children) who still have seizures have never been referred to a specialist tertiary epilepsy centre.

The Epilepsy12 audit found that tertiary centres have only been involved in the care of 60% of children with epilepsy in the UK who required tertiary care.

NICE states that if seizures are not controlled, treatment fails or there is diagnostic uncertainty, people should be referred to a tertiary centre within four weeks. There is clearly unmet need for more treatment reviews leading to tertiary referrals.

Of those referred to a tertiary centre in the last five years (77 respondents),

- 26% (20) report having less seizures
- 14% (11) say their seizures are now not as bad
- 10% (8) report achieving seizure-freedom

**Recommendation**

- The NHS Commissioning Board to adequately plan and provide tertiary epilepsy services, including guaranteeing fair and ample access to non-drug interventions.

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“My GP is well informed and very supportive, but when my seizures were coming more frequently last year she referred me back to [the] neurology department at Kings College. I… am currently changing to new AEDs.”

Patient Survey respondent 254

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Case study – Beverley from Coventry

I was first referred to a specialist centre in Birmingham in about 1990. I’ve had epilepsy from being a child and over the years have had problems controlling my seizures, despite trying a range of epilepsy medicines.

It was some years later, after successfully replacing phenobarbital with a newer drug, that my consultant asked me about trying a Vagal Nerve Stimulation (VNS) device. I was referred to another hospital and soon fitted with a VNS. Although it hasn’t completely stopped my seizures, the implant has enabled me to reduce my medication, which has had a positive impact and helped to improve my quality of life. It’s important that people like me are not forgotten, are continually assessed and made aware of other treatments that could be beneficial.
6. Care planning...

Care plans are a key priority of the NICE Clinical Guideline for the epilepsies (2004 and 2012) and the National Service Framework for Neurological Conditions (2005).

Less than half (47%, 43/91) of acute trusts stated that their patients with epilepsy are routinely offered care plans.

Only 14% (128/947) of people with epilepsy reported having a written care plan that describes their epilepsy, daily and emergency treatment, need for regular reviews and lifestyle issues. In 2009, the same number of people, 14% (34/252) reported having a care plan.

Recommendation

- All clinicians to ensure that their patients with epilepsy are offered a personalised care plan, shared with all professionals involved in their care and produced in conjunction with an epilepsy specialist.

Case study – NHS Yorkshire and the Humber

Epilepsy Action has been working closely with NHS Yorkshire and the Humber to develop a patient care planning template within SystmOne. This was developed in partnership with epilepsy specialist nurses, consultant neurologists, GPs with a specialist interest in epilepsy and practice nurses. It promotes good practice in care planning by encouraging people with epilepsy to set goals and contribute to action planning. The tool also aids wellbeing improvement by structuring the annual review process and enabling accurate, high quality information to be given to patients. For more information about the SystmOne care planning work, please visit www.epilepsy.org.uk/acriticaltime

Dr Martin McShane, Director – Domain 2 – NHS Commissioning Board

7…and annual reviews

Annual reviews of a person’s epilepsy and their treatment are essential. They provide a checkpoint at which to evaluate whether a person’s treatment and care package is working for them, or whether it is still appropriate. We know from our members that where reviews do not take place, people can go for many years taking medication that does not work for them, experiencing negative side-effects and living with seizures that they need not have.
Adults should have a regular structured review with their GP, but depending on the person’s wishes, circumstances and epilepsy, the review may be carried out by the specialist (NICE Clinical Guideline 137, 1.20.2). This includes those who have difficult to control epilepsy, or have greater or more complex needs.

Nearly two thirds (63%, 597/947) of adult respondents were offered or took part in a treatment review in the last 12 months. In 2009, 66% (169/260) of respondents had been invited for a review in the previous 15 months.

Children and young people should have a regular structured review with a specialist (NICE Clinical Guideline 137, 1.20.3). Seven out of ten (70%, 131/188) of children and young people (aged 18 or under) were offered or took part in epilepsy review in the last 12 months. Of those that did have a review, 57% (75/131) of childhood reviews were held with an epilepsy specialist (epilepsy specialist consultant/paediatrician, or ESN).

68% (206/305) of adults who are still having seizures were not offered an epilepsy review.

Recommendation

• Primary care clinicians to review and refer their adult patients with epilepsy, who continue to have seizures, to a specialist in epilepsy. If this does not lead to an improvement in care, these patients should be referred to tertiary services for further management.

"Appointments with health professionals are short and I feel that I have benefited by finding more information… My annual review consists of my GP asking if my medication is still working but doesn’t cover any lifestyle issues. I’ve only recently become aware of the full implications of my memory loss - and that was by going to an Epilepsy Action event."

Patient Survey respondent 549

“It has been slow with the specialists unwilling to review when things altered and began to worsen. After a diagnosis of JME [juvenile myoclonic epilepsy] it turned out I had cortical malformations caused by a genetic mutation. Years were wasted because I was never listened to and never had an MRI scan. It has affected my work greatly as I work as a scientist in blood transfusion and could no longer do shift work.”

Patient Survey respondent 549

Case study – West Sussex County Council and the West Sussex Epilepsy Working Group

West Sussex County Council developed an easy-read diary following an audit of patients at a local neurology clinic. It found that just over half came armed with the relevant seizure records and medication information, and just under half were supported by a support worker or family carer who knew them well enough to provide useful and relevant information about their epilepsy. For more information about the West Sussex seizure diary, please visit www.epilepsy.org.uk/acriticaltime
8. Women’s health

Having epilepsy affects the care and treatment choices of women and girls throughout their lives. The drugs a woman takes to treat her epilepsy could impact on her fertility, the effectiveness of her contraception, the health of an unborn baby, development of the child and in the longer term, her bone health.

Epilepsy Action’s Ideal World for Women survey 2012 found, of the 100 women surveyed who are or have been pregnant during the last five years:

- Only 41% (41/100) saw a neurologist during their pregnancy.
- Only 59% (59/100) saw an epilepsy specialist nurse.
- And only 29% (29/100) saw an epilepsy specialist consultant.

Over a third (36%, 131/366) of women with epilepsy of child bearing age have not received information and counselling on contraception, conception and pregnancy. This is despite pre-conception clinics being in the NICE Clinical Guideline recommendations, and this activity providing additional payments for GPs through the Quality and Outcomes Framework (QOF).

Quality care, support and information throughout life could lead to optimum seizure control and a reduced impact on mother and baby’s wellbeing. For more information about epilepsy and women’s health, please see Epilepsy Action’s publication “Having a baby” and “HealthE mum-to-be”.

Case study – Northampton General Hospital’s transition process

Northampton’s transition service derived from many adolescents reporting a lack of services to meet their health needs and facilities to express their opinions. Led by the paediatric consultant and paediatric epilepsy specialist nurse (ESN), a résumé of the patient’s diagnosis and treatment is discussed with the consultant neurologist and adult ESN. Any queries/concerns around the diagnosis are discussed and a treatment plan agreed. A flexible approach is adopted that enables those who would benefit from staying in paediatrics to do so, and those who are mature to be transferred earlier to adult care. For more information about the Northampton transition arrangements, please visit www.epilepsy.org.uk/acriticaltime

“I am very happy about the treatment that my daughter and I have received from the paediatric consultant and the specialist epilepsy nurse at our local hospital. From the time that she was diagnosed to the present time, they have provided an excellent, friendly service, both at our regular hospital appointments and on the occasions where I have contacted the epilepsy nurse by telephone for some general advice.”

Patient Survey respondent 764
9. Transition

For many people, moving from one branch of services to another is a difficult and daunting time. For many young people, the movement from paediatric to adult services is the time when they begin to take responsibility for their own treatment and welfare, the point at which they take control of their own care. A structured transition by a named clinician is a NICE Guideline recommendation (1.17.4).

Only 32% (50/158) of young people (between 13-21 years old) have ever discussed moving from paediatric to adult services with a health professional. And two thirds (65%, 52/80) of acute trusts state that they do not offer transition clinics for young people moving from paediatric services to adult services. In 2009, this was 64% (51/78).
10. Advice and information

Access to quality, straightforward advice and information is crucial to enable patients to be independent. Information creates informed patients, and informed patients experience better outcomes.

• Less than half (44%, 412/947) of patients reported that they had been provided with general epilepsy information from a health professional.

• Around half (50%, 472/947) of patients reported being given information about their medication and its effects from a health professional.

Just under two-thirds (64%, 606/947) of the people who completed our patient survey told Epilepsy Action that they feel informed about their epilepsy. Just over half (55%, 524/947) trust their doctors to make decisions about their healthcare. This emphasises the important role that patients place on medical staff as a source of advice and guidance.

Only 13% (126/947) of respondents had been given information about epilepsy related death. Another 28% (266/947) said they hadn’t received any information, but would like to. Epilepsy Action believes that it is very important for people with epilepsy and their families to be aware of the risks associated with epilepsy, including epilepsy related death (NICE Guideline recommendation 1.3.11).

Epilepsy Action has a wide range of advice and information on the health and social effects of epilepsy, from specific treatments to advice on accessing benefits, available to both medical professionals and to patients. To access this information, please visit www.epilepsy.org.uk/info

Case study – Catherine from Nottingham

“It's really important to be well informed about your epilepsy and that you receive as much information as possible to help you make decisions about your own health.

When I had my first child, the only information I was given about epilepsy and pregnancy and the possible risks of my epilepsy medicine, sodium valproate, was that I carried an increased risk of having a child with spina bifida, but that the condition could be detected by a scan at 20 weeks…” To keep reading Catherine’s story, please visit www.epilepsy.org.uk/acriticaltime
11. The patient experience

Patients with epilepsy have a great deal to offer in the development of services and pathways. Their knowledge about the support and care they would like to receive, and when, can make the difference between an average service and good service, and between a good and an excellent one.

We found, that of the participants in our patient’s survey:

- Around half of people (52%, 494/947) are happy with their epilepsy treatment.
- And around half of people (52%, 494/947) say they receive a good epilepsy treatment.

**Recommendations**

- Members of Parliament to pursue this report with their local commissioners and providers to ensure this report is acted upon. Local councillors should ensure that this report is raised with and responded to by their Health and Wellbeing Boards.
- The Health Select Committee to conduct its first ever enquiry into the availability and quality of healthcare services available to people with epilepsy.
methodology

This report was compiled from information gathered through four surveys, carried out by Epilepsy Action. They were designed and analysed using Snap Surveys software (version 10). Responses could be submitted, by paper and online, between 27 April 2012 and 10 September 2012.

- A survey, conducted primarily through Freedom of Information requests, of Primary Care Trusts, Primary Care Trust clusters and shadow Clinical Commissioning Groups (CCGs). This received 147 responses from a total of 208 requests placed (a response rate of 71%).

further reading

Atlas of Variation 2011
RightCare, 2012.

Adult ESN Competency Framework (2012)
Epilepsy Nurses Association (ESNA) and Royal College of Nursing (RCN).
www.esna-online.org.uk

Epilepsy12
Royal College of Paediatrics and Child Health, 2012.
www.rcpch.ac.uk/epilepsy12

Epilepsy in England: Time for change
Epilepsy Action, 2009.
www.epilepsy.org.uk/timeforchange

Epilepsy: a resource pack for primary care
Epilepsy Action, 2012.
www.epilepsy.org.uk/toolkit

HealthE mum-to-be
Epilepsy Action, 2013.
www.epilepsy.org.uk/womenscampaigns

The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care
National Institute for Clinical Excellence (NICE), 2012.
www.nice.org.uk/cg137

St Elsewhere’s Clinical Report
National Audit of Seizure Management in Hospitals (NASH), 2012.
www.nashstudy.org.uk

Wasted Money, Wasted Lives: the human and economic cost of epilepsy in England
www.epilepsy.org.uk/wmwl

The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care
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National Audit of Seizure Management in Hospitals (NASH), 2012.
www.nashstudy.org.uk

Wasted Money, Wasted Lives: the human and economic cost of epilepsy in England
www.epilepsy.org.uk/wmwl
Epilepsy Action has a range of resources to aid commissioners including our updated Epilepsy primary care resource pack.

This includes:

- Information on epilepsy, and what information different patients may require.
- A guide to the health services people with epilepsy need (in line with the updated NICE Clinical Guideline).
- Practical resources to be used in care. This includes a template care plan, a review checklist, a template seizure diary and a guide on how to meet the epilepsy indicators of the Quality and Outcomes Framework.

A commissioning guide to epilepsy is also downloadable, to help design good quality epilepsy services in the new commissioning environment.

To access the toolkit please visit: www.epilepsy.org.uk/toolkit

For further information, please contact Sadaf Adnan at sadnan@epilepsy.org.uk or 0113 210 8800.

This resource is supported by an educational grant from GlaxoSmithKline.
“We know that there are historic weaknesses in the commissioning of services, which the epilepsy charities and stakeholders have drawn attention to in recent reports, correspondence and parliamentary questions... the urgency for change is all the greater because these failures carry huge costs, as well as having a massive impact on the lives of people with epilepsy. There are also potentially very significant savings from unplanned emergency admissions to be made by getting this right, which goes hand-in-hand with improvements in outcomes including life expectancy and a reduction in the number of tragic sudden deaths from epilepsy.”

(The Right Honourable David Cameron MP, Prime Minister, May 2011).

Getting more information

Call our Epilepsy Helpline:
freephone 0808 800 5050  text 07537 410 044
Email helpline@epilepsy.org.uk
Twitter @epilepsyadvice

www.epilepsy.org.uk