



## **Consensus Statement in Response to the Recently Published NICE Guideline on the Diagnosis and Management of the Epilepsies**

Expert clinical epileptologists and representatives of the epilepsy voluntary sector met this week to review various survey findings characterising the current state of epilepsy care and to compare against standards outlined in the recently published NICE guideline. 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.

Epilepsy is the most common serious neurological condition affecting 1 in every 133 people in the UK. It is not acceptable that epilepsy-related deaths in 39% of adults and in 59% of children are potentially or probably avoidable. Only 52% of patients achieve seizure freedom when around 70% could be seizure free with appropriate management. This equates to around 80 thousand patients or approximately 2 per General Practitioner's list.

### ***Current status of epilepsy care***

The expert consensus was that little progress has been made since 2001 when, in his Annual Report, the Chief Medical Officer described epilepsy as a 'disease in the shadows', and since 2002, when the National Sentinel Clinical Audit of Epilepsy-Related Deaths was published. Current services fall well short of the standards set out by NICE in terms of waiting times for specialists and diagnostic tests, and research findings indicate that little is likely to change in the next four years.

On average, current waiting times for first referral to see a specialist after a suspected seizure is between 8-10 weeks (significantly longer in some areas); woefully short of the NICE standard of 2 weeks. In fact, findings presented at the consensus meeting suggest that only about 10% of patients are seen within this timeframe. Waiting times for investigations also fall short of NICE standards set at 4 weeks – average waiting times seem to range from 5 weeks for an EEG to 24 weeks for an MRI. The excessive waiting times for MRI scans – the most important tool recommended by NICE to identify a cause for epilepsy – encourages neurologists to refer patients for much less sensitive CT scans instead. One survey showed that 62% of neurologists always, regularly or occasionally admitted to this practice.

With these long waits for diagnostic tests and referrals from GP to specialist, patients are being put at risk; some are not being referred at all or are being lost between primary and secondary care.

NICE states that misdiagnosis rates for epilepsy in the UK are between 20-31%, underlining the importance of access to epilepsy specialists.

Reassuringly, perhaps, 95% of the 74 GPs surveyed said they would be undertaking the epilepsy quality markers in the new GMS contract, which calls for an annual review of their patients, and the implication of secondary care referral should the patient not be seizure free or be experiencing side effects. However, most GPs (76%) are not aware of the impact this will have

on waiting times to see specialists; a concern raised by 37% of neurologists, who recognise that epilepsy is already chronically under-resourced.

The provision of patient information was also shown to be poor, with only about 50% of patients receiving any kind of general epilepsy information, and only 8% receiving information about the risk of epilepsy-related death.

Although many of the above concerns have been highlighted by the Government as areas to be addressed, PCTs seem powerless, or unwilling, to implement improvements. Of the 160 Primary Care Trusts surveyed, only 26% indicated that it was likely that epilepsy would be included in their Local Delivery Plan for 2005-8 (although a further 46% suggested it was possible), compared with the 19% that include it currently. In 75% of cases, reasons given for non-inclusion were that 'national targets take priority' and that 'national targets leave insufficient funding'.

It is crucial that all PCTs meet the criteria for provision of epilepsy services specified in NatPACT (National Primary and Care Trust Development Programme).

### ***What are the solutions?***

The expert group is aware that the shortage of neurologists and other epilepsy specialists is not going to improve overnight and calls for a number of short-term solutions. In the medium term the group believes that addressing this shortage is the principal change needed to ensure epilepsy services improve sufficiently to achieve the standards set by NICE.

#### *In the short term (next 2 years)*

The expert group is calling for a national plan to increase the number of epilepsy specialist nurses from 140 to 600 across all epilepsy disciplines (adult, paediatric, learning difficulties). Nurses play a critical role in treatment monitoring, offering advice and support to patients and families, and education for patients and GPs, therefore providing much needed support to people with epilepsy, the primary care team and to neurologists.

Secondly, consensus opinion was that those working in the profession need to ensure that every patient has a clear and comprehensive personal care plan (as recommended by NICE) that is shared by the specialist and GP. This would include findings of a patient annual review which should detail whether a cause for the epilepsy has been considered, seizure type and frequency, treatment, treatment history, and whether the patient had developed any new problems that might be related to the epilepsy and its treatment, along with lifestyle issues, risk management and emergency advice

Thirdly, a national plan of epilepsy training for GPs, A&E doctors and other general paediatricians and clinicians is needed to increase their epilepsy knowledge base to the appropriate level required for them fulfil their respective roles.

The final short-term solution, which could have major and immediate impact, is for all GPs to actively identify the two patients with epilepsy within their practice who are currently experiencing seizures but who could, with optimal treatment, be seizure free, and to ensure they are appropriately referred to specialists for a more thorough review.

*In the medium term (next 5-10 years)*

The group is calling for the Government to immediately put in place a programme to increase the number of adult neurologists from 352 to 1,400; paediatric neurologists from 75 to 150; learning disability specialists from 340 to 500; and neuroradiologists from 110 to 160, all within 5 to 10 years. This plan must start now given the 8 years it takes to train and gain the relevant experience to manage this most complex and difficult to diagnose neurological condition.

### **Implementation requires funding**

The consensus group recognises that this will require serious investment – as much as £150 million per year, equivalent to only £340 per person with epilepsy. Investment now will help address years of under investment, as money spent on increasing numbers of qualified healthcare 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.

The Joint Epilepsy Council, in its recently published manifesto for epilepsy, has shown how improvements in epilepsy care could realise savings of up to £158 million per year, the annual cost of epilepsy misdiagnosis based on figures from the National Institute for Clinical Excellence, and £66 million per year through reduced cost of Disability Living Allowance for people with epilepsy. Together this is more than enough to fund the improvements being called for.

### **The Consensus Group**

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