

**Focus Group
Proposal to appoint an Epilepsy Nurse Specialist for Berkshire West
A patient and carer perspective
23rd July 2012**

1. Background

Patients and their representative groups have been urging Berkshire West PCT over a long period of time of the need for a local Nurse Specialist in Epilepsy. In September 2008 the local epilepsy voluntary sector presented a detailed business case, describing the clinical and financial benefits of such a post, offering pump prime funding. That opportunity was not taken up by the PCT. In 2010 West Berkshire Neurological Alliance and West Berkshire LINK undertook research among people affected by epilepsy, again recommending that such a post be created. In Summer 2012 the PCT set aside funds to create such a post, although voluntary sector pump priming is no longer available. Patients and the epilepsy voluntary sector established this focus group. Its aim was to generate an up-to-date patient and carer perspective on how and why the nurse specialist role might best be developed to benefit people affected by epilepsy. The focus group builds on the above. The findings are consistent with earlier findings and with those in many other parts of the country.

2. Format and limitations of the focus group

Eight people affected by epilepsy contributed to the discussions, two male, six female. An individual with epilepsy led the discussion, with notes taken by an independent observer. The age range of those present was 18-50 approx. All contributors had a long-standing association with epilepsy, four were family carers and one was a paid epilepsy carer. An informal agenda was proposed, see Appendix, with attendees encouraged to take a broad approach and speak across the subject headings, keeping within the bounds of 'what would be of most help to people affected by epilepsy?'

The text in '*blue italics*' is the record-keeper's capture of the statements made by attendees. Attendees of the focus group have checked and validated the record and its interpretation to be accurate.

3. Main agreements and recommendations

1. The post should be based mainly in the community, ideally at least 80%, probably more.
2. Anyone who has a diagnosis of epilepsy or who looks after someone with epilepsy should have easy, unrestricted and direct phone access to the nurse specialist.
3. The role should embrace the provision of information on living with epilepsy, support and reassurance for patients and families, stress reduction, general epilepsy training and some more specialised epilepsy training.
4. The role should ensure carers are specifically informed and otherwise supported to know how to respond in a range of possible scenarios. The nurse should work with carers, the Ambulance Service and others to reduce and optimise use of emergency services and to minimise the frequency and length of hospitalisations.
5. The role should include providing specialised advice for those with epilepsy considering or experiencing pregnancy.

6. The role should include some special focus on the needs of the younger epilepsy population and those looking after them.
7. The role should have a special focus on medications use-and-review, side effects, keeping safe and where applicable on associated lifestyle factors such as home and work environment, sleep, food, work and other key daily routines.
8. The post will need strong links to other service streams in the NHS, Social Care, State Benefits, staying in work, driving and transport and related subjects.
9. The job description should be carefully defined and the appropriate clinical and cost impact of the post should be monitored and reported upon at the earliest opportunity, as there is a belief that one nurse will not be sufficient to meet the need, and that cost-effectiveness to justify additional nurses will be easy to demonstrate.
10. Separately, but in tandem, epilepsy patients and carers agreed to come together more, to raise awareness of epilepsy and to provide peer group support.

4. Main issues identified

4. 1. The need to raise standards for epilepsy in the community. In general, those present regarded local GP knowledge about living with and managing epilepsy as *'poor or worse'*. GPs often take an approach of treating epilepsy patients with: *'what they assume is depression'*, whereas patients are more likely to need help to understand *'what is my epilepsy?'*, *'what will happen to me next?'*, *'how can I manage it?'*, these being specific, justified anxieties not requiring treatment for depression. *'GPs give counselling of the wrong type'*, *'GPs don't understand the emotional side from the perspective of the patient.'* *'A lot of the information is wrong.'* *'The advice I've had from my GP about epilepsy and pregnancy is not good enough.'*

Also: *'My social worker doesn't understand me.'* *'The nurse must train social workers and GPs that we are not crazy.'*

4. 2. Misconceptions about 'what is a seizure?' There is a general misconception that: *'When the shaking stops, the fit is over'*. *'Some seizures are followed by rapid recovery, whereas others take days to wear off'*. Many professionals, in particular, ambulance crews, need better training on how to assess individual care requirements following a seizure, to reduce the number of unnecessary hospitalisations.

4. 3. Major carer issues. Carers may be faced with critical decisions when a loved-one has a seizure, decisions that could carry a severe legal penalty if the carer gets it wrong. None of the patients had ever received any training in epilepsy and only one carer had any training, but only incidentally *'as part of lifeguard training'* and not in relation to his specific caring role. The professional carer noted that: *'Training in epilepsy costs £50 a head'*, a deterrent to care agencies to implement adequate training. *'The needs of carers are often overlooked.'* *'The views of carers are often ignored.'*

Carers identified that if they could agree with a nurse specialist the criteria to follow when faced with whether or not to call the emergency services, that would ease the major burden of making a mistake could result in serious legal proceedings.

5. Objectives, tasks and outcomes

5.1. Quick and ready access to support throughout. The nurse must be accessible: *'People with epilepsy should have an absolute right to phone the nurse.'* *'You need it quick'*. *'Parents need someone to call about their baby or their children.'*

5.2. When, where, what and how? Those present readily identified that the great majority of useful things that the nurse should do would be in the community, not in a hospital setting. *'Prevention is better than cure.'*

Whereas there will be some need for the nurse to conduct some activity within the hospital setting, the role should be conducted essentially: *'at GP centres', 'in patients' homes', 'in care homes', 'out and about', 'in schools',* covering all age ranges but with a particular emphasis on *'younger age ranges'*. *'When I am in hospital it is the consultant I need to see, not the nurse specialist'*

Home visits are regarded as core: *'we need home visits', 'better in your own home to avoid the build up of emotions'*. The need for home visits could arise once someone has had a first or second seizure, perhaps before a diagnosis is formally agreed: *'to answer questions,' 'to provide reassurance and counselling', 'to provide further contact information such as about local support groups', 'to context the condition in terms of driving, work, family relations, lifestyle, etc', 'to help entering a new life'*.

Questions that can arise include very basic questions such as *'is it infectious', 'have I got a brain tumour?' 'is this normal?', 'am I cured?'*. *'Seeing an expert in epilepsy is essential, early counselling.'* *'A schedule of where the nurse clinics will be held should be published in advance, so people know where they can see the nurse. That should include schools.'*

A nurse specialist is likely to be able to assist epilepsy patients throughout the epilepsy journey: *'immediately following the first episode of epilepsy', 'at any time afterwards', 'as further seizures happen', 'as new questions and management questions arise', 'as progression in frequency or extent of seizures happens', 'for guidance on side effects of drugs', 'most people have to try several drugs', 'sometimes side effects are worse than the epilepsy'. 'to discuss options following long periods of freedom from seizures', 'to advise on having a baby and family planning', 'which medications are safe during pregnancy'* and related matters.

5.3. Stress reduction. The NHS in general and a nurse specialist in particular should give priority to *'reducing the stress'* of having to live with epilepsy, so people can *'get on with their lives'*. Ways of achieving this are described throughout this report.

5.4. Ambulance Service costs. Some patients are heavy users of the Ambulance Service, too often becoming hospitalised unnecessarily. Better training of carers, Ambulance crews and A&E staff can reduce the inconvenience, distress and costs that go with this. *'Back and forth, back and forth for no good reason.'*

5. 5. Hospital staff costs. Often when epilepsy patients are taken into hospital the emergency department staff tend to focus on cuts and bruises, but they can lack knowledge of epilepsy. *'Do they treat the head injury or the epilepsy? They treat the head injury.'* This can result in patients being kept in hospital beds awaiting a neurology consultant, but there are so few Consultants that patients can be stuck in hospital for little reason, until the neurologist appears who then *'just sends them home'*.

'Ward staff don't know what to do.' In instances when epilepsy patients are in a hospital ward, ward staff often lack knowledge about epilepsy, which can upset important daily medical and other routines. Some core training of hospital staff is required, noting the priority is to reduce hospitalisations. *'Yes, you may need to go to hospital, but not if they don't know what to do.'*

5.6. Waiting for essential diagnostics. One attendee reported; *'waiting time for a brain scan is 6 months'*, clearly regarded as unacceptable. A nurse specialist may be able to ensure that more urgent cases are fast-tracked more appropriately. That leaves one further problem: *'Scanner staff don't know what to do.'*

5.7. The training role. Who needs training from the nurse? *'GPs', 'epilepsy patients', 'family carers of people with epilepsy', 'paid care staff', 'ambulance crews', 'emergency staff in the hospital', 'ward staff', 'social workers', 'school staff', 'employers', 'the general public', 'nationally, awareness of epilepsy is poor.'* *'People go quiet about their epilepsy.'*

As stated above, the nurse should help families to understand the *'criteria to adopt when deciding whether or not to summon the emergency services or other professional medical help'*. There is also a need to train more individuals in *'the use of Buccal midazolam'*

The need for the nurse to have a range of information leaflets of various descriptions and purposes were mentioned, along with the need for patient groups to have their own capacity to supply relevant information.

5.8. Will one nurse be able to cope?

The job description should be carefully defined and the appropriate clinical and cost impact of the post should be monitored and reported upon at the earliest opportunity, as there is a belief that *'one nurse will not be sufficient to meet the need'*, and that *'cost-effectiveness to justify additional nurses will be easy to demonstrate'*.

6. What patients and carers can do

'We need to raise public awareness.' *'We should get people with epilepsy to do this.'* *'We should have a regular slot in the market place.'* Much further discussion followed these inputs and a separate meeting will be arranged to progress what can be done to improve awareness and peer group support.

7. Other statements recorded

'Every fit should be logged.' (not everyone felt this necessary)
'It's not necessary to phone the nurse every time I have a fit.' (not everyone agreed)
'I have to go into hospital at Oxford for dentistry as they say I need a special anaesthetist in case I bite the dentist.'

Appendix

The informal agenda prompts

1. Why do we need an epilepsy nurse?
2. What tasks should be the nurse's priority?
3. Where should the nurse be available?
4. How should patients be referred?
5. Outcomes that matter:
6. What would you write into the nurse specialist's job description?
7. Success factors in establishing a nurse specialist post?
8. What else is needed in addition to a nurse specialist?

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