



Understanding the Service
Needs of People Living with
Epilepsy:

The West Berkshire Study

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- **Epilepsy** is the most common chronic disabling neurological condition in the United Kingdom, affecting **380,000 people in England** [\[i\]](#),[\[ii\]](#).
- The number of people living with epilepsy at any one time in the general population is **5.0 per 1000** (in 1995).
- The prevalence is:
 - **lower in children** (3.0 per 1000 for 5-9 year olds and 4.0 per 1000 for 10-14 year olds)
 - and **higher in older people** (7.0 per 1000 in 70-74 year olds and 7.5 per 1000 in 75-79 year olds).

[\[i\]](#) Muir TM, Bradley A, Wood SF, Murray GD, Brodie MJ (1996) An audit of treated epilepsy in Glasgow. West of Scotland Epilepsy Research Group. *Seizure* 5(1):41–46.

[\[ii\]](#) Wallace H, Shorvon S, Tallis R (1998) Age-specific incidence and prevalence rates of treated epilepsy in an unselected population of 2,052,922 and age-specific fertility rates of women with epilepsy. *Lancet* 352: 1970–1973.

[\[iii\]](#) Cockerell OC, Johnson AL, Sander JWAS, Hart YM, Goodridge DM, Shorvon SD (1994) Mortality of epilepsy: results from a prospective population-based study. *Lancet* 344: 918–921.

- People with epilepsy have a **risk of premature death** that is **2–3 times higher** than in the general population [\[iii\]](#) .
- Around **800 people** with epilepsy **die annually** mainly due to uncontrolled seizure activity.

- Published in May 2002;
- Highlighted serious deficiencies in services for people living with epilepsy in England including:
 - poor management of patients;
 - lack of re-referrals of patients from GPs to neurologists;
 - lack of information being given to patients and their families about the risk of fatality from their illness.
- The audit concluded that:
 - 54% of adults and 77% of children with epilepsy received inadequate care;
 - and that 42% of epilepsy deaths annually were potentially avoidable.

NICE

- **National Institute for Clinical Excellence (NICE)** is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.
- On 1 April 2005 NICE joined with the Health Development Agency (HDA) to become the new **National Institute for Health and Clinical Excellence** (also to be known as NICE).

NICE Guidelines on Diagnosis and Management of Epilepsy

- **On October 27th 2004**, the National Institute for Clinical Excellence (NICE) published '*The epilepsies: The diagnosis and management of epilepsies in adults and children in primary and secondary care*'.
- The guideline aims to ensure that people with epilepsy, wherever they live in England and Wales, can access treatments and interventions that are based on the best available evidence.

Priorities Highlighted in NICE Report

- All individuals with a recent onset suspected seizure should be seen **urgently** by a **specialist** to ensure **precise and early diagnosis** and **initiation of therapy**.
- **Drug therapy** should be **tailored** to seizure type, epilepsy syndrome, co-administered medications, any other illnesses and individual lifestyle factors and preferences.
- All individuals with epilepsy should have a **comprehensive care plan** that is **agreed** between the individuals, their family and/or carers and primary and secondary care providers.

Priorities in NICE cont'd:

- All individuals with epilepsy should have a **regular structured review at least yearly**.
- Individuals with epilepsy should be referred to a **tertiary service** as soon as possible **if their seizures are not controlled** and/or there is **uncertainty** about their **diagnosis**, or **treatment failure**.
- Individuals with epilepsy and their carers should **participate as partners in all decisions about their healthcare**.
- **Women of childbearing potential** should be fully informed about treatment choices and their **options during pregnancy and afterwards** to minimise risk to the child and mother.

West Berkshire Neurological Association

- **West Berkshire Neurological Alliance (WBNA)** is an umbrella organisation for local voluntary groups representing people affected by various neurological conditions.
- It also **represents and supports individuals living with neurological conditions who are not affiliated to any local support group.**
- Member organisations of the WBNA provide a range of non-statutory services on a voluntary basis, which are supplementary and complimentary to those provided by Newbury & Community Primary Care Trust (PCT).
- The WBNA is a registered charity (No. 1081021).

The West Berkshire Study

- In West Berkshire there was no local voluntary group working specifically with people living with epilepsy.
- There were **acknowledged gaps in current service provision** and a mutual desire by both Newbury and Community primary care trust and the voluntary sector to **identify these gaps** and to decide how they might be reduced with **equity, quality and effectiveness** in mind.
- It is against this background that **Newbury and Community primary care trust (Newbury PCT)** and **West Berkshire Neurological Alliance (WBNA)** decided to work in partnership to try to:
 - estimate the **burden of disease** in the area
 - and **understand how patients living with epilepsy think about current service provision and whether or not it meets their needs.**

Aims of the West Berkshire Study

- To determine the **prevalence** of people living with epilepsy in Newbury & Community PCT area in West Berkshire;
- **To understand the service needs** of those living with epilepsy and their carers/families who are resident in West Berkshire.

Methods

- **Survey of GP records** to get anonymised data on people living with epilepsy attending GP practices in West Berkshire;
- **Focus group** with local people from the West of Berkshire to get their views on living with epilepsy and the local services provided by the NHS.

Results

| GP Practice | Female | Male | Total |
|---------------------------|---------------|-------------|--------------|
| Falkland Surgery | 86 | 90 | 176 |
| Downland Practice | 47 | 33 | 80 |
| Chapel Row Surgery | 20 | 23 | 43 |
| Hungerford Surgery | 48 | 42 | 90 |
| Lambourne Surgery | 31 | 28 | 59 |
| Burdwood Practice | 59 | 54 | 113 |
| Thatcham Medical Centre | 141 | 131 | 272 |
| St. Mary's Road Surgery | 70 | 54 | 124 |
| Eastfield House Practice | 50 | 57 | 107 |
| Kintbury Medical Practice | 31 | 25 | 56 |
| Northcroft Surgery | 48 | 34 | 82 |
| PCT Total | 631 | 571 | 1202 |

Limitations on routinely collected data from general practice:

- Sex was the only demographic information collected was sex.
- We have no information on:
 - the **duration** of the diagnosis & **nature** of epilepsy;
 - the type of treatment prescribed for individual patients,
 - the nature of any **further investigations** performed (e.g. EEG, MRI brain etc.)
 - or whether or not they were **referred to a neurologist** and if so, how frequently.
- This data is therefore **extremely limited** and really gives us only **basic quantitative** data based on a diagnosis of epilepsy.

Above the national average?

- There are 107,722 patients registered with Newbury PCT GPs.
- Thus the overall prevalence of people living with epilepsy in the general practice population of West Berkshire is about 1.1% or 11.0 per 1000 population.
- This compares with the previously cited national prevalence of 5.0 per 1000 population.
- However:
 - We do not have an age breakdown for this population in West Berkshire and as prevalence rates are greater in older age groups, our data may be skewed if a larger number of older patients are included.
 - Also, the precision of the data used in the national study was greater and thus the prevalence rate could be expected to be lower.

Treatment of Epilepsy

- Nearly half (48.1%) of patients with a diagnosis of epilepsy attending GP practices in Newbury PCT are on **NO medication**;
- We have **no data on the number of patients attending neurologists locally or elsewhere** for management of their condition.
 - Patients are seen for secondary care at the Neurology department of the RBH in Reading.
 - No data is routinely available on the number of persons attending this service by postcode;
 - Extracting such information would require additional resources not available within the scope of this research project.

Focus Group Work

- Despite an active publicity campaign to recruit participants, **only 5 people** attended the focus group which took place on December 10th 2003 in a community centre in central Newbury.
- **Three men and two women** attended, with ages ranging from the mid-20s to over 70 years.
- All have lived with epilepsy for many years and had different variations of the condition.
- Due to the small number of participants, more detailed data on personal histories will not be presented in order to protect confidentiality of participants.
- **It is also impossible to say how representative their views and experiences are of all people living with epilepsy in the area.**

Key themes emerging from focus group work

- All reported **experiences of stigma** and a lack of understanding from society in general, workplace colleagues, employers and also GPs/healthcare professionals.
- Participants described often a **long time** passing before the **formal diagnosis of epilepsy** was made;
- Patients also described negative experiences during which, under questioning by doctors about the potential causes of their seizures, **they were asked about drug or alcohol misuse**;
- Participants described **how friends and relatives** were often the **first people to notice** that they had signs or symptoms of epilepsy;
- Participants described **protracted experiences with therapeutic interventions** and a range of negative experiences **before their epilepsy was manageable**;

Key themes cont'd:

- Some participants described experiences of periods of stability on particular drug therapy coming abruptly to an end with resumption of seizure activity- this can have **significant deleterious effects on social functioning, employment and relationships**;
- Participants described significant **negative effects of medication** on them, especially in relation to feeling tired, drowsy and depressed;
- The most vociferous complaint made concerned **lack of knowledge by GPs and other healthcare professionals**, including dentists, about epilepsy and its management, especially in relation to **drug therapy and drug interactions** with anti-epileptic medications.

Positive aspects from focus group

- All participants greatly valued the role of **consultant neurologists** in their care and were confident that they received excellent care from them;
- **Community pharmacists** were universally praised, especially in relation to their vigilance regarding potential drug interactions with other prescribed medications, and also with regard to explaining certain side effects from prescribed anticonvulsants.
- Participants acknowledged the need for **GPs to manage their general health**;
- The participants recognised the need for support from **fellow persons living with epilepsy** and recommended the foundation of a support group within **West Berkshire**.

Conclusions from study

- Over 1200 people registered with practices in West Berkshire live with epilepsy, **over 1 % of the total population of people registered with local GPs.**
- The **needs of this group of vulnerable people are extremely varied**, just as epilepsy is not a single discrete entity but has a range of manifestations.
- Old and young, male and female, the relatively healthy and the generally infirm are all represented in this patient group.
- There is **no 'one size fits all' response** to the health service needs of such a diverse group.
- This has been explicitly recognised in the recently released NICE guidelines.

Role of the GP

- GPs are **essential** to the management of any long term medical condition;
- They have a key role in **structured reviews** of the care of their patients living with epilepsy;
- GPs and other healthcare professionals may **not** have **specific expertise** in managing epilepsy and therefore may not appreciate the potential for serious drug interactions with co-administered medications and/or the range or severity of side effects of prescribed medications.
- **There is a clear training need identified here for all members of the primary care team.**

Role of the Neurologist

- Both NICE and local focus groups agree on the **central role of the consultant neurologist in managing patients**;
- It is essential that patients are seen for diagnosis and management **early and regularly**;
- Access to neurologists difficult due to current **under-staffing and lack of resources to meet need**;
- Gap could be filled by increasing the role of **Specialist Nurses** but they can only complement, not supplant, the role of the consultant.
- People living in **remote and rural areas** have particular problems in accessing specialist care.

Role of the Pharmacist

- The community pharmacist has a **key role** to play in managing patients living with epilepsy;
- Often sees patient **more frequently** than other clinical specialists/GP;
- Need to exploit this opportunity to add value to the care of the patient, especially in the area of advice re: medications, **side-effects and drug interactions**.
- Need to provide **more suitable surroundings** for consultations to take place than shop floor, however.

Role of the Patient

- Patients and their families/ carers need to be empowered to take a proactive role in designing their own care plan;
- Role for support groups is obvious:
 - peer support/education;
 - act as advocates for their fellows;
 - Work with local NHS bodies to help improve services;
 - Expert patient programmes.

Where to from here?

- Within PCTs and Acute Trusts, programmes of review and reform of services are currently underway following a directive from the Chief Medical Officer;
- Voluntary organisations and community groups should seek to actively engage with this programme through the **Expert Patient Programmes** and the **Patient Advice and Liaison Service (PALS) Officers** in their local PCTs.

Thank You for your Attention.

Any Comments or Questions