

Epilepsy: Factsheet

Tower Hamlets Joint Strategic Needs Assessment 2010-2011

Executive Summary

Epilepsy is the most common chronic disabling neurological condition in the UK and is a symptom of different neurological disorders rather than a single disease entity. It is characterized by seizures and can have many causes. There is NICE guidance on the diagnosis and management of the epilepsies in adults and children in primary and secondary care. The main treatment modality is anti-epileptic drugs (AEDs).

The crude prevalence rates for epilepsy in Tower Hamlets is 7.7 per 1,000, which is comparable to neighbouring boroughs, Newham (7.9 per 1,000) and City and Hackney (7.1 per 1,000), and England (7.7 per 1,000). There is a significantly lower reported prevalence rate of epilepsy among the local South Asian population (6.6 per 1000). This ethnic difference in prevalence has also been noted in other parts of the UK.

Primary care data shows that the proportion of people with epilepsy who have been seizure free in the previous 12 months is lower than national average (67.7% compared to 74.4% nationally). Admission rates are also 2 times higher than the national average. The excess in admissions accounts for at least £330,000 of additional health care costs. This suggests that enhanced care in the community may help to reduce burden on secondary care services, and reduce costs overall.

Tower Hamlets has specialist adult and paediatric epilepsy services in secondary care at the Royal London Hospital. From November 2010 to July 2011 the adult service will lose 2 Consultants and 1 Nurse Specialist.

Data is lacking on service usage, impact and on service users views. Four gaps have been identified in the service by local experts: epilepsy community clinics, a combined Learning Disability and children's services clinic, an expert patient programme, and a transition service for those moving from children's to adult's services.

Recommendations

1. Secondary care to break down outpatient appointments by diagnosis of users.
2. To carry out an evaluation of the community service, focusing on:
 - a. The reasons for the low rates of control and high secondary care attendance
 - b. The impact of the service on users
 - c. Service user views
3. To engage stakeholders in considering four gaps in the current services:
 - a. A network of community epilepsy clinics
 - b. A combined Learning Disability Clinic within the children's services
 - c. An expert patient programme
 - d. A transition service for those moving from children's to adult's services
4. To investigate local cultural barriers to epilepsy diagnosis and management.

1. What is Epilepsy?

Epilepsy is the most common chronic disabling neurological condition in the UK. It is characterised by recurrent seizures. Epileptic seizures are the clinical manifestation of abnormal, excessive or synchronous neuronal activity in the brain. Epilepsy can have many causes and should be seen as a symptom of different neurological disorders, rather than a single disease entity.

There is no identifiable aetiology for epilepsy in 62% of cases¹. Vascular disease and tumours are the cause in 15% and 6% of cases respectively. This means that for a large proportion of patients, particularly younger patients, there are no primary prevention measures. Therefore, the focus of management for these patients is secondary prevention of further seizures. However, among the older population 49% are due to vascular disease and 11% to tumours suggesting that primary prevention in the form of reducing cardiovascular disease and cancer risk factors could help to reduce the burden of disease in the elderly².

Epilepsy is associated with learning disabilities (LD). Community studies have indicated prevalence rates ranging from 6% amongst children with mild LD (IQ, 50–70) to 24% in severe LD (IQ, <50) and 50% in those with profound LD (IQ, <20). A reasonable estimate of the prevalence of epilepsy in patients with moderate to severe LDs probably ranges between 1 in 4 and 1 in 5 such patients³.

The standardised mortality rate for patients with epilepsy has been found to be between 2.5 and 3.0 times that of the general population⁴.

Most people with epilepsy lead normal lives. Patients can therefore feel that they do not need to attend clinical appointments or reviews, nor feel the need to be compliant with their medication. This can lead to poor control of seizures. In addition to the adverse effects of the drug therapies, other factors which contribute to morbidity are the effects and unpredictable nature of seizures, their underlying causes, and social exclusion and stigmatisation. Problems are commonly encountered in education, employment, driving, personal development, psychiatric and psychological aspects (mood disorders, anxiety disorders and psychosis) and social and personal relationships⁵. Children may have attention difficulties, learning difficulties or cerebral palsy⁶.

2. What is the local picture?

There are 1,965 people recorded with epilepsy on GP practice registers⁷. The crude prevalence rate for epilepsy in Tower Hamlets is 7.7 per 1,000, comparable to neighbouring boroughs, Newham (7.9 per 1,000) and City and Hackney (7.1 per 1,000), and England (7.7 per 1,000)⁸.

There is a significantly lower reported prevalence rate of epilepsy among the local South Asian population. Amongst people over 18 this was 6.6 per 1000 compared to 13.6 per 1000 for the White population⁹. This has been reported previously in the literature, with a study of Bradford also showing a lower prevalence of epilepsy in the South Asian populations¹⁰. Research is needed into this difference, with a focusing on cultural attitudes around epilepsy in the South Asian population.

¹ Sander, J.W., et al, *National General Practice Study of Epilepsy*, 1990, Lancet, Vol. 336, pp.1267-71

² Ibid

³ Lhatoo, SD and Sander, JWAS, *The Epidemiology of Epilepsy and Learning Disability*, 2001, *Epilepsia*, Vol. 42, pp. 1528-1157

⁴ *Prognosis of epilepsy: a review and further analysis of the first nine years of the British National General Practice Study of Epilepsy, a prospective population-based study*. Cockerell, OC, et al. 1, 1997, *Epilepsia*, Vol. 38, pp. 31-46.

⁵ Department of Health, *Clinical Standards Advisory Group. Services for Patients with Epilepsy*, 2000, London

⁶ Beckung, E and Uvebrunt, P., *Impairments, disabilities and handicaps in children and adolescents with epilepsy*, 1997, *Acta Paediatr*, pp.254-60

⁷ CEG 2010

⁸ CEG 2010

⁹ CEG 2010

¹⁰ Wright et al, *A population-based study of the prevalence, clinical characteristics and effect of ethnicity in epilepsy*, *Seizure: European Journal of Epilepsy*, Vol.9, Issue 5, 2000

One study has found that epilepsy prevalence is 25% higher in the most socially deprived areas¹¹. Given that Tower Hamlets is one of the most socially deprived boroughs in the country, it may be that the normal prevalence of epilepsy found in the borough represents under-diagnosis or the balancing out of ethnic and deprivation factors.

In terms of morbidity very few patients with epilepsy are housebound. However 7% of people with epilepsy in Tower Hamlets also have a learning disability which will affect their case management¹². Amongst people with epilepsy in Tower Hamlets, there is a very low yearly mortality rate, and it is comparable to the rate in City and Hackney and Newham¹³.

Fourteen per cent of people with epilepsy require an interpreter, with a greater need for interpreters for people aged under 18 years, reflecting the larger proportion of people from Bangladesh in this age group¹⁴.

3. What are the effective interventions?

NICE guidance recommends (evidence grade in brackets from A – highest to E – lowest):¹⁵

- All patients with suspected seizures should be seen by an epilepsy specialist within 2 weeks (evidence level A). The diagnosis of epilepsy should be made by a specialist with access to investigations and should determine the seizure type, epilepsy syndrome, aetiology and co-morbidities (evidence level C).
- The main treatment option for epilepsy is antiepileptic drugs (AEDs). These are effective and are generally recommended after a second epileptic seizure (evidence level A). Unfortunately, AEDs have many adverse effects which can increase the burden of co-morbidity in patients and lead to non-compliance. Psychological interventions may be used as an addition to AED to improve quality of life in some individuals with refractory epilepsy (evidence level A). Surgery has a small but increasing and expensive role, particularly in complex, refractory epilepsy. For a subset of patients it is the only treatment that offers the possibility of a cure.
- People with epilepsy should have a comprehensive care plan that includes medical as well as lifestyle issues, which is agreed between the patient, carers and primary and secondary care providers. Detailed information on how to recognise a seizure, first aid and the importance of reporting further attacks should be provided to the patient, and their carers if appropriate. Information needs to be provided around careers, driving, insurance, social security, welfare benefits, sudden death, recreational drugs and alcohol, sleep deprivation, sexual activity and the importance of adherence to medication regimes.
- All patients should have access to Epilepsy Nurse Specialists (ESNs) and have regular annual structured reviews by a specialist or generalist depending on their control of their epilepsy (evidence level D).

NICE guidelines for Groups requiring special considerations:

Children:

Management of epilepsy may be best achieved through active child-centred training models (evidence level A).

¹¹ Gaitatzis, A., Majeed, A., Purcell, B., *Epilepsy prevalence and prescribing*, 2002, Health Statistics Quarterly, pp. 23-31

¹² CEG 2010

¹³ NHS Information Centre's Compendium of Clinical and Health Indicators

¹⁴ CEG 2010

¹⁵ (NICE) National Institute for Clinical Excellence, *The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care*, London, 2004

Transition support is essential from paediatric to adult services. Before transition to adult services, the patient should have a review of diagnosis and management, and put in touch with local support services (evidence level D).

Women:

Antiepileptic drugs (AEDs) have interactions with oral contraception, as well as adverse effects on the fetus (teratogenicity) (evidence level A in some drugs). Therefore, women of child-bearing age should be counselled about the potential reduced efficacy of oral contraceptives, and should be advised about other contraceptive options (evidence level A). They should also be counselled about conception, pregnancy, caring for children and breastfeeding, and menopause (evidence level C).

Patients with Learning Disabilities (LD):

Management for patients with LD should be undertaken in a multidisciplinary team, ideally with a specialist in LD. Correct diagnosis is more difficult in those with LD (evidence level C). Also, mortality is higher in those with epilepsy and learning disabilities. All such individuals should have a risk assessment carried out (evidence level B). Adverse effects of AEDs should be closely monitored.

Patients from ethnic minorities:

Patients from ethnic minorities face particular challenges with epilepsy. Language barriers could lead to misdiagnosis and difficulties accessing appropriate care. An interpreter with both cultural and medical knowledge is needed to overcome these difficulties (evidence level D). Written information should be available in the patient's own language (evidence level D).

4. What are we doing locally to address this issue?

- In primary care we do not currently have a GP with specialist interest in epilepsy or community held clinics.
- In secondary care, there are 2 Consultant Paediatric Neurologists at the Royal London Hospital who manage the referrals for East London children with epilepsy. There is a dedicated children's Epilepsy Specialist Nurse. They generally see patients up to 18 years of age, sometimes above if they remain in full-time special needs education. The service does not see all patients with epilepsy as some children are managed by general paediatricians.
- The service has expressed concerns regarding managing the transition between child and adult services.
- In adult services (aged 16+) in autumn 2010 there was a full multi-disciplinary team including 3 Epilepsy Specialist Nurses, 2 Consultant Neurologists and 1 Consultant Neurophysiologist. However, by July 2011 due to staffing changes there will be 1.4 (WTE - whole time equivalent) Epilepsy Specialist Nurses and 1 Consultant Neurologist working 0.4 WTE. A specialist Learning Disability Clinic is jointly run by an Epilepsy Clinical Nurse Specialist and a Learning Disability Epilepsy Liaison Nurse to address their complex health and social care needs. This is not currently replicated in children's services. There is also a specialist Women's Clinic which is linked to a High Risk Antenatal Clinic, with midwives ensuring that all pregnant patients with epilepsy are reviewed.
- In addition, an Outreach Clinic is run alongside a GP practice in Plaistow where they review patient's management and advise the GP on further management and discuss psychosocial issues. There are currently no other community clinics.
- The Epilepsy Nursing service also provides a telephone helpline service between the hours of 9am -5pm.

A Bengali Health advocate is available at the Epilepsy Nursing Service.

- The National Society for Epilepsy and Epilepsy Action provide support for East London patients and carers.
- An expert patient programme is not currently available in the area.

5. What evidence is there that we are making a difference?

There are 1,965 people with epilepsy under the care of GP's¹⁶. Analysis of QOF data shows that Tower Hamlets has a significantly lower percentage of patients (aged 18 and over) with epilepsy and on anti-epileptic drugs who have been seizure free for the last 12 months recorded in the last 15 months (67.7%) compared to Newham (69%), City and Hackney (68.2%), London (72.3%), whole of England (74.4%)¹⁷.

In 2008/9 the Epilepsy Specialist Nurses reviewed 649 patients in Outpatients and 928 patients on the wards and in A&E. This includes patients from outside Tower Hamlets. The number of patients seen by consultants in outpatient clinics is not available since the diagnosis of each outpatient review is not recorded.

There were 520 epilepsy-related admissions in 2009/10 which equates to an average of 1 epilepsy-related admission per year for every 3.9 patients in Tower Hamlets¹⁸. This is much higher than the national figure of 1 admission for every 8.4 patients. This 2-fold increase in admissions in Tower Hamlets suggests low levels of control in the community. It also reflects the challenges facing epilepsy services in more deprived areas. Epilepsy admissions tend to be emergency admissions, and studies have found that emergency admissions tend to be in areas of socio-economic deprivation¹⁹.

Admissions related to epilepsy cost an estimated £606,000 in 2009/10¹⁸. If the admissions rate for epilepsy in Tower Hamlets could be brought down to the national average, the borough would save £332,000 per year.

A&E attendances and hospital admissions reflect the ethnic and age breakdown of the wider Tower Hamlets population. The highest number of A&E attendances and hospital admissions are from the Bangladeshi population in the under 18 age group, and from the White population in the 18 years and over group.

6. What is the perspective of the public on services?

This has not been ascertained.

7. What more do we need to know?

1. The reason for the high admission rates amongst the Tower Hamlets population with epilepsy.
2. We don't know the impact of our services on the quality of life of its users.
3. The diagnosis of outpatient neurology appointments and therefore the accessibility and usage of these services by people with epilepsy.
4. The data that does exist is not disaggregated by all social groups (e.g. deprivation, gender, religion, sexuality). This prevents fuller assessment of how well our service meets their different needs.
5. The public's perspective on epilepsy and the services offered by NHS Tower Hamlets.
6. An understanding of the ethnic differences in epilepsy prevalence.

¹⁶ CEG 2010

¹⁷ CEG 2010

¹⁸ SUS data 2010

¹⁹ Majeed, A., et al, *Cross sectional study of primary care groups in London: association of measures of socioeconomic and health status with hospital admission rates*, British Medical journal, 2000, pp. 1057-60

8. What are the priorities for improvement over the next 5 years?

What are the key insights?

- Tower Hamlets has a lower rate of controlled epilepsy than the regional and national average (67.7% seizure free in past 15 months compared to 72.3% London and 74.4% England).
- Hospital admissions for epilepsy in Tower Hamlets are around 2 times the national average, suggesting control of epilepsy is low in the community.
- The additional cost associated with the excess admissions is at least £330,000 per annum.
- Data is lacking on service usage, impact and on service users views.
- Four gaps have been identified in the service by local experts: community clinics, a combined Learning Disability and children’s services clinic, an expert patient programme, and a transition service for those moving from children’s to adult’s services.

What are the Key Recommendations?

1. Secondary care to break down outpatient appointments by diagnosis of users.
2. To carry out an evaluation of the community service, focusing on:
 - a. The reasons for the low rates of control and high secondary care attendance
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4. To investigate local cultural barriers to epilepsy diagnosis and management.

9. Key Contacts & Links to Further Information

- General queries on JSNA Factsheets email: JSNA@towerhamlets.gov.uk
- Factsheet author: Natalia Clifford, Public Health Strategist, Natalia.clifford@thpct.nhs.uk
- NICE guidelines for epilepsy: <http://guidance.nice.org.uk/CG20/NICEGuidance/pdf/English>
- Epilepsy Action: www.epilepsy.org.uk

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Date signed off by Senior JSNA Leads:	April 2011	Signed off by (Public Health Lead):	Dr Somen Banerjee	Date signed off by Strategic Group:	n/a	Sign off by Strategic Group:	
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