

Parkinson's Disease: Factsheet

Tower Hamlets Joint Strategic Needs Assessment 2010-2011

Executive Summary

Parkinson's disease (PD) is a progressive neuro-degenerative condition that affects a person's ability to control their movements.

The prevalence of Parkinson's Disease has been estimated nationally at 100-180 per 100,000¹. GP records show that a total of 236 people in Tower Hamlets have Parkinson's Disease. Therefore the prevalence is 95 per 100,000². There is a wide ethnic variation in prevalence which can be explained by distribution of age-ranges within the different ethnicities of Tower Hamlets. Services in Tower Hamlets are comprehensive, individualised and evidence-based, following the pathways suggested by the National Institute of Health and Clinical Excellence (NICE)³. Despite this, 33% appear not to be receiving the specialist care that is recommended by NICE. Usage of multi-disciplinary services also appears to be low. Lee-Silverman Voice Therapy (LSVT) is not available for Tower Hamlets patients. There is a high level of satisfaction with the PD nursing service. Data on the impact of the service on users is not routinely collected.

Recommendations

1. To ensure that the remaining 33% of people living with PD patients have the opportunity to see:
 - a. A specialist clinician.
 - b. A PD Nurse or equivalent.
2. To promote the use of the additional community services.
3. To provide access to LSVT for Tower Hamlets patients.
4. To evaluate the Tower Hamlet's service, focusing on quality of life impact.
5. To carry out an equality impact assessment of the PD service.
6. To encourage all multi-disciplinary and social services to record the diagnosis of service users and relevant equality information such as age, gender, ethnicity, religion, sexuality, etc.

1. What is Parkinson's Disease?

Parkinson's disease (PD) is defined as a progressive neuro-degenerative condition¹. The underlying cause is unknown, but it is characterised by a progressive loss of dopamine-containing cells in the substantia nigra, an essential movement area of the brain. The person's movement therefore becomes more and more affected as the condition progresses.

The characteristic symptoms are: loss of postural reflexes (control of changes to the position of the upper body), hypokinesia (reduced movement), bradykinesia (slowness of movement), rigidity (muscle tension) and a 4-6Hz resting tremor which collectively are labelled "Parkinsonism". Though Parkinson's disease is the most common cause of Parkinsonism, it can also be induced by drugs, cerebrovascular disease, forms of dementia, multi-system atrophy and progressive supranuclear palsy¹.

¹ National Collaborating Centre for Chronic Conditions, Parkinson's disease: national clinical guideline for diagnosis and management in primary and secondary care, NICE, 2006

² CEG 2009

³ NICE, *Parkinson's disease: diagnosis and management in primary and secondary care*, CG35, 2006

Although PD is initially a movement disorder, other impairments frequently develop, including psychiatric problems such as depression, insomnia and dementia. The condition inevitably progresses to cause significant disability and handicap with impaired quality of life for the affected individual and their family and carers.

NICE estimates UK prevalence of PD at 100-180 per 100,000 and an annual incidence of 4–20 per 100,000¹. It is slightly more common in males and there is a significant rise in prevalence with age. There are no other convincing risk factors for PD. The total annual cost of care including NHS, social services and private expenditure per patient in the UK in 1998 was estimated at £5,993 of which direct NHS costs made up £2,298¹.

2. What is the local picture?

There are 236 people recorded on GP registers with Parkinson's Disease (PD) in Tower Hamlets, producing a prevalence of 95 per 100,000². This is slightly lower than the 100-180 per 100,000¹ estimated nationally. Although data limitations prevent direct comparison of local with national data, the difference could be attributable to the lower than average age of the Tower Hamlets population or a level of under-diagnosis. As the local population ages, it can be expected that the prevalence of PD will rise.

Primary care data showed significantly higher prevalence in the white population of Tower Hamlets compared to other ethnicities². The data are not split by age and ethnicity simultaneously so standardised rates cannot be reported. Higher prevalence is likely to be explained by the older age structure of the white Tower Hamlets populations.

Hospital admissions and deaths are commonly due to a Parkinson's Disease-related injury such as a fall, rather than the condition itself. This makes recorded admission rates and mortality rates unreliable. Secondary care data recorded 26 admissions for Parkinson's Disease in 2009/10⁴.

Social care data does not include specific information about particular health conditions but many people with Parkinson's will be using social care services for physical disabilities in Tower Hamlets.

3. What are the effective interventions?

PD is a progressive disease for which there is no known cure. As there are no definitive risk factors, primary prevention is not possible. Primary care should identify patients, but formal diagnosis and regular review should be carried out by a specialist³. Treatment options in PD are limited to symptom control for Parkinsonism and associated disorders, and adaptations to the activities of daily living. Drug treatments, although initially effective for most, eventually fail after several years.

NICE recommends the following interventions (Evidence level A is the highest)³:

- Pharmacological interventions for symptom control (for parkinsonism, mental health problems, dementia etc.) – evidence ranges from A-D according to drug.
- Surgery (deep brain stimulation) for a small subset of patients – evidence level D.
- Parkinson's Disease Nurse Specialist – evidence level C.
- Physiotherapy – evidence level B.

⁴ SUS 2010

- Occupational therapy – evidence level D.
- Speech and language therapy (Lee Silverman Voice therapy) - evidence level B.
- Palliative care - evidence level D.

Social Care

People living with Parkinson’s and their carers can also benefit from social care input as part of an integrated-care approach. Social workers may facilitate care coordination and provide linkage to physical or psychological care across a range of health care settings. People may experience anxiety or depression as well as physical limitations, and may therefore be eligible (under FACS criteria) for social care. People may also benefit from preventative services (some of which may be commissioned by social care) to address challenges relating to life disruption, social isolation and sometimes living with uncertainty around prognosis. Social care, working in partnership with health services, may also be appropriate to address any palliative care needs.

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

Patients are mostly identified in General Practice and referred to secondary care as recommended by NICE. There are a few patients who are cared for exclusively by their GP. As per NICE guidance, the Parkinson’s Disease Nurse (PDN) is encouraging GPs to refer all PD patients to secondary care.

There is one lead Consultant who takes on the majority of PD cases at BLT. He works closely with the PDN who reviews new cases within 4 weeks. Depending if there are any complications they will make a decision as to how often the patient needs to be seen and if the patient needs to be referred to a member of the multi-disciplinary team. The PDN looked after approximately 130-150 Tower Hamlet residents living with Parkinson’s Disease in 2009/10, which has risen slightly to 158 in 2010/11. The PDN also sees people from other boroughs. This increased workload has reduced the PDN’s ability to provide regular specialized care to housebound patients.

Additional services provided cover all the main NICE recommendations and are listed below with 2009/10 usage numbers provided. This appears lower than might be expected. Of note, due to a lack of staffing, the evidence-based Lee-Silverman Voice Therapy is not provided. Support for patients and carers is also available from the Parkinson’s Disease Society’s East London branch⁵ and the Carer’s Centre Tower Hamlets⁶.

Service	Remit	Numbers of people with Parkinson’s (2009/10)
Disability Options Team (DOT)	<p>2010: A multi-disciplinary team, incorporating physiotherapy, occupational therapy, speech and language therapy, psychology and social services, along with a case manager to co-ordinate the needs of patients with a range of medical conditions, including those with Parkinson’s Disease. Open access - patients can self-refer or they can be referred by any healthcare contact they have. DOT is part of the Community Rehabilitation Service.</p> <p>2011: There is no longer a case-manager.</p>	<p>12 referrals to DOT Physiotherapy and 11 to DOT occupational therapy in 2009/10. Other services do not record condition specific data.</p>

⁵ <http://www.parkinsons.org.uk/>

⁶ <http://www.carers.org/>

Falls Team	Falls primary and secondary prevention	4 patients - 3 of these were domiciliary, 1 was in a group setting.
Mile End Inpatient Rehabilitation (Bancroft Ward)	Inpatient Rehabilitation	9 patients
Ability Bow	Specialist Exercise Referral Service for people with disabilities and long-term health conditions	4 patients
BLT Inpatient/Outpatient Visits	Secondary care admissions	26 inpatient admissions by 20 Tower Hamlets PD patients
Social Care	A large proportion of service users with physical disabilities use home care or equipment and adaptations, with substantial numbers receiving meals, attending day services or receiving direct payments and personal budgets. In the future, increased numbers of these service users should be receiving personal budgets, resulting in a wider range of services individually commissioned by the service user to meet their support needs.	No condition specific data is available

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

The main aim of interventions is to ensure that patients maintain as high a quality of life as possible for as long as possible. There is strong national evidence to support most of the local interventions³, however local impact data is not available in this respect.

Tower Hamlets is working hard to deliver an individually tailored service, which is facilitated by the multiple pathways for patients to access the specialist input they need. This has increased the number of residents that are now under the care of the PDN to 158, but despite this, 33% are still not accessing specialist care. This lack of a central point of care used by everyone may explain the low apparent usage of the other additional services.

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

In 2008 a questionnaire was given to 80 people seeing the Parkinson's Disease nurse and 34 responded⁷. The vast majority of the patients were very satisfied (55.9%) or satisfied (38.2%) with the nurse. 76.5% felt "definitely" well looked after by the Parkinson's nurse, and 91.2% said they had about the right amount of time with them. Communication appears to have been viewed positively. 73.5% said their condition was explained to them and 100% said they had their medications explained to them. 94.1% stated that had a contact number for their Parkinson's Nurse in case of any problems. The wider public's view was not sought.

⁷ Internal Barts and the London survey of people with Parkinson's Disease, 2008.

7. What more do we need to know?

1. Most importantly, we don't know the impact of our services on the quality of life of its users.
2. Many health and social care services do not record the diagnosis of the patients they see. This means we are unable to assess service usage for people with PD in Tower Hamlets.
3. Usage of the rehabilitation services appears low, and the reasons for this and the underlying need for the service amongst local people with PD are not known.
4. The data that does exist is not disaggregated by different social groups (e.g. deprivation, ethnicity, age, gender, religion, sexuality). This prevents an equality assessment of how well our service meets their different needs.
5. There is a need to gather more detailed views of patients and the wider public in the service, and engage them in service development.

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

What are the key insights?

- The service is comprehensive, individualised and evidence-based.
- A slight increase in service users referred to specialist PD nursing care has occurred since 2009/10.
- 33% of people diagnosed with Parkinson's Disease (PD) are not under specialist secondary care services.
- There is relatively low utilisation of services provided by the community teams.
- The speech and language therapy services do not currently have the resources or training to deliver Lee-Silverman Voice Therapy.
- The PD Nursing service has high levels of satisfaction.
- Data is lacking on the full extent of the service's usage and impact.

What are the Key Recommendations?

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9. Key Contacts & Links to Further Information

NICE guidelines for Parkinson's: <http://www.nice.org.uk/CG035>

Parkinsons UK: www.parkinsons.org.uk

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