

Fair Care for Parkinson's

Parliamentary briefing – July 2009



The problem

In many parts of the country, people affected by Parkinson's are not receiving the key services that they need^{1,2}. The **Fair Care for Parkinson's** campaign calls for action to tackle the inequalities in access to health and social care.

The solutions

Governments, health and social care regulators, providers and commissioners must act now so that people with Parkinson's can get consistent, appropriate services, wherever they live. The Parkinson's Disease Society (PDS) is calling for:

- effective monitoring of Parkinson's services for compliance with national guidelines and standards
- strong leadership at national and local level, to ensure the needs of people with Parkinson's are met
- a review of the health and social care workforce so that sufficient skilled staff are in place to deliver appropriate care
- full implementation of the recommendations contained in the report of the All Party Parliamentary Group (APPG) for Parkinson's Disease inquiry, *Please mind the gap: Parkinson's disease services today*

How can parliamentarians help?

- Write to the Prime Minister and the Secretary of State for Health highlighting the issues raised by the Fair Care for Parkinson's campaign.
- Table parliamentary questions and adjournment debates.

MPs can also take additional action:

- Contact local NHS and social service providers and commissioners in your constituency to highlight the above issues.
- Sign Early Day Motion 1821.
- Find out about the experiences of people with Parkinson's in your constituency. Contact the PDS Policy and Campaigns team for further information about PDS branches in local constituencies.



The evidence

PDS research³ has revealed significant gaps in access to services in different parts of the UK.

- More than a quarter of people with Parkinson's have never talked to a Parkinson's Disease Nurse Specialist (PDNS) and four out of ten people with the condition have not spoken to one in the last 12 months.
- Most carers are still unaware of their rights to a carers' assessment; caring has had a detrimental impact on the health of over half of survey respondents.
- Although more than four out of five carers indicated that they needed a break from caring, just under half had actually managed to have one.
- Most people with Parkinson's are still not assessed for or are receiving therapies to help them manage their condition.
- Almost one in five of those who reported having personal care needs, were not receiving this support.
- More than one in four of those who reported needing home help have never received this.
- Only 19% of people with Parkinson's felt that doctors, nurses and other hospital staff understood the condition well.

The APPG Inquiry report⁴ also highlighted specific barriers to people affected by Parkinson's accessing services:

- Little impetus and monitoring to drive implementation of the NICE Guideline and other national standards.
- Policy making without due consideration of the impact on long-term degenerative conditions such as Parkinson's. Specifically Government policies such as Payment by Results⁵ and the 18 week referral to treatment target⁶ have compounded difficulties for people with Parkinson's when accessing specialist review appointments and therapy services⁷.
- Lack of leadership for neurological services at national and local level

What good services look like

Clear, evidence-based guidelines and standards exist for Parkinson's services^{8,9}.

These include:

- access to a specialist for diagnosis and ongoing review
- access to a Parkinson's Disease Nurse Specialist (PDNS)
- access to therapy services (such as physiotherapists, speech and language therapists, and occupational therapists)
- access to palliative care services from the point of diagnosis
- access to appropriate social care services including domiciliary care
- support for carers including respite breaks
- access to information about health and social care services to enable people to get the services they need

These services ~~cost~~ save money

Adequate access to key services for people affected by Parkinson's improves quality of life, clinical outcomes and ultimately results in cost benefits for the NHS and local authorities.

Below is just one example of how better Parkinson's services can save money.

Parkinson's Disease Nurse Specialists can help reduce costly hospital admissions and reduce length of hospital stays resulting in cost benefits to the NHS:

- Community-based services for people with Parkinson's, could save an estimated £56million for the NHS or 30% of the money spent on supporting people in care homes¹⁰.
- PDNSs care can reduce hospital admission for people with Parkinson's by 50%¹¹.
- Use of a PDNS potentially results in estimated savings of £6million¹².
- PDNSs are cost neutral to health services¹³.
- Local studies have demonstrated financial benefits at primary care trust (PCT) level:
 - A PDNS in Harlow showed that by preventing hospital admissions over a 12-month period in 2006, the local PCT saved £80,448.
 - A PDNS in Bristol saved £2,310 in 2005 by diverting 30 outpatient appointments away from the local neurology consultant. The PDNS additionally undertook 216 appointments in a nurse led clinic. There were ten averted hospital admissions which potentially saved the local NHS Trust £58,240.
 - Productivity was improved in Conwy and Denbighshire NHS Trust when, over a six-month period, a PDNS undertook 541 patient consultations in a nurse-led clinic, thus saving consultant appointments for other patients. This had an impact on waiting list targets and a cost saving of consultant time of £50,550.

1. *Life with Parkinson's – Room for Improvement*, Parkinson's Disease Society, April 2008. This contained results from the largest ever survey of people of Parkinson's and their carers in the UK (13,000 people)

2. *Please mind the gap: Parkinson's disease services today*, report of the Inquiry into access to health and social care services for people with Parkinson's disease and their carers (APPG for Parkinson's Disease, July 2009)

3. Ibid. 1

4. Ibid. 2

5. www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/NHSFinancialReforms/DH_900

6. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4134668

7. PDS scoping exercise to consider how the Society could best support appropriate therapy provision for people with Parkinson's (Autumn 2007)

8. Parkinson's disease – National Clinical Guideline for diagnosis and management in primary and secondary care, National Collaborating Centre for Chronic Conditions, Royal College of Physicians, 2006

9. *National Service Framework for Long Term Neurological Conditions*, Department of Health, 2005

10. Thomas S et al on behalf of the PDS UK Primary Care Task Force, *Moving and Shaping, A Guide to commissioning integrated services for people with Parkinson's disease*, Parkinson's Disease Society, 2006

11. Hospital inpatient and outpatient figures obtained from Hospital Episodic Statistics data (HES) showed 6,313 admissions for Parkinson's Disease in 2004/5. Cost data of £1,220 per admission (2006/7 Payment by Results tariff) would indicate a PDNS could reduce care for 3,157 patients (NICE Guideline, 2006)

12. Expert opinion suggests a PDNS could reduce outpatient care by 40% by taking over clinical monitoring and medication adjustment. Outpatient attendance for Parkinson's is estimated at 62,569 which is 14% neurology follow up (Reference costs 2005). Based on HES data (2004/5) Parkinson's disease represents 14% of all finished consultant episodes which has been used as the basis for estimating the proportion of outpatient attendance. Cost data of £103 per attendance obtained from the 2006/7 Payment by Results tariff (NICE Guideline, 2006).

13. Jarman B et al *Effects of community-based nurses specialising in Parkinson's disease on health outcome and costs*. *British Medical Journal* 324, 1072 2002

About Parkinson's disease

Parkinson's disease is a long-term, degenerative, fluctuating, neurological condition with no known cure. It can affect all activities of daily living including talking, sleeping, walking, swallowing and writing. It is estimated that 120,000 people in the UK have the condition. The average age of onset of Parkinson's is between 50 and 60 years of age, although one in seven will be diagnosed before the age of 50 and one in 20 will be diagnosed before the age of 40.

About the PDS

The Parkinson's Disease Society (PDS) has 30,000 members and over 300 local groups throughout the UK. It provides support and information to people with Parkinson's, their carers and families, and information and training to professionals to improve the quality of care. It is the leading voluntary funder of Parkinson's research.

Further information

For more information about the Fair Care for Parkinson's campaign, contacting local PDS branches, or briefings for parliamentary activities, please contact the PDS Policy and Campaigns team on: campaigns@parkinsons.org.uk

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