

Parkinson's Disease Society

Policy and Campaigns briefing

Autumn 2009

PDS calls for Fair Care for Parkinson's at Party Conferences



Following the successful launch of the Fair Care for Parkinson's campaign we're bringing Fair Care to the Conservative, Labour and Liberal Democrat Party Conferences, in an attempt to tackle the inequalities in access to health and social care faced by people with Parkinson's and their carers.

In partnership with the British Dental Association, the Association of British Healthcare Industries and Breakthrough Breast Cancer we will be running fringe events exploring how consistently high-quality care for all can be achieved in a political climate of increased localism.

The Fair Care for Parkinson's campaign highlights huge variations in access to health and social care services across the UK. Whether someone with Parkinson's has access to key services, such as specialist nursing, therapy provision and the full range of treatment options, simply depends on where they live.

The fringe events will consider how the Liberal Democrat, Labour and Conservative politicians in Westminster can ensure fair care for people with Parkinson's and other conditions if decisions about care and services are increasingly being made at local level.

From Whitehall to the town hall – no longer a national health service?

Liberal Democrat – Tuesday 22 September, 18:15 – 19:30, Tregonwell Room, Bournemouth International Centre

Labour – Tuesday 29 September, 18:00 – 19:30, Osborne Room, Hilton Metropole

Conservative – Tuesday 6 October, 17:45 – 19:00, Marquee 3, MICC

For further information contact Emily Cogbill at ecogbill@parkinsons.org.uk



The PDS is calling for:

- effective monitoring of Parkinson's services for compliance with national guidelines and standards
- strong leadership at a national and local level, to ensure the needs of people with Parkinson's are met
- a review of health and social care workforce so that sufficiently 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 you can help:

- Sign EDM 1821 to support the Fair Care campaign and the APPG's report recommendations.
- 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.
- Attend our Fringe event 'From Whitehall to the town hall – no longer a national health service?'

APPG Inquiry Report: *Please mind the gap: Parkinson's Disease services today*

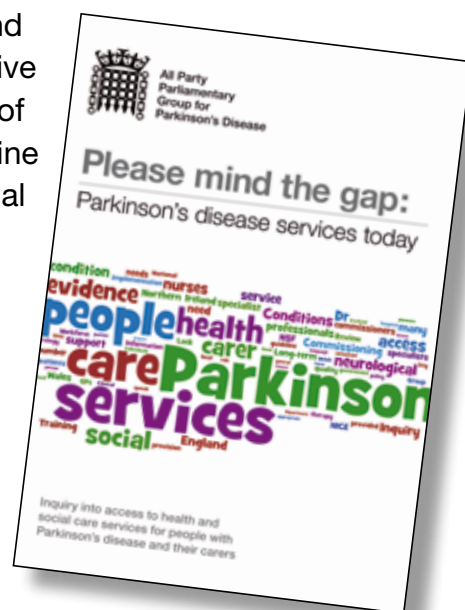


Baroness Gale, Chair of the APPG handing the inquiry report to Ann Keen MP, Under Secretary of State for Health Services

The All Party Parliamentary Group for Parkinson's Disease launched its Inquiry Report *Please mind the gap: Parkinson's Disease services today* at a Parliamentary reception in July 2009.

The Inquiry Report highlighted the following 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



- Lack of leadership for neurological services at national and local level

The report recommendations included the need for:

- improved leadership for Parkinson's and other neurological services at local and national level
- appropriate drivers to support implementation of national guidance for neurological conditions and strengthen service monitoring

- better commissioning and planning of services for people with Parkinson's through the provision of evidence and guidance
- strengthened workforce planning so that sufficiently skilled professionals are available to deliver high-quality Parkinson's care

It is hoped that the APPG Report will help engage key national and local decision makers in tackling the inequalities in access to services which the report highlighted, across England, Wales and Northern Ireland.

How you can help:

- Sign EDM 1821 to support the APPG's report recommendations.
- If you are a Parliamentarian, you can join the Parkinson's APPG and help to champion the needs of people with Parkinson's, their families and carers. Please contact Emily Cogbill on 020 7932 1362.

EDM 1821: Parkinson's Disease Inquiry Report

That this House welcomes the findings of the All Party Parliamentary Group for Parkinson's Disease Inquiry into health and social care, which concludes that there are systemic problems with access to key services for people with Parkinson's and their carers throughout England, Wales and Northern Ireland; endorses its recommendations, including that the Department of Health should hold a five-year review of progress towards implementation of the National Service Framework for Long-term (Neurological) Conditions; believes that there is a pressing need for stronger national leadership on neurological services in England, Wales and Northern Ireland; and further welcomes the newly launched Fair Care for Parkinson's campaign by the Parkinson's Disease Society, which aims to improve services for people affected by the condition.

Fair social care for Parkinson's

The Government has finally published the long-awaited Green Paper setting out its plans for the future of social care in England.

Reform to social care needs to happen. The social care system is already under immense strain and the recent APPG for Parkinson's Inquiry Report identified major inequalities in access to social care, with many

people with Parkinson's missing out on the care they need. Problems with accessing information about social care were also a major barrier for many people.

There is much to welcome in

the Green Paper, which sets out a vision for delivering care and support in the long term. The introduction of a National Care Service with a universal information system could provide a much-needed, long-term solution to these problems, very much in line with the problems identified in our Fair Care for Parkinson's campaign.

We particularly welcome the focus on preventative measures, many of which are cost effective. A national assessment process has the potential to address the inequalities that currently exist in social care support across the country. Everyone needs to know about the support available to them, and a universal information system has the potential to ensure that everybody knows where to go for help. We also welcome proposals for increased joined up working between health and social care, and other areas of support.

We look forward to the White Paper setting out details of how these initiatives will be taken forward and are keen to work with Government



and parliamentarians to ensure fair social care for all people with Parkinson's.

The end of disability benefits?

The most controversial aspect of the Green Paper is the Government's plans to abolish Attendance Allowance to help fund social care. The proposal has alarmed members of the PDS, 41% of whom receive Attendance Allowance. These concerns are shared by many disabled people and unless the Government is prepared to rethink its plans it risks undermining their plans for care reform.

The Green Paper admits that Attendance Allowance is a popular benefit that provides disabled people with the financial flexibility they need to meet the needs of their condition – in effect the perfect direct payment. Our Members' Survey identified a range of costs associated with Parkinson's, from domestic help and aids and adaptations, to heating and laundry costs, increased insurance premiums and mobility and transport costs. Though a National Care Service would meet some of these needs, it wouldn't meet all of them – leading our members to fear that they will lose out from the Government's planned reforms.

We are particularly concerned that civil servants have confirmed that money from scrapping

Attendance Allowance underpins all three models. There is a world of difference between replacing Attendance Allowance with a system that meets 100% of all care costs, and a system that pays between 25 and 30%.

In launching the Green Paper, Secretary of State for Health Andrew Burnham said: "To fund this new entitlement, we will consult on plans to bring other benefits, for example Attendance Allowance, into social care funding".

Yet despite Mr Burnham's assurances, people aren't being given the opportunity to discuss these important proposals. There are no consultation questions about Attendance Allowance in the Green Paper, and a recent presentation run by the Green Paper team as part of The Big Care Debate made no reference whatsoever to abolishing disability benefits.

The debate about how social care is funded in the future needs to happen, but it needs to be an honest and open discussion. A major change to the benefits system cannot be sneaked into a wider debate on social care.

We hope for a major rethink about these proposals when the White Paper is published – otherwise we will be placed in the unwelcome position of having to oppose the Government's plans for much needed reform.

Further information

If you would like more information about any of these issues or a briefing on your local area please email the Policy and Campaigns team on: campaigns@parkinsons.org.uk

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