

Parkinson's Disease Society

Policy and Campaigns briefing

Winter 2008

Minister welcomes APPG inquiry into access to services



Ann Keen MP; Parliamentary Under Secretary for Health Services speaking at the inquiry launch

The PDS is extremely concerned about inequalities in access to services for people affected by Parkinson's as highlighted by our biggest ever survey of people with the condition; *Life with Parkinson's: Room for Improvement*. We are therefore pleased that the All Party Parliamentary Group (APPG) for Parkinson's disease has launched an inquiry into inequalities in access to services at a reception jointly hosted by the PDS in the House of Commons on 19 November.

Speaking at the reception, Ann Keen MP (Parliamentary Under Secretary for Health Services) welcomed the initiative. The Minister went on to encourage participation in the inquiry through the submission of evidence and stressed this was a chance for stakeholders' views to be heard.

Attendees – of which there were approximately 45 Parliamentarians, over 70 people affected by Parkinson's and key policy stakeholders – also

heard speeches by Baroness Gale (Chair of APPG), Steve Ford (Chief Executive of the PDS) and Doug MacMahon (Consultant Physician) as well as two people with Parkinson's disease who described their personal experience of accessing services.

The inquiry will be investigating access to key health and social services for people with Parkinson's disease and their carers and hopes to engage key national and local decision makers in tackling inequalities in access to services across England, Wales and Northern Ireland.

The Call for Evidence has been published and can be found on the APPG's webpage www.parkinsons.org.uk/appg.

How you can help:

- MPs, Peers and organisations with an interest in this field are invited to submit written evidence.
- If you are an MP: find out what problems there are with accessing services in your constituency and encourage people with Parkinson's to submit evidence to the inquiry. This can be done by contacting PDS branches within your constituency (the PDS website, <http://www.parkinsons.org.uk/local-to-you/find-local-branches.aspx> provides information and contact details for local branches). The APPG has produced a form downloadable at www.parkinsons.org.uk/appg to assist people with Parkinson's in submitting evidence.
- If you are a Parliamentarian, you can join the Parkinson's APPG and help to champion the

needs of people with Parkinson's disease, their families and carers. Please contact Emily Cogbill on 020 7932 1362.

The Parkinson's Disease Society acts as Secretariat for the APPG for Parkinson's Disease.

PDS reaction to the Queen's Speech

Following the Queen's Speech on 3 December the Parkinson's Disease Society are looking ahead to the next year in Parliament and the key legislation that will affect people with Parkinson's and their carers. Most notable are the Welfare Reform Bill, the Single Equality Bill and the National Health Service Bill. The articles below cover these Bills, what the PDS is calling for, and how you as a Parliamentarian can help.

Welfare Reform Bill

The Welfare Reform Bill announced in the Queen's Speech offers an important opportunity to improve support for people with a disability or condition such as Parkinson's to remain in, or return to, work.

Our members' survey earlier this year showed that under a third of working people with Parkinson's are in employment, though many people would continue to work if the right support was in place.

The proposals in the *no one written off* Green Paper, if incorporated in the Bill, would do much to improve the support available to people with disability or illness to continue in, or return to, employment. However, we would like to see a stronger commitment to support disabled people to retain their existing jobs and measures to ensure that employers have better information and assistance to support people with Parkinson's and other disabilities to remain in work.

We are concerned about proposals in the Green Paper to reform Employment Support Allowance (ESA). Our members survey² identified that nearly half of all working age people with Parkinson's are on Incapacity Benefit (recently replaced by ESA). Some of the proposals in the Green Paper would create unnecessary problems for people with Parkinson's and their carers, in particular:

- plans for increased compulsion and threat of sanctions for those deemed capable of work –

given the poor understanding of the condition by professionals due to its complex and the fluctuating nature we are concerned that some people with Parkinson's could be put under inappropriate pressure to find work

- plans for all existing Incapacity Benefit claimants to undergo a new medical assessment, the Work Capability Assessment, between 2009 and 2013 – a large number of additional claimants undertaking the new assessment before it is properly reviewed is likely to lead to mistakes
- proposals to require carers on Income Support to claim Jobseekers Allowance instead.

We need your support to ensure that the legislation addresses these issues. We would like to see the Bill include:

- measures to monitor the number of people on ESA from the main impairment groups, including Parkinson's, particularly in relation to sanctions, appeals and numbers supported back to work
- mechanisms to ensure that any health professional making a decision about a complex disorder like PD has had training on this issue
- a stronger focus on employment retention
- a delay in rolling out Work Capability Assessment (WCA) to Incapacity Benefit claimants by at least a year so that the effectiveness of the WCA can be properly reviewed and problems ironed out
- measures to improve access to training opportunities for people with a disability or condition such as Parkinson's.

How you can help:

- The PDS will need your support to ensure that the Bill makes a positive difference to the lives of people with Parkinson's.
- If you would be interested in tabling amendments to the Bill or raising these concerns during key stages of the Bill's passage please contact Dave Clark on: 020 7963 9307 or email dclark@parkinsons.org.uk for further information.

¹ *Life with Parkinson's – Room for Improvement*, Parkinson's Disease Society, April 2008.

² *Life with Parkinson's – Room for Improvement*, op cit.

Single Equality Bill

As expected, the Queen's Speech contained details of a Single Equality Bill. This has been welcomed by the Parkinson's Disease Society as a positive step building on existing anti-discrimination legislation. As a degenerative, long-term neurological condition, Parkinson's disease can affect all aspects of daily living. People with Parkinson's require appropriate mechanisms to be in place to ensure they are able to access a range of goods and services or remain in employment. The PDS knows from its recent members' survey that two out of five people with Parkinson's find it difficult to access key public transport services and 17% of people with Parkinson's gave up work because of the condition. Difficulties such as these can have a significant impact on people's independence, financial situation and quality of life, and Government policy to tackle this discrimination can do much to improve these situations.

The provisions contained in the Bill include:

- providing a framework for all existing equalities legislation
- ending discrimination on the grounds of age in the provision of goods and services, including areas such as healthcare and insurance
- using public sector procurement to boost equality in the private sector
- enabling tribunals to recommend changes in entire workplaces – not just benefits to one individual.

The PDS is calling for:

- ensuring existing Disability Equality Duties are not watered down
- ensuring people 'perceived' as having a disability or 'associated' with a disabled person (such as carers) get appropriate protection via the law
- improvements in mechanisms to ensure the spirit and letter of the law is adhered to, for instance in cases where discrimination has taken place in an employment setting

- ensuring a simplified legal system for people suffering from discrimination to have their claims heard.

How you can help:

- The PDS will be looking to engage MPs and Peers during the passage of the Bill through Parliament. If you are interested in supporting people with Parkinson's on this issue, please get in touch.
- For further information, please contact Anjuli Veall: 020 7932 1323; aveall@parkinsons.org.uk

National Health Service Reform Bill

The PDS welcome the proposals in the Bill to place a duty on the NHS to take account of the core principles set out in the NHS constitution. We believe this legislation must, in a real and meaningful way, ensure the NHS is more responsive to the local communities and give greater scope for patients to shape the care they receive.

We are encouraged to see the Government's commitment to improving quality across the NHS. Parkinson's is a complex condition requiring many interventions and treatments, all of which are necessary for people to maintain their mobility and preserve their quality of life. There is evidence that the quality of services that people with Parkinson's currently receive varies significantly across England.¹

The PDS is calling for:

- 'quality' to be defined by patient experiences as well as by clinical outcomes
- robust processes for regulating how well the NHS is delivering the rights within the NHS constitution
- strengthening of the NHS responsiveness to the local community and putting patient's choice at the centre of their care
- drugs and treatments that have been recommended by NICE for use in the NHS being offered consistently across England.

How you can help:

- The PDS will be looking to engage MPs and Peers during the passage of the Bill through Parliament. If you are interested in supporting people with Parkinson's on this issue, please get in touch.
- For further information, please contact Clare Moonan: 020 7963 9322; cmoonan@parkinsons.org.uk

¹Life with Parkinson's – Room for Improvement, Parkinson's Disease Society, April 2008.

Full stop to prescription charges for Parkinson's

The PDS is working in partnership with other leading patient groups and charities to bring about a swift end to prescription charges for all people with long term conditions. This follows the commitment given by the Prime Minister in September 2008 to abolish prescription charges for people with cancer from April 2009 and all people with long term conditions in the coming years.

Parkinson's is a progressive condition, for which no cure currently exists. Medication is extremely important in helping people with Parkinson's manage their symptoms and continue to lead normal and independent lives. The PDS is concerned that prescription charges act as a barrier to some individuals obtaining

the medication they require. For people with Parkinson's this can lead to poor management of the condition and complications that may result in greater cost to health and social services.

The PDS is particularly concerned about the additional financial hardship prescription charges present for younger people with Parkinson's. The progressive nature of Parkinson's means that many people who develop the condition in their 30s, 40s or 50s may need to leave paid employment before normal retirement age. As a person's condition progresses, their partner or other family members may have to stop working to help care for them.

Additional costs associated with Parkinson's include increased travel costs such as taxi fares and parking charges for hospital appointments, higher than average fuel bills due to additional heating and washing needs, and paying for respite care. Prescription charges are yet a further financial burden for those who do not fall within one of the exemption categories.

The PDS will be submitting evidence to Professor Ian Gilmore's review of prescription charges, which is due to report to Ministers by Summer 2009.

How you can help:

- The PDS will be in contact shortly with more information about how you can support this campaign in Parliament.

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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