

Parkinson's Disease Society

Policy and Campaigns briefing

Autumn 2008

Parkinson's disease dementia – unrecognised and overlooked

The Parkinson's Disease Society (PDS) welcomes the prioritisation of dementia by the Government in the recently published consultation document *Transforming the quality of Dementia Care* but is concerned that the document makes no mention of Parkinson's disease dementia.

What is Parkinson's disease dementia?

Parkinson's disease dementia (PDD) has unique features that distinguish it from other dementias. In the early stage, people's memories are largely intact but they develop cognitive (thinking) changes, making complex tasks difficult. They may also experience depression, hallucinations and delusions. As the condition progresses, apathy and excessive daytime sleepiness is prominent in PDD. Behavioural problems and memory loss can make day-to-day tasks increasingly difficult, ultimately leading to a need for 24-hour care. PDD is extremely difficult for both the individual and their family to come to terms with. Many people describe the double blow of having to learn to live with Parkinson's and then having to cope with the PDD on top.

PDD is a significant sub-type of dementia. Epidemiological studies show around one in three people with Parkinson's will have some form of PDD, which represents up to 40,000 individuals in the UK with this condition who need care and support. PDD cannot therefore be described as a rare form of dementia and warrants inclusion in the Government's plans for the future of dementia care.

The PDS response to the consultation:

The PDS supports the majority of the recommendations made within the draft dementia strategy and believes that, if fully implemented, it will make a significant difference to the lives of many people with dementia, and their carers and families. However, we are concerned that the unique issues relating to PDD may not get fully addressed in practice and individuals with the condition will be disadvantaged as a result.

There are barriers to the diagnosis of all types of dementia as a result of a false belief that nothing can be done and the misconception that it is a normal part of ageing. However, for the diagnosis of PDD there are added barriers arising from the slowness of speech, delayed response and lack of facial expression inherent in Parkinson's, making diagnosis of PDD additionally difficult.

Added to the challenges of diagnosis is the limited knowledge and awareness of PDD among professionals. Around a third of the respondents to a training needs analysis of healthcare professionals identified they were not confident in identifying the mental health symptom of Parkinson's - and 70% identified they had a training need around PDD. There are also important training needs for care home staff as many residents will have PDD.

Poor integration of specialist Parkinson's and mental health services, and the lack of shared care guidelines in many areas can lead to gaps in the patient pathway for people with PDD.

This must be addressed as a core element of service improvement when the strategy gets implemented.

The PDS welcomes the acknowledgement of a need to strengthen the dementia research base, but calls for funding strategies to include research into PDD. The PDS has committed £1.2 million to PDD research, but asks for the Government to ensure that the charity sector is not the only source of funding for research into this condition.

The PDS is calling for:

- the inclusion of PDD as a core component within the ongoing work of the Government's dementia strategy
- public and professional awareness campaigns to include PDD
- the development of core competencies for dementia care to encompass knowledge and expertise in Parkinson's and PDD
- dementia pathways to be integrated across Parkinson's and mental health services, with the development of appropriate shared care guidelines

For more information, please contact Clare Moonan on 020 7963 9322 or cmoonan@parkinsons.org.uk

How you can help

- Include Parkinson's disease dementia in any debates or briefings you may be involved in concerning dementia and the implementation of the Government's dementia strategy.
- Ensure any work you are doing in your constituency to encourage improvements in local dementia services takes into account the needs and issues of people with Parkinson's disease dementia.

End of Life Care Strategy

In July 2008, the Department of Health published the first ever End of Life Care Strategy, which aims to provide increased choice and improved care for all adults approaching the end of their life. As part of the Strategy, primary care trusts (PCTs) are now required to provide an end of life care plan and, in so doing, bring greater transparency and improved co-ordination between services and resources.

For people with Parkinson's and their carers, this represents a significant step: as an incurable degenerative condition, it is important that the palliative care requirements (including at the end of life) are considered.

In spite of the recommendations contained in the NICE Guideline for Parkinson's and the National Service Framework for Long-term Neurological Conditions, PDS research and experience has shown that people with advanced stage Parkinson's are not getting the support they require at this stage of the condition. The PDS looks forward to working closely with the NHS and social care providers to ensure effective implementation of the Strategy takes place at a local level.

The PDS is calling for:

The PDS wants all people with Parkinson's and their carers to get access to high-quality, appropriate, end of life care services as part of a wider effective implementation of existing and new national standards. In particular, the PDS wants implementation to become a reality for hard to reach groups, such as those living in residential care.

How you can help

- Table questions relating to the implementation of the End of Life Care Strategy in your local area.
- Continue to lobby local NHS and social care organisations around lack of implementation of existing national standards relating to palliative care and Parkinson's disease (as outlined in the NICE Guideline for Parkinson's and the NSF).

National Carers' Strategy – an answer to carers' woes?



In June this year, the Government published its new National Strategy for Carers, *Carers at the heart of 21st-century families and communities*.

The Strategy sets out ambitious goals for improving the lives of people who provide care to family and friends and includes new money for

additional respite breaks, improved information and better support for young carers.

There are a number of important new initiatives in the 2008 Strategy. Importantly, a Standing Commission on Carers has been established to oversee the delivery of the Strategy. There is also a commitment to improve data collected about carers, with a question on carers to be included in the 2011 Census, a module on carers in the next Omnibus Survey and the development of a new carer experience survey.

The Strategy includes plans to train a range of professionals, including GPs and other health staff, and staff in Jobcentre Plus and social care, to better understand carers' needs. Lack of recognition and respect from professionals has long been a concern of carers and a wide-ranging programme of training is an important step towards addressing these problems.

There are also new measures to address carers' health, including piloting an annual healthcheck for carers and a plan to pilot the provision of respite care so that carers can attend medical appointments. However, this welcome initiative is not going to be piloted for at least three years. This reflects a wider concern that, despite excellent long-term intentions, not enough is being done for carers now.

The PDS response to the strategy:

The PDS supports the majority of the recommendations made within the Strategy; however, it feels that some vital issues have not been addressed. The Strategy has crucially done nothing to change the rigid £95 earning limit on Carer's Allowance, or the 21-hour study rule that deters carers from returning to study. There are also no immediate changes to carers' benefits. Carer's Allowance remains at just £50.55 per week and excludes most people in receipt of a pension. The Income Task Force made a series of recommendations to ministers that could have been implemented in the short term, but the Government chose to defer changes until a wider reform of benefits. In the meantime, as identified in Carers UK's 2007 research *Real change not short change*, many carers are living in poverty.

There are other important omissions from the Strategy. One of the main concerns raised by carers of people with Parkinson's is that of long waits for aids and adaptations and it is disappointing that there is no mention of this. Scant attention is paid to the particular needs of former carers, and it is important that the Omnibus Survey and carer experience surveys include questions on former carers.

The Impact Assessment of the Health and Social Care proposals in the Strategy includes an admission that **"a number of ambitions set out in the 1999 Strategy on carers have not been fulfilled."** The PDS does not want to see a similar message repeated in a 2018 Carers Strategy and looks forward to further measures to deliver the Strategy's commendable goals.

How you can help

- Please sign EDM 1409 and EDM 1545, which both call on the Government to address the current inflexibility in the £95 earnings disregard limit of Carer's Allowance.
- Ensure that your party's election manifesto contains commitments to address the needs of carers, including issues around providing greater financial support in terms of the Carer's Allowance.

APPG for Parkinson's disease to launch inquiry



PDS members Karen Rose and Marion Wale speaking at the APPG inaugural meeting

The All Party Parliamentary Group (APPG) for Parkinson's disease is to conduct an inquiry into access to services for people with Parkinson's.

Following the launch of the PDS report *Life with Parkinson's today – room for improvement* at the inaugural meeting of the APPG, the group has decided to further investigate the inequalities in the access to services which the report highlighted. The report detailed findings of our recent Members' Survey, alongside country-specific reports for Wales, Scotland, England and Northern Ireland. Over 13,000 people took part in the survey which provided significant insight into the lives of people with Parkinson's and their carers, and the quality of and accessibility to services and support. It is hoped that the inquiry will help engage key national and local decision makers in tackling inequalities

in the availability and quality of appropriate health and social care provision for people affected. As highlighted by the *Life with Parkinson's* report, these inequalities continue to exist, despite the clear quality standards and evidence base set out in the National Service Framework for Long-Term Neurological Conditions and NICE Guideline for Parkinson's disease.

The inquiry will be taking place three years after the publication of the first NICE Guideline for Parkinson's disease and four years after the publication of the National Service Framework for Long-Term Neurological Conditions. It is hoped that the inquiry will provide a clearer picture of current implementation of these national guidelines as well as signalling how this could be improved in the future.

The inquiry will be launched at a joint parliamentary reception hosted by the APPG for Parkinson's disease and the Parkinson's Disease Society in November of this year.

How you can help

- Join the Parkinson's APPG and help to champion the needs of people with Parkinson's disease, their families and carers.
- If you are a parliamentarian and are interested in joining the Parkinson's disease APPG, please contact Emily Cogbill on 020 7932 1362 or at ecogbill@parkinsons.org.uk

The Parkinson's Disease Society acts as secretariat for the group.

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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