

Media Release
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Perspectives of living with dementia
– study shows how complex it is for patients and carers

Whilst cognitive function can be improved by the medicines currently available for the treatment of dementias, the positive effects of improved socialability, initiative and motivation on the patient and their carer as well as their capability of coping with everyday life should not be overlooked says a research report published by the Pharmacy Practice Research Trust (the Trust) today. The report suggests that care for people with Alzheimer's disease and dementia needs to be more holistic in its approach and that the assessment tools used for treatment options are not sensitive enough.

Denise Taylor, Senior Teaching Fellow, Department of Pharmacy and Pharmacology at the University of Bath explored patient and carer perspectives over time of the use of medicines for dementia and their impact on coping with day-to-day life. The research showed that the wider improvement in personality achieved by the medicines for dementia such as improved social skills, orientation and initiative which positively affected personal and wider relationships outweighed the improvements in memory.

The study, commissioned by the Trust and supported by a Galen Award, also identified a need for improved information for carers about how a dementia can affect an individual and the changed behaviours that can result. "Carers need to know that these are part of the disease and not a deliberate action on the part of the person with dementia" says Ms Taylor.

The research emphasises the extent to which medication is often not an option for people in early to mid stages of dementia and how important support is for these patients and their carers.2

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Through a series of case studies involving the patient, their carer and the associated professional team over 13 months, the study highlights some of the real issues faced by all those involved in the care of people with dementia especially when other health problems are present such as hearing or eyesight difficulties. The spouses of those with dementia all described in various ways how difficult they found it living with this different person who wasn't the person that they married and wondered if it was the end of their lives as they knew it. One carer described how all their friends seemed to "disappear" after the diagnosis and others became embarrassed going out with a partner who just sat beside or across from them and said absolutely nothing.

Says Denise Taylor; "My study also showed that patients rarely fit the assessment measurements used to guide treatment as recommended by NICE¹, such as the Mini Mental State Examination. This was shown to be telling 'only half the story' and did not accurately reflect for some participants the true impact of their dementia or their medication on their day to day life."

Commenting on the research, Beth Allen, Acting Director of the Trust said: "Although no pharmacists were recruited to this study, they could play a part in the support of people with dementia and their families. This could be through the provision of information and including medicines for dementia in Medicine Use Reviews to ensure the most effective use of medication, support with compliance and titration regimens."

Ends.

¹ NICE Technology Appraisal Guidance 111. Donepezil, galantamine, rivastigmine (review) and memantine for the treatment of Alzheimer's disease. National Institute for Health and Clinical Excellence November 2006. www.nice.org.uk.

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Notes to editors:

1. *Living with medicines for dementia – patient and care perspectives.* Miss Denise Taylor, Senior Teaching Fellow, Dept of Pharmacy & Pharmacology, University of Bath.

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<http://www.pprrt.org/Documents/Publications/Living%20with%20Medicines%20for%20DementiaII.pdf>

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2. Research Methodology

The research was undertaken using a case study research methodology. 7 case studies were recruited with people with newly diagnosed mild dementia and their carers and where possible their prescriber and healthcare professional providing support. Interviews were the main method used to collect data in order to explore in greater depth the subjective experience of taking medicines for dementia (or not) and how these produced affects and effects in daily life. Participants were offered the option of recording their thoughts in a daily diary. Shared care records were accessed to compare subjective with objective findings.

3. The Pharmacy Practice Research Trust

The Pharmacy Practice Research Trust was established by the Royal Pharmaceutical Society of GB in July 1999 as an independent research charity with a broad objective to promote and develop the field of pharmacy practice research. Its trustees are drawn from senior health policy makers, leading academics, industry and retailers.

The Trust has invested around £2m in research; 30% supporting capacity building in pharmacy practice research and 70% on commissioned research. The Galen Award is one of two practice research awards available to members of the Royal Pharmaceutical Society of Great Britain; it is made annually to a total value of £10,000 funded by a bequest by Rowland Henry Williams.

Annual grants from the Pharmaceutical Trust for Education and Charitable Objectives and the Leverhulme Trades Charities Trust also contribute to the funds of the Pharmacy Practice Research Trust. For further information and to access reports of Trust commissioned research go to: www.pprt.org.uk