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Specialist nurses should form part of the post-diagnostic care and support network for living well with dementia

Shibley Rahman  
*BPP University*

Kate Swaffer  
*University of Wollongong, ks260@uowmail.edu.au*

Peter Gordon  
*NHS Scotland*

Facundo Manes  
*INECO*

Jane Marsters  
*Brighton and Sussex Medical School*

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SPECIALIST NURSES SHOULD FORM PART OF THE POST-DIAGNOSTIC CARE AND SUPPORT NETWORK FOR LIVING WELL WITH DEMENTIA

Shibley Rahman 1,* Kate Swaffer 2 Peter Gordon 3 Facundo Manes 4 Lucy Jane Marsters 5

1 BPP University, London, 2 University of Wollongong, Wollongong, 3 NHS Scotland, Dundee, United Kingdom, 4 INECO, Buenos Aires, Argentina, 5 Brighton and Sussex Medical School, Brighton, United Kingdom

Objectives: There have been numerous concerns that the health and care system in England is too fragmented, and lacks sufficient focus for a person with dementia or caregiver to navigate through the system. This makes it difficult for people to live well with dementia. The aim of this study was to conduct a preliminary online survey into citizens’ attitudes to what post-diagnostic support in the English jurisdiction could look like.

Methods: 90 respondents completed the online “SurveyMonkey” survey, invited from a Twitter account with around 13000 followers. The survey could only be completed once. Participants were invited to be a person who had just received a “timely” diagnosis of dementia in the English jurisdiction.

Results: You were most likely to see your General Practitioner if you were aware of dementia and had noticed memory problems (49%) rather than simply talk to friends and family (33%), but you were likely to take action as soon as possible (92%). You were most likely to wish to have follow up from a neurologist and community psychiatric nurse (39%), with input from a specialist nurse in a multidisciplinary team (74%). However, you would (just) prefer to have a specialist nurse as your ‘care coordinator’ (47%) rather than a “dementia adviser” (34%), but to have a primary caregiver’s input in formulating a personalised care plan (46%).

(Respondents further stated that the decision to implement clinical nursing specialists should be based on clinical outcomes (76%).)

Conclusion: The results from this preliminary survey identify the clinical nursing specialist as key stakeholder of future importance in the English jurisdiction, working together with a person living with dementia and the primary caregiver in the post-diagnostic care and support network. This will vastly improve likelihood of living well with dementia.

References: Peel E, Harding R. (2014) ‘It’s a huge maze, the system, it’s a terrible maze’: dementia carers’ constructions of navigating health and social care services. Dementia (London), Sep, 13(5), pp. 642-61.

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