

## **End of life care - why those with dementia have different needs**

*Dr Nathan Davies, NIHR School for Primary Care Research Post-Doctoral Fellow, Research Department of Primary Care and Population Health, UCL, Royal Free Campus, London, NW3 2PF*

[Nathan.davies.10@ucl.ac.uk](mailto:Nathan.davies.10@ucl.ac.uk)

*Dr Steve Iliffe, Emeritus Professor, Research Department of Primary Care and Population Health, UCL, Royal Free Campus, London, NW3 2PF*

The British Medical Association (BMA) and Royal College of Physicians (RCP) have recently reported on end of life care.<sup>1 2</sup> They call for changes to end of life care,<sup>1</sup> but also report steady progress in the recognition of patients who are dying, and in the amount and quality of communication with patients who are able to communicate.<sup>2</sup>

It is disappointing that the RCP does not mention those who are unable to communicate, such as people with dementia. People with dementia often lack cognitive capacity and the ability to communicate verbally towards the end of life. These communication difficulties underline the importance of advance care planning, but not all people with dementia and their families are willing to have such conversations.<sup>3</sup> This can make decisions around end-of-life care difficult.<sup>4</sup> The BMA highlighted communication difficulties, calling for more training to better equip doctors to have these conversations.

Dementia is not only complex from a cognitive perspective, but people with dementia are often frail and may have multiple comorbidities. This raises a question about who should provide end-of-life care. The complexities of dementia mean that no one specialist may be best suited to care for the person at the end of life. Although a combination of specialities may seem desirable, this could undermine care continuity.

Many people with dementia live in the community and are cared for by their relatives, home care workers, care home assistants and their general practitioner. With this end-of-life care should be seen as part of everyone's role.

1. Wise J. BMA calls for changes to end of life care. *BMJ* 2016;**352**(1527).
2. Royal College of Physicians. End of Life Care Audit – Dying in Hospital: National report for England 2016. In: RCP, ed. London, 2016.
3. Davies N, Maio L, Rait G, et al. Quality end-of-life care for dementia: What have family carers told us so far? A narrative synthesis. *Palliative Medicine* 2014;**28**(7):919-30.
4. Davies N, Manthorpe J, Sampson EL, et al. After the Liverpool Care Pathway—development of heuristics to guide end of life care for people with dementia: protocol of the ALCP study. *BMJ Open* 2015;**5**(9).