

A community of practice approach to end of life care

Dementia UK and Hospice UK have teamed up to launch a Community of Practice on end of life care in dementia and are inviting new members to join. **Karen Harrison Denning** explains why the group was deemed necessary.

Increasing quantities of policy and guidance are being published worldwide to influence and promote palliative and end of life care for non-malignant life-limiting conditions. But it is only since publication of the NICE/SCIE Dementia Guideline (2007), where several best practice recommendations were made regarding palliative and end of life care, that we have seen a growing impetus for its availability to families affected by dementia specifically.

However, there are concerns in some settings and services that they are ill-equipped to care for this group of people, both in relation to environment and to knowledge and skills.

People with dementia, particularly those in the advanced stages, can experience poor end-of-life care because they are often not perceived as being in the dying phase of their illness, despite the fact that they are frequently bed-bound, doubly incontinent and unable to communicate (Sampson *et al* 2011).

At the same time health and social care services may not be optimally configured to meet their complex needs and a parliamentary report evidenced how people with dementia are still unable to access palliative care services (House of Commons Health Committee 2005).

There are also various other factors involved, such as a poor understanding of the pathophysiology of dementia among professionals (Thuné-Boyle *et al* 2010) and a lack of

knowledge about managing the symptom burden (Harrison Denning & Cooper 2016).

End of life care pathways

Care pathways are structured multidisciplinary care plans that detail essential steps in caring for patients with specific clinical problems, including those in the last days of life. These care pathways were designed with the aim of ensuring that the most appropriate symptom management occurs at the most appropriate time, and that it is provided by the most appropriate health professional (Chan *et al* 2016).

The Liverpool Care Pathway for the Dying Patient (LCP) was one such approach, which included a complex set of interventions and resulted from a desire to replicate in hospitals the standard of care for the dying found in many hospices. It supported palliative care options for patients in the final days or hours of life to help doctors and nurses provide quality end of life care.

There were anxieties, however, that the LCP was being widely abused and reduced, in some settings, to a tick box exercise with patients being casually assessed as terminal, then heavily sedated and denied water so the diagnosis became self-fulfilling (Department of Health 2013). Indeed, a recent update of a Cochrane Review of the effectiveness of end of life care pathways (Chan *et al* 2016) found there still to be limited evidence concerning

their clinical, physical, psychological or emotional effectiveness.

The government's decision to withdraw the LCP following a high profile review has left in its wake a significant level of public mistrust of clinical decision making for people dying with dementia (Harrison Denning *et al* 2012) and a hole in the systems and processes to support this decision making. Many practitioners lack the confidence to provide end of life care for someone with dementia, both those from palliative care and those from dementia care backgrounds (Harrison Denning & Cooper 2016).

Shared learning to improve care

In 2015, Dementia UK and Hospice UK established a Community of Practice specifically for clinicians in both dementia care and palliative and end of life care to come together to share knowledge, skills and experience, and to learn from each other. This innovative approach built upon developments in each organisation before coming together.

Dementia UK developed an Admiral Nursing special interest group in 2008 specifically to explore practice development needs in working effectively with families where the person with dementia was nearing the end of life (Harrison Denning & Wharrad 2010). What became apparent during this project was that knowledge and skills in this area often spanned the specialities of dementia and



palliative care and, while joint working could be facilitated in complex cases, there needed to be focused practice development for both specialist staff groups.

Hospice UK came to a similar conclusion when, in 2011, it scoped the key challenges facing hospices in relation to dementia. An aim in establishing the Community of Practice was to offer a practice development solution to address the significant shifts in demography and disease facing clinicians providing individualised and person-centred care for people dying with or from dementia. We wanted to enable both groups of specialist staff to become more agile in responding to the changing profile of people with dementia requiring palliative care.

A Nominal Group Technique (NGT) (Delbecq & Van de Ven 1971) was used in the inaugural Community of Practice meeting to help staff from both groups to identify their learning needs (Harrison Denning & Cooper 2016). Participants identified 13 themes, of which five were ranked as learning priorities

that could be met during future meetings. These were: communication in dementia; educating others; understanding and influencing policy; care in different settings; and pain assessment and management. Shared learning through the Community of Practice is one way of harnessing knowledge, skills and expertise across the two care domains with the common objective of improving the lives and deaths of people with dementia.

The Community of Practice is at an embryonic stage, but the power of shared learning through it is not to be underestimated and it will be evaluated at various stages to measure its impact and outcomes. Membership is open to professionals from any discipline and from any dementia care setting. If you are interested in hearing more of the planned events, contact the author at karen.harrison-dening@dementiauk.org or

The government's decision to withdraw the Liverpool Care Pathway left a significant level of public mistrust of clinical decision making for people dying with dementia

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Alternatively, go to www.hospiceuk.org and then click on "Professional Networks and Associations" in the drop-down box under "What we offer." Scroll down the page to the "Dementia end of life care: special interest group" link.

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