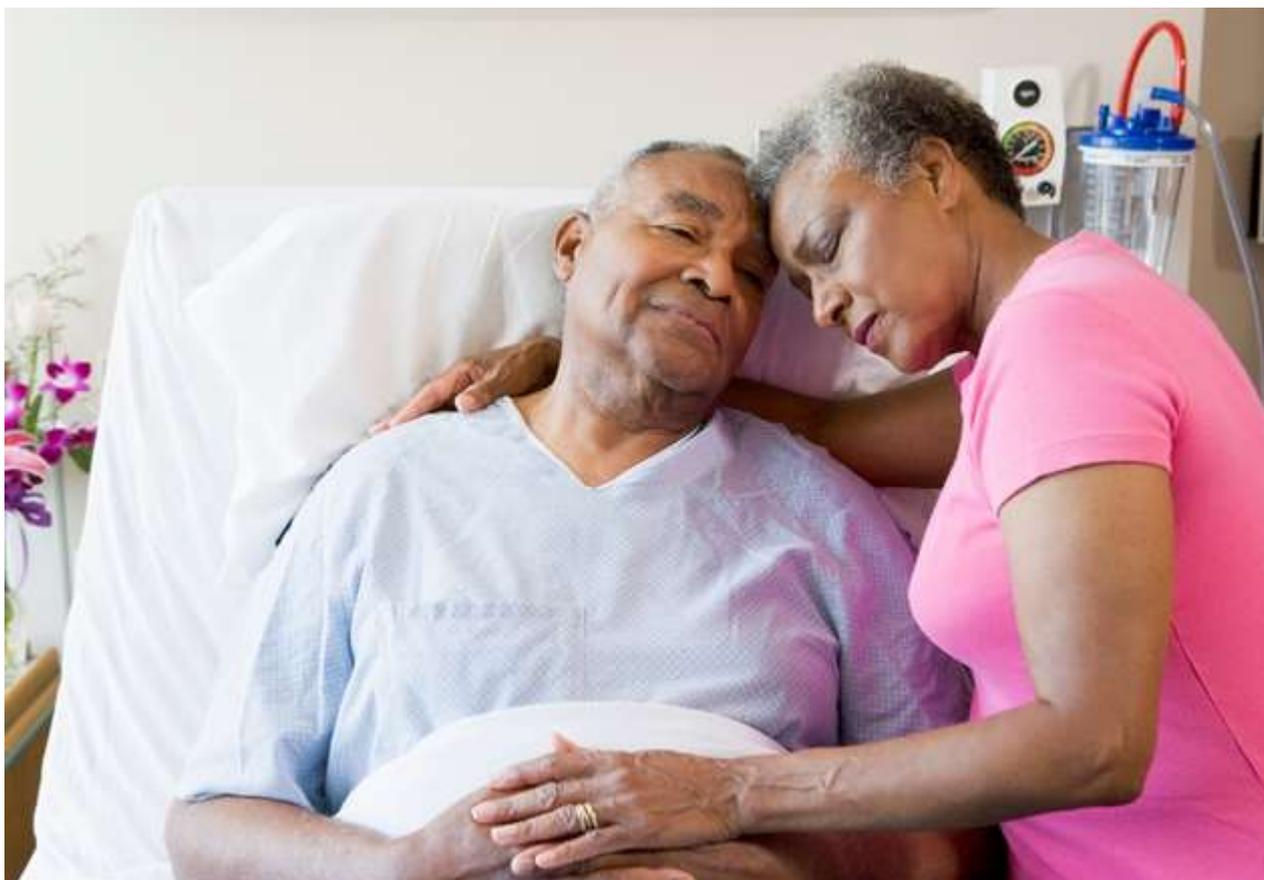


# Pain and Dementia: what do we know and what can we do?

Author: Eleanor McConnell  
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Editorial | Care



Eleanor McConnell from Hospice UK writes about a Community of Practice event, led by Hospice UK and Dementia UK, that examined how carers can enact effective pain management techniques for people with dementia.

“I have been very privileged to be part of this group from the beginning and have attended each session. I have found each session has offered something different but is always relevant and informative. Will be looking forward to the summer event.”

Towards the end of last year around 75 practitioners and clinical leaders in dementia and end of life care gathered together to share their knowledge and skills in an event called: ‘Pain and Dementia: what do we know and what can we do?’ The event focussed on highlighting ways in which person-centred care models have been successfully used to communicate with dementia patients and treat their pain.

The day began with an overview of the state of the research and evidence base for pain in dementia from Dr Liz Sampson, Reader in the Division of Psychiatry at UCL. She highlighted that, in spite of the fact that the number of people with dementia is rising steadily and predicted to surpass one million by 2025, the evidence base for pain in dementia remains small.

The reasons behind this lack of research are rooted in obstacles that practitioners in the room were very familiar with – it is often difficult for patients to remember the location, duration and frequency of

their pain, with some forgetting how to conceptualise pain altogether. Given these challenges, it is hugely important that practitioners use assessment tools and pain scales that can be understood by patients with a wide range of communicative abilities.

This theme was expanded upon by Jan Leeks, Senior Lecturer at the University of Hertfordshire, in her session: 'Enhancing well-being through positive communication with people living with dementia approaching end of life'. Jan had participants up on their feet trying to communicate requests and problems back to back, without being able to use certain words. In spite of the restrictions they imposed, these exercises in lateral thinking demonstrated that communication at the end of life, though limited, is perfectly possible and very necessary to enhance patients' wellbeing.

Jane Chatterjee, Lecturer in Palliative Care at St Gemma's Hospice, showed how practitioners at St Gemma's have developed a pain assessment toolkit that put these supportive communication methods into practice. Building on Liz's point that 50% of people with dementia are unable to use the FACES pain tool, she advocated the use of different pain scales for different people, allowing for a far more personalised system. She also placed emphasis on the importance of using tools like the Disability Distress Assessment Tool (Dis DAT) to help carers establish when patients are distressed, and be able to differentiate that from being in pain. Knowing the habits and context in which distressed behaviour occurs, it was argued, helps carers to keep sight of the patient's personhood, and communicate more effectively.

Following this, Emily Pardoe-Billings, Dementia Support Worker at St Giles Hospice, and Sophie Meredith, Dementia Support Worker at Pathways 4 Life, presented the results of a project conducted in collaboration between their two organisations that aimed to reduce hospital admissions for people living with dementia in care homes. The project operated in 33 care homes across Walsall, and focused on upskilling care staff through 1-2-1 coaching and development sessions. The project saw significant successes, with a proven reduction in falls and incontinence, as well as in 999 calls, and was Highly Commended at the WMHASN Innovation Awards.

The funding of the project has now been extended to May 2017, and Emily and Sophie hope that their approach, which has shifted the care homes it operates in from a task-oriented framework to a more person-centred approach, will continue to roll out across more care homes in the community.

Sharing from experience is at the heart of what made this Community of Practice such a valuable experience for participants, which is why it was great to see how the methods of care and communication we had heard about during the day had been applied in real-life cases. Ann Regan, Specialist Nurse in Dementia for end of life, went into detail on several cases to show how pain management techniques were applied to dementia patients at the end of life in an individualised and person-centred way.

The day finished with Dr Karen Harrison Denning, Director of Admiral Nursing at Dementia UK inviting participants to share their reflections on what they had learned during the day, and to begin developing an action plan which could bring that learning into every day practice, as well as share it with others.

One participant, for example, said: "I learnt about the importance of considering pain for those with dementia, about the practical problems in addressing this need and strategies to address this. Due to this community of practice our hospice is working in partnership with the local mental health care trust, looking at palliative care needs in inpatients with advanced dementia. This has increased hospice referrals from this group and allowed care planning and use of our local palliative care coordination system."

If you are interested to access the presentations and find out more about the Community of practice, please visit the Hospice UK website