

End-stage dementia patients deserve the same access to palliative care as people with cancer

There is an urgent need to improve end-of-life care for older people in the final stages of dementia, according to an international review published in the May issue of Journal of Clinical Nursing.

“We must act now to stop people with dementia from suffering from protracted, potentially uncomfortable and undignified deaths” says Jan Draper, Professor of Nursing for The Open University, UK.

“The management of dementia is becoming a major international public health concern because people are living longer which means that more people are likely to develop this disease.”

Professor Draper teamed up with Deborah Birch, a Clinical Nurse Specialist working with older people in Lincoln, UK, to review 10 years of published research. They carried out a detailed analysis of 29 studies, from the USA, UK, Canada, Israel, Switzerland, Ireland, the Netherlands, Sweden and Finland.

“Our review has reinforced the importance of providing appropriate palliative care to individuals suffering from end-stage dementia and clearly identified some of the barriers to extending such provision” says Professor Draper.

“These include concerns that such an expansion might lead to skills and funding shortages and, in turn, compromise the ability of existing palliative care teams to provide care to cancer patients, who tend to be the main recipients of this kind of care.

“We believe that clinicians and patient groups caring for patients with advanced dementia need to work together with specialist palliative care providers and health commissioners to develop, fund and evaluate appropriate cost-effective services that meet the needs of both patients and their families.

“If this is achieved, these improvements have the potential to increase people’s quality of life and reduce the amount of time they spend in acute hospitals.”

Birch and Draper say that the findings of their review indicate a number of ways that colleagues across healthcare disciplines can work together to enhance the quality of care they provide older people in the end stages of dementia. These include:

- Communicating the diagnosis of dementia in a sensitive way and indicating, as clearly as possible, how the disease is likely to progress.

- Acknowledging the potential influence that the individual beliefs and values of the healthcare team - such as difficult drug and treatment decisions - may have on the care provided.

- Improving and providing timely and accurate communication about key issues, including the role of advanced directives, such as living wills or do not resuscitate orders.

- Reconsidering aggressive medical treatments that have limited benefits and may cause further discomfort to dying patients.

- Encouraging professionals, carers and, where possible, patients to work together to plan appropriate care tailored to the needs of the individual.

- Reinforcing the need for multi-disciplinary ways of working.
- Reconsidering the most appropriate place to deliver end-of-life care.
- Acknowledging the right of all older people dying from end-stage dementia to have access to high-quality specialist palliative care services.

“Palliative care services are used to providing care for cancer patients, but high-quality care for people with end-stage dementia does not appear to be given the same priority” says Professor Draper.

“In the UK, for example, it has been a relatively neglected topic in relation to policy, planning, practice development and training.

“Population trends suggest that life expectancy is increasing and this will mean that more people are at risk of developing dementia, which affects one in 1,000 people under 65 but rises to one in five once people are over 85.

“Dementia is a progressive terminal illness for which there is currently no cure and patients dying from the disease have significant healthcare needs.

“Despite this, they are often denied the palliative care services that could improve their comfort and quality of life.”

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