

# Palliative care covers more than end-of-life issues: why is this not common practice in dementia care and what are the implications?

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Historically, palliative care services have been closely related to oncology but over time gradually extended to other conditions. As a result of recent scientific advances in the field of medicine, combined with steadily increasing life expectancy, people are increasingly being diagnosed with terminal conditions much earlier and living longer. Consequently, palliative care may now cover a lengthy period stretching from diagnosis of a life-threatening condition up to and beyond the point of death. The WHO defines palliative care as “*an approach that improves the quality of life of patients and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain, and other problems, whether physical, psychosocial or spiritual.*” (1).

There is a body of literature which suggests that a palliative care approach from the diagnosis onwards could help prevent unnecessary suffering and pain, enhance symptom management, enable informed decision making and help address spiritual and social aspects of care, thus contributing towards improving the quality of life of people with dementia and their families (1,2). The White Paper on palliative care in dementia (3) proposes a two-tier model consisting of: (I) a palliative care approach which refers to all treatment and care, and should be offered to every person with dementia; and (II) specialist palliative care for people with dementia with complex problems.

However, the initial association between palliative care and the end of life is still prevalent. Whilst numerous governments in Europe have shown commitment to providing a balanced portrayal of living with dementia and tackling the stigma surrounding dementia (4), several studies suggest that stereotypes of dementia, focusing

predominantly on the advanced stages, persist, even though ironically, many lay people and healthcare professionals do not recognise dementia as a terminal condition (5). Moreover, there may also be differences between and amongst different healthcare professionals regarding the way they perceive and portray palliative care for people with dementia and their families.

Lay perceptions of palliative care being linked to the end of life and negative stereotypes of dementia may contribute towards ethical dilemmas for healthcare professionals. According to the WHO (1) definition of palliative care, “it is the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual”. However, in trying to fulfil their ethical duty, healthcare professionals may be faced with an ethical dilemma (i.e., be in a situation in which their moral principles or values are in conflict, making it difficult to interpret or decide what would be the right or wrong course of action or attitude to take) (6).

On the one hand, in keeping with the principle of beneficence, they may wish to propose palliative care services; on the other hand, in keeping with the principle of non-maleficence and based on their sensitivity to their patients’ needs and wellbeing, they may be hesitant to do so, based on concerns about this causing distress. Disclosing a diagnosis of dementia may also sometimes cause distress despite it being widely accepted that people have a right to be offered timely diagnosis. The difference perhaps lies in the combined perceptions of dementia and palliative care, the association of palliative care with impending death and the frequent lack of palliative services or support in the early stages of dementia.

If the current understanding of palliative care is linked

to end-of-life care, being offered palliative care may lead to distress of the person and their family. Kydd (7) refers to the potential upset to patients and families caused by referring someone with an illness (which could be potentially life limiting) for palliative care services if they understand such services as being for people for whom death is imminent. Some people with mild to moderate dementia and/or their relatives may not understand the potential benefits of palliative care for them. This may lead to resistance from family members to the person with dementia being offered palliative care. Support is clearly needed so that healthcare professionals have the necessary time and support to discuss within a safe environment such ethically sensitive situations and to engage in an interpretive dialogue with all concerned (6,8). For this to be possible, this dilemma must be recognised and this is often not the case.

Palliative care services suited to the needs of people with dementia and their relatives throughout the whole disease trajectory do not exist in many parts of Europe. Although palliative care seeks to improve quality of life (1,2), many people with dementia and their families are not receiving it from the point of diagnosis onwards. The palliative care needs of people with mild and moderate dementia have not been adequately addressed and literature looking at the potential impact of palliative care on their quality of life is sparse, even though there is a substantial interest in understanding quality-of-life issues in dementia (9).

Greater clarity is needed about the nature and possible benefits and challenges of providing palliative care in the early stages of dementia. How, for example, is palliative care in the early stage of dementia different from standard/person-centred care? How can it be integrated into existing care and involve specialists from different domains? If it is not significantly different to standard/person-centred care, does it make sense to specifically label it as being palliative?

Kydd and Sharp (10) suggest that “challenging and timely conversations” with people with dementia and their relatives are needed, and that such conversations should focus on the individual perspective of quality of life, including discussions about living well with dementia and also the difficulties that may lie ahead (e.g., capacity to make decisions). More information is needed about how people

with dementia feel about this. Meanwhile, recent feedback from Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD\*) highlights the need to change the way that palliative care for people with dementia is portrayed and perceived by lay people, healthcare professionals and service providers. The EWGPWD also emphasises the need for greater awareness of the eligibility of people with dementia to palliative care services and more clarity about the nature of services required and how these differ from standard dementia care. Finally, the EWGPWD insists on the need to involve people with dementia and families in palliative care research and service design (e.g., through public and patient involvement).

In conclusion, palliative care in dementia should cover more than end-of-life issues but in many countries, this is still not the case. In response to our initial question, we posit that negative perceptions of and the stigma associated with both dementia and palliative care have a significant impact on this, particularly in the early stages of dementia. We call for a greater involvement of people with dementia and their families in discussions and in the development of palliative care services for dementia.

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### Footnote

*Conflicts of Interest:* The authors have no conflicts of interest to declare.

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\* In 2012, Alzheimer Europe set up a European Working Group of People with Dementia (EWGPWD). The EWGPWD is composed of 11 people with dementia from different countries and with different types of dementia. The EWGPWD works to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia.

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