

## COMMENTARY

# Palliative care for older people with dementia—we need a paradigm shift in our approach

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## Abstract

Older people with dementia have multiple palliative care needs, with pain, agitation, dyspnoea, aspiration and pressure ulcers being common and persistent in advanced dementia. Anticipating the person's possible symptoms requires knowledge of the whole person, including the type of dementia, which is problematic when the dementia type is often not documented. A palliative care approach to dementia should look at symptoms across the four pillars of palliative care, but in reality, we tend to over-focus on physical and psychological symptoms, while spiritual and emotional needs can be overlooked, especially around the time of diagnosis, where such needs may be significant. Advance care planning (ACP) is a central tenet of good dementia palliative care, as the person may lose their ability to communicate and make complex decisions over time. Despite this, care planning is often approached too late, and with the person's family rather than with the person; much of the literature on ACP in dementia is based on proxy decision-making for people in residential care. Thus, we need a paradigm shift in how we approach dementia, beginning with timely diagnosis that includes the dementia type, and with services able to assess and meet emotional and spiritual needs especially around the time of diagnosis, and with timely ACP as an integral part of our overall approach.

**Keywords:** dementia, palliative care, advance care planning, prognostication, grief, older people

## Key Points

- A palliative care approach is an integral part of dementia care, appropriate from the time of diagnosis.
  - Advance care planning (ACP) should be a continuous process, beginning early in the course of dementia to facilitate the person living with dementia being fully involved in decision making.
  - Any service for people living with dementia needs to be able to provide emotional and spiritual support to the person and their family.
  - Determining the type and stage of dementia is key for proactively assessing for palliative care needs and for prognostication and ACP.
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Dementia is an umbrella term for multiple progressive diseases that affect neuronal function and survival. Regardless of the initial or predominant cellular injury (i.e. protein accumulation, inflammation or ischemia), ongoing aberrant neuronal signalling leads to cascades of worsening and more multi-factorial cellular injury, and ultimately neuronal death. The reported median survival from diagnosis is 1.1–8.5 years, varying by patient cohort and study setting, and influenced by the dementia type, with longest survival reported for people with Alzheimer's disease (AD), regardless of age of onset [1]. People with advanced dementia have multiple palliative care needs, but are less likely to be referred to specialist palliative care (SPC) services than people with cancer [2]. Pain, agitation, dyspnoea, aspiration and pressure ulcers are common and persistent in advanced dementia [3]. The assessment and management of palliative care needs of a person with dementia is complicated by their cognitive and communication difficulties, while prognostication is complicated by the slow disease progression, occasional remission and frequent comorbidities.

### **Anticipating palliative care needs**

All older people with dementia are individuals, with a unique health profile, individual life experience and cultural background, and varying family and peer networks. Notwithstanding this, the type and stage of dementia can significantly influence palliative care needs. In AD, the person usually experiences initial cognitive and non-cognitive (or psychological) symptoms. Early spiritual and social symptoms are also very common, associated with dementia stigma, the response of others, uncertainty about the future, and declining functional abilities that affect relationships, occupation and hobbies. In contrast, physical symptoms such as dyspnoea or pain typically occur later, often associated with advanced dementia and limited life expectancy. Common dementia staging tools typically reflect AD progression, e.g. the Global Deterioration Scale and the more detailed Functional Assessment Staging Test, both by Reisberg, which are specifically designed for AD, but also the Clinical Dementia Rating scale [4], which focuses on cognitive impairment and its effects on activities of daily living, again most relevant to AD.

Scales used to identify indicators for the clinician to assess for palliative care needs also reflect severe AD, even if this is not explicitly stated. Both the Supportive and Palliative Care tool (SPICT) and the Gold Standards Framework (GSF) equate loss of speech with advanced dementia, along with falls and fracture (SPICT) and pressure ulcers (GSF). An issue arises for an older person with a non-AD dementia, where physical symptoms can pre-date, or occur early in, the dementia course. For example, in vascular dementia, a person may have limited speech or swallowing difficulties even in mild dementia. A person with a Parkinsonian dementia (such as Parkinson's disease dementia, dementia with Lewy bodies, or progressive supranuclear palsy (PSP)) may

have early, prominent falls, and hence injury-related pain, contractures, pressure ulcers, etc., or may have marked swallowing difficulties and hence dyspnoea or anxiety, despite early-stage dementia. Frontotemporal dementia (FTD) is a relatively less common cause of dementia in older compared to younger people, but the peak incidence in one recent large French memory clinic network study was 75–79 years [5]. In language-variant FTD, a person may have severely impaired speech in early-stage dementia. It therefore follows that accurately determining and documenting the type of dementia, and knowing the symptomatology of that dementia type, are pre-requisites for holistic and timely assessment of palliative care needs. However, in cohorts of people with dementia admitted to hospitals in Ireland and England, only 35–73% had dementia type recorded [6–8], indicating that work needs to be done to improve the performance of dementia sub-typing.

### **Advance care planning**

Advance care planning (ACP) is a key part of palliative care for an older person with dementia. Unlike other incurable diseases, a person with dementia may lose the ability to make decisions and communicate their wishes early in the disease progression. Knowing the dementia type allows the clinician to pre-empt particular problems with ACP, such as early speech disturbance (Parkinsonian dementias; FTD language variants), or early executive dysfunction (any dementia that predominantly affects frontal lobes), where conversations around future care may need to happen promptly. Unfortunately though, for many people with dementia, even in AD where there can be a prolonged window for ACP, such conversations do not routinely take place. Most of the literature on ACP in dementia is based in residential care, where decisions are often made with families on behalf of the person with dementia. This 'too late and without you' approach may reflect a reluctance to adopt a palliative care approach in early-stage dementia. Some people with dementia do not want to prioritise future planning, instead concentrating on living as well as possible in the present; equally, clinicians report difficulties in finding the optimal time to have conversations about future care [9]. Regardless of the causes, there are insufficient studies of ACP performed directly with people with dementia living in the community. The existing data indicate that ACP improves mood and quality-of-life in people with mild dementia [10], and that GPs can be trained to support ACP [11].

### **Emotional distress and grief**

Within age-related and dementia services, the focus on palliative care needs often relates to physical and psychological symptoms, while spiritual and emotional needs can be overlooked, including peri-diagnosis, where such needs may be significant. Dementia is a highly feared condition, second

only to cancer is some population-based surveys, and more feared in others. There is also significant societal stigma surrounding dementia. Thus, a dementia diagnosis in an older person can trigger them to reflect on their identity, role and sense of life-achievement, and worry about their perceived future and anticipated suffering. As dementia progresses, the person can grieve for lost abilities, such as driving capacity, and for anticipated future losses (e.g. not recognising a loved one), at a time when they may increasingly struggle to express their feelings and concerns. Peer support, counselling and interpersonal therapy thus need to be part of any service for people living with dementia, in all settings. In later dementia stages, the approach may have to change from activities that require good cognitive and communication ability (e.g. counselling, therapy and grief work), to supporting the person's personhood and spirituality.

Family, friends and significant others can also have significant emotional and spiritual needs. Anticipatory grief, i.e. anticipating the future loss of the person through death, is common, further complicated by distancing via personality and relationship changes, or transition to residential care. Dementia types with marked personality and behaviour change, such as behaviour-variant FTD, or PSP, can be associated with heightened emotional distress and grief in families. Equally, bereavement in dementia can be complicated. Families may have adjusted over time to disease progression so that the ultimate death of the person is a shock; core carers (especially spousal carers) can experience a particular void, with complex feelings of relief, grief and guilt, and challenges in rebuilding their life after an often prolonged and all-consuming caring role. Intensive bereavement and emotional support, involving both fixed session and as-needed counselling, and access to weekly peer-support groups, alleviated family depression and improved resilience in one trial [12]. Earlier support led to a greater reduction in families' depressive symptoms, both pre- and post-death.

Thus, dementia and aged-related services that provide care for people with dementia need to incorporate emotional and spiritual support into their service provision, and to provide easy access to bereavement support services where more complex grief support is needed.

### Service components and integration

The European Association of Palliative Care (EAPC) white paper on dementia palliative care [13] includes 11 domains. These reflect core principles of palliative care, including 'optimal treatment of symptoms and providing comfort', and dementia care, including 'person-centred care, communication and shared decision-making'. A survey of academics, and clinicians and service managers working in dementia and/or palliative care, in the UK and Ireland, explored community-based dementia palliative care provision [14]. Core components included (1) support of 'meaningful living' via music and art therapies, social activities,

etc.; (2) support of the family via formal and peer-support networks, 24/7 support, effective respite, fast access to services, home support that increased as needed; (3) information for the person with dementia and family; (4) education and training for healthcare professionals; (5) early ACP. Overall, services needed to be flexible and responsive, linked with other relevant pathways and systems, and with a designated person to coordinate all aspects of care, such as a 'key worker'. The provision of appropriate practical equipment, such as commodes, wheelchairs, hospital beds and hoists, is another facet of an effective service [15].

Models of care vary widely. A dementia palliative care service can be SPC-led, dementia-service led (including those provided by primary care, mental health and age-related services), or integrated between SPC and dementia services. There is some evidence to support all three models, including specific evidence for geriatrician-led services such as hospital-level care at home available 7 days a week, environmental assessment, communication around goals of care, and ensuring easy access to both skilled practitioners and practical care [16]. There is as yet limited evidence for truly integrated services, with current descriptions more of interdisciplinary partnerships, such as a dementia nurse specialist joining a community SPC team, or a palliative care nurse joining community primary care teams.

To summarise, we need to consider palliative care as a normal and integral part of dementia care, appropriate from the time of diagnosis. This paradigm shift would facilitate timely emotional and spiritual support to people and their families and allow opportunities for meaningful ACP with the person, rather than late, proxy-derived decision making. Prognostication tools need to be used with care, taking a holistic approach to the person, which considers their dementia type and stage, other comorbidities, and personal history. Integrated working across teams, be these situated in age-related services, memory services, primary care or SPC, makes sense, but optimal models are currently lacking.

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