

A palliative approach to dementia care

Considering the “whole person”.

Sharing compassion and companionship from diagnosis until the end of life.

Helping patients and loved ones prepare for the future.

Fostering open discussions about advanced disease and the end of life.



Traditionally, palliative care has been described as a holistic person-centred approach to patient care focusing on improving quality of life in people with serious chronic illness. More a philosophy than a rigid framework, a palliative approach extends beyond managing physical or cognitive symptoms. It considers psychological, emotional and spiritual well-being supporting both individuals and their loved ones and ensuring dignity and comfort from diagnosis through the end of life. Dementia is a progressive neurological condition that affects cognition, communication and independence. It often profoundly impacts quality of life of both those diagnosed and their loved ones. In many illnesses, such as cancer, a palliative approach is introduced early on and integrated alongside curative treatments. In dementia however, it is often only considered in later stages. Yet, given the complex and evolving challenges of dementia, including progressive cognitive decline, behavioural and emotional symptoms and the strain on carers, a palliative approach can provide meaningful support from the time of diagnosis.

How a palliative approach to dementia care can benefit your patients and their supporters



Be a companion on the dementia journey

As dementia progresses, so do the needs of individuals and their supporters. Early on, support may focus on helping them adjust to the diagnosis and navigate available resources. Knowing that they have a trusted companion throughout the journey, someone who embraces them and their family with care and support, can have an immensely positive impact on those affected. A palliative approach emphasises relationships built on trust, ensuring that people affected by dementia never feel alone on their journey.



Consider the “whole person”

A key principle of palliative care is recognising individuals beyond their diagnosis. Dementia care should honour a person's values, life experiences and identity, addressing not only physical and cognitive needs but also social, emotional and spiritual well-being. In practice, this might mean facilitating meaningful connections, supporting religious or cultural rituals or creating opportunities for personal reflection and peace. Small but thoughtful interventions, such as reminiscing about past experiences, engaging in one's favourite activities or playing familiar music can help preserve a person's sense of self and dignity.



Help patients plan for the future

Like other progressive illnesses, dementia necessitates early discussions about future care preferences. A palliative approach encourages proactive conversations about medical, legal and financial planning while the person with dementia still has the capacity to express their wishes. Ensuring that preferences for future care such as treatment choices, living arrangements or advance directives are clearly documented can provide peace of mind for both patients and their families.



At first, the idea of palliative care felt daunting, but for me, it came to represent comfort and reassurance. After my partner's diagnosis, I felt like I was just discharged and left to figure things out on my own. But with palliative care, there was a sense of continuity, I wasn't abandoned. I felt included, supported, and truly looked after throughout the whole journey.

Former dementia carer



Support carers

Caring for a loved one with dementia is an emotional journey that can be both deeply meaningful and rewarding, but also overwhelming. Family carers often carry an immense responsibility while facing uncertainty, exhaustion and grief along the way. A palliative approach recognises their experience, ensuring they feel seen, heard and supported – throughout the dementia journey and beyond. Simply knowing that their role is acknowledged and their emotions are validated can provide comfort. Creating spaces where carers can share their fears, frustrations and hopes without judgement can make a profound difference.



Facilitate open conversations about the end of life

While end-of-life care is just one aspect of a palliative approach, it is an essential one. Open, compassionate discussions about what dignity and comfort mean in the final stages of life allow individuals and families to feel prepared. Many carers express a desire for guidance on what to expect, how to provide comfort, and how to cope with anticipatory grief. Providing emotional support, bereavement resources, and reassurance that they are not alone in this process can help families feel more at ease as they navigate this difficult stage.



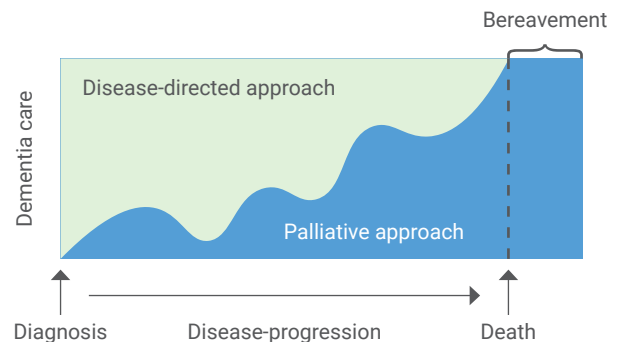
Adapt the level of palliative care provided based on the progression of dementia

The level of palliative care required by individuals depends on their dementia type, as well as their personal story and context. Typically, those who receive an early diagnosis will initially have more emotional, spiritual and psychological symptoms, rather than physical ones. As the condition advances, these needs may increase and vary, with typically more physical symptoms emerging over time. The most intensive level of support is usually required towards the end of life. It is important to remember that every person is a unique individual. Therefore, the scope and intensity of palliative care must be adjusted to meet each person's specific needs. Where symptoms are causing significant distress or are difficult to manage, this may include support from palliative care specialists.



It gives me peace of mind knowing that my wishes for the future are written down. Even as things change, I trust that the people around me will respect what I want and make decisions based on what matters to me. That kind of reassurance means a lot.

Person with dementia



Examples of a palliative approach to dementia care

In England, a dementia service incorporates a palliative care approach into standard dementia care. Thus, people with dementia at any stage have a holistic needs assessment, advanced care planning and ultimately good end-of-life care. These services are highly flexible in their working patterns to meet the needs of users. Activities are guided by the person's history, personality and preferences, emphasising their independence and empowerment. The service staff also help to support the person with dementia in making advance care plans, thereby ensuring that future care aligns with their wishes. This diminishes potential carer guilt and distress when making important decisions on their behalf.

Close collaboration with GPs and community nurses is essential to ensure necessary equipment is in place, when the end of life approaches. One service offers up to three support visits from the team for the carer following the death of a person with dementia. If additional support is warranted, a referral to bereavement services is made. Another service offers a bereavement call and a follow-up three months later from the bereavement counselling team.

In the Republic of Ireland, a Specialist Palliative Care service based at an acute hospital accepts people with life-limiting illnesses, such as dementia. Within such services, community palliative care Clinical Nurse Specialists are trained in dementia care, and end-of-life support is available 24/7 through an external "night nurse" service.



This information sheet has been developed by Alzheimer Europe and the European Association for Palliative Care, in collaboration with the European Working Group of People with Dementia and the European Dementia Carers Working Group.



Funded by the European Union (AI4HOPE, 101136769). Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the Health and Digital Executive Agency. Neither the European Union nor the granting authority can be held responsible for them. This work was funded by UK Research and Innovation (UKRI) under the UK government's Horizon Europe funding guarantee [Grant No. 101136769].