

# Dementia & Palliative Care

Summary of Marie Curie and the Marie Curie Palliative Care Research Department's joint response to the NICE Guidelines Consultation on dementia - assessment, management and support for people living with dementia and their carers

## Background

Dementia is a degenerative brain disorder which has various symptoms such as memory loss, issues with reasoning and speech, confusion and a decreased ability for activities of daily living. Alzheimer's, mixed and vascular dementia are the most generally known types of dementia. Dementia is a progressive and life-shortening condition. Nowadays, in the UK, 850,000 people live with the disease. By 2025, the numbers will rise to over 1 million and to 2 million by 2051<sup>1</sup>.

## Palliative care

A **palliative care approach** to people living with dementia offers a focus on comfort and planning ahead through the different stages. As dementia is a life-limiting condition, it is essential that a palliative care approach is adopted at the start of the dementia trajectory, to ensure discussions and future planning start while the person with dementia still has mental capacity. Palliative care is an integral part of caring for people living with dementia from diagnosis onwards and not solely for people reaching the 'end of life'. Care planning should be flexible, person-centred and aim to discuss the person's wishes with their family and people involved in their care: carers, GP, other health and social care professionals. Also, the planning should take into consideration the unpredictability of the disease's progression. If it is deemed that the person does not have the capacity to make a decision on their own behalf, that decision should be taken in the best-interest of the person living with dementia.

**Hospital admission** should be avoided if possible. Hospital admissions can have a particularly negative impact on people living with dementia, leading to disorientation, delirium and increased morbidity which may result in lengthy hospital stays before the individual can be discharged safely. The impact of an unfamiliar environment on people with dementia frequently outweighs the benefits of the care they can receive in hospital, particularly as appropriate care can be available in community settings via district nurses and specialist services (though these are not always available). Hospital admissions can be highly disruptive to the individual, their carers and their loved ones, and may introduce unnecessary stress and complication to already difficult circumstances.

**The nutritional needs** of people with dementia approaching the end of their lives might be challenging as some people may be unable to eat or drink. It is important that health professionals consider the food and drink preferences of the person as well as the person's familiarity with the individual who is helping them to eat and what can be done to put the person at ease.

**Moving between care settings** may be necessary but may increase disorientation. The priority in these cases should be limiting the number of moves a person with dementia needs to undergo. In the decision process, it is essential to consider the family, carers or those who care for them regarding their needs and the support available to them after each transition.

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<sup>1</sup> <https://www.alzheimers.org.uk/about-us/news-and-media/facts-media>

## Support for carers

Family and friend carers of people with dementia often become proxy decision makers at end of life if the person with dementia has lost capacity. This can be very difficult for carers, particularly if they are unsure of the wishes of the person with dementia. To support them in this role they need to be involved and kept informed of the medical needs of their relative. They should be signposted to services that may be able to support them. Carers should be offered training, information and support to help them understand dementia and how it might progress, including symptoms and disease management and communication adaptation. It is important to be aware that carers of people living with dementia are at a higher risk of depression, poor physical health and increased mortality in combination with carer burden, grief and anxiety. Providing the right emotional support will require a person-centred approach and may require peer support such as carer groups or online forums, or support from professionals with specialist expertise in mental health and dementia. Nonetheless, these services are subject to availability with variability across geographical areas.

## For more information

For standards and measures on palliative care, see the NICE quality standard on [end of life care for adults](#)

For guidance on care for people in the last days of life, see the NICE guideline on [care of dying adults](#)

For the principles for care at end of life developed, see the [National Palliative and End of Life Care Partnership](#)

For the value of palliative care's application in caring for people living with dementia, see [the European Association for Palliative Care's White Paper](#)