

Place of death PALLIATIVE CARE & END OF LIFE

This evidence theme on place of death is a summary of one of the key topics identified by a scoping review of the palliative care research.

Key points

- Dying in one's place of choice is associated with increased satisfaction with end-of-life care. A person may prefer dying in their own home, an aged care residential facility, or a hospital.
- Aged care staff's knowledge of the expected course of a terminal illness or of the natural signs of approaching death may influence their end-of-life care decisions, particularly when faced with sudden or unexpected deterioration. This may lead to unnecessary treatments, or a transfer to the hospital when making the person comfortable may be a better option.
- Multidisciplinary palliative care teams providing care to people in their own homes or within residential aged care facilities can increase the chances of an older person dying in the home environment.

Why does the place of death matter?

Dying at 'home'—one's own home or a residential aged care facility (RACF)—is considered a positive outcome of quality palliative care. [1] Many older people want a peaceful, pain-free death in their homes rather than in an Emergency Department or hospital ward. [2, 3] Although an <u>acute care transfer</u> may be necessary near the end of life due to a medical crisis (i.e., a cardiovascular event, a fall, an infection, or an uncontrolled pain or symptom burden), it may be more appropriate and in keeping with a person's wishes, to be supported to die in the familiar home setting. [2, 3]



Where do people receiving aged care die?

We identified twelve reviews that describe factors associated with an older aged care recipient dying in a particular location, which may or may not be their preferred place of death. [2-13]

Preferred place of death

Evidence suggests that when a person dies in their preferred place, their satisfaction with end-of-life care is improved. [2] However, where someone dies is influenced by a wide range of factors. These include the level of social support available to them, access to healthcare, and the nature of the person's illness. [2] Although a large proportion (approximately 82%) of older people express a preference for dying in their homes, this is not always achieved. [2, 3, 7] Additionally, there are conflicting findings on where people living with dementia are more likely to die [5, 11], although one review suggests many do not eventually die at home. [13]

Older people also have preferences for dying in a specific type of environment. [8-10] Those residing in RACF often prefer a comfortable, private, spatial layout and home-like atmosphere with sufficiently skilled staff and clinicians who can identify and recognise illness trajectories and initiate individualised ACP. [8-10] RACF should also provide older people with a sense of belonging, comfort, support, and familiarity, especially in facilitating good staff-resident relationships and providing continuity care that meets the older person's needs. [7, 8] For older people in home care, this may include accessing appropriate equipment and adapting the home layout and environment to align with their needs. [13]

Dying in hospital

The available research suggests a hospital death may be more likely if:

- A person living with dementia is male, older, and has good access to hospital services. [5]
- The dying person lives on their own or has a terminal condition other than cancer. [2]
- RACF residents have less access to nursing [4] or General Practitioner care [3] as the end-of-life approaches.
- An advance care plan is not in place to communicate preferences for end-of-life care. [3]
- Direct care staff lack the knowledge to recognise signs of approaching death and how to make a person comfortable at the end of life. [3]

Older people admitted to hospital at end-of-life may experience rapid cognitive and functional decline, which increases the risks of hospital-related deaths. [12] Therefore, while being hospitalised at the end of life is often appropriate care, residential aged care staff should work to avoid transferring a person who would prefer to die in the home setting. [4]

Dying in a home setting

The evidence suggests people are more likely to die in their own homes or RACF if:

- They have a preference for a home death. [2]
- Cancer is the cause of death rather than some other cause. [2]
- They are supported to die in the home setting by the involvement of specialist health practitioners in their care [6, 13] or a multidisciplinary palliative care team. [2]
- They receive an early, rather than late, referral to a palliative care service. [2]
- There is an advance care plan or 'do not resuscitate' order in place that details the preferred place of death. [2, 3]
- An informal caregiver is present, particularly one with a strong ability to cope, manage medications and symptoms, and support the person's wish to die at home. [2]
- A person with dementia living at home has strong social networks and receives personal and nursing care support from home care providers. [13]

Limitations

Many of the reviews covered in this evidence theme describe the available research on place of death as being scarce and of low quality, especially when focused on people living with dementia. [5] [13] Reasons provided include small numbers of participants, little information about interventions, and potentially important differences between the settings researched. [2, 3, 6] This may reduce the degree of certainty about some factors influencing place of death.

What can an individual do?

- Increase personal understanding of the signs that a person may be nearing the end of their life.
- Speak to care recipients and encourage them to consider developing an advance care plan/advance care directive that includes information on where the person would like to die.
- Encourage care recipients to have regular conversations with their family, friends, carers, and aged care staff about their wishes for end-of-life care.
- Be aware of each person's place of death preference or where you may find this information when needed.
- Be prepared to support the place of death preference and have open discussions about what might make it challenging to fulfil a particular wish.
- Understand the factors that may influence a person's wishes for a specific place of death, including improved knowledge of estate planning.
- If required, ensure people nearing the end of life have good access to healthcare professionals and specialist palliative care expertise.



What can the organisation do?

- Support staff to develop their skills in discussing end-oflife preferences with care recipients and their families and develop the confidence to advocate for nonhospital care when this is in the person's best interest at the end of life.
- Provide ongoing education around the need to have 'difficult' conversations; this may include discussions on developing <u>advance care plans</u>.
- Ensure aged care recipients have access to high-quality palliative care services early in the course of a lifelimiting illness.
- Support healthcare professionals and multidisciplinary palliative care teams to work within the residential aged care setting to provide direct care or train facility staff in end-of-life care.

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