



Communication at End of Life

PALLIATIVE CARE & END OF LIFE

This evidence theme on communication at end of life is a summary of one of the key topics identified by a scoping review of the palliative care research.

Key points

- Good communication between people with life-limiting illnesses and their health care professionals is important for achieving a high quality of palliative care and positive end-of-life experiences for older people and their families.
- Most older people receiving aged care services express a willingness to discuss the end of life, preferring not to 'leave it too late' and valuing honest communication with clarity of meaning. Some older people or their family members will avoid discussing prognosis and the end of life. Cultural differences may also influence the level and type of information people will want to receive.
- The evidence suggests sensitive, ongoing communication about what someone might expect at the end of life can increase the likelihood that they receive high-quality palliative care and care that aligns well with their personal wishes. Family satisfaction with care is also increased with the duration and frequency of open and patient-centred end-of-life discussions.

Why is communication at end of life important?

Good communication between people with life-limiting illnesses and their health care professionals is important for achieving a high quality of palliative care and positive end-of-life experiences for older people and their families. [1, 2] Open and sensitive communication can enhance a person's knowledge of their condition, the potential benefits and side effects of treatments, as well as their prognosis. [1] It also presents an opportunity to explain the purpose and benefits of palliative care for the individual and the family unit. These discussions can help a person develop a realistic understanding of what the future might entail, empowering them to make active plans around any personal life goals, as well as for their future care. [3] Quality communication can also strengthen the relationship and trust between the older person and family and the health professionals providing care, increasing the likelihood the person will receive services that reflect their needs. [3]

When health professionals involve families of aged care residents in detailed discussions about goals of care and keep them updated on changes and deterioration, family members appear more likely to see the need to move from a curative approach to palliative-oriented care. [2] Clear and open communication that death is a probability for older people in aged care and that it may be impending for their loved one might, therefore, prevent families from requesting burdensome interventions near the end of life. [2, 4] Overall, the evidence suggests that open conversations at the end of life can contribute to improving a dying person's quality of life. [5]

Whose role is it to initiate discussions of end of life?

Most older people in aged care settings express a willingness to discuss the end of life, preferring not to 'leave it too late' and valuing honesty and clarity in communication with health professionals. [6] These conversations may be initiated by the person, a family member, or an informal carer. They might also be introduced by a health care professional such as a registered nurse within an aged care facility [1] or the person's regular general practitioner. [7] Ideally goals of care discussions based on a shared understanding of a likely prognosis should start 6 to 12 months before death and prior to a crisis event such as hospitalisation. [8] They should also continue to take place until the person's death. [9]

Some older people and their families will avoid discussing end of life matters. This may be for cultural or religious reasons, out of fear of hearing a negative prognosis, or a desire to maintain hope and positivity. [10] Health care professionals may need to explore the reasons behind a lack of engagement before any end-of-life communication takes place. Once these reasons are understood, the clinician might proceed by sensitively preparing the person and their family over time for the inevitability of death, rather than trying to convey a lot of confronting information all at once. [9] Where end-of-life discussions take place is an important consideration. Comfortable, homely, and private meeting spaces well away from busy thoroughfares may offer people a better environment for expressing their emotions and engaging in frank and sensitive discussions than public areas or clinical spaces.

General practitioners who have built long-standing relationships with their patients may be best placed to perceive a person's willingness to engage in discussions around palliative and end-of-life care and proceed accordingly. [11] However, the effectiveness of general practitioner end-of-life communication will depend on the individual clinician's communication skills and ability to create a collaborative relationship with the patient and family. [12] Some general practitioners delay informing patients and their families of approaching death until very late. They may have difficulty identifying patients at-risk of dying [13] or be unwilling to communicate bad news in case

it results in a loss of hope. [14] Some general practitioners fear that end-of-life communication may damage the patient-clinician relationship; however, it appears honest communication of this kind tends to strengthen it. [15]

For people living with dementia, the evidence suggests end-of-life conversations involving the family should start as early as possible and be ongoing. [16] This can help create a system of support around the family, providing them with time to process the terminal nature of dementia. It may also facilitate advance care planning while the person with dementia is still able to make decisions. [2, 4, 16] In a time of crisis, family members (or a non-family substitute decision-maker) may become central in communicating the person's wishes to aged care staff or to acute care staff if the person with dementia is transferred to the emergency department or hospitalised. [17] For more information on end-of-life considerations for people with dementia, see the evidence themes Advance Care Planning and Palliative Care in the Dementia Care section of the Hub.

End-of-life communication with people from diverse cultural or ethnic backgrounds and their families requires a culturally informed approach that respects and responds to individual differences in past experiences, beliefs, and values. For example, some cultures exclude the dying person from discussions of prognosis [4] while others may have different ways of interpreting the meaning of pain, suffering and grief (e.g., as a test of spiritual faith). [18, 19] Language barriers may also come to the fore during end-of-life discussions. Professional interpreters may be necessary during these important and sensitive conversations and may be preferable to relying on family members to interpret. [18]

What do we know about communication at end of life in aged care?

We identified three systematic reviews, summarising 61 studies, that discussed communication at the end of life in aged care settings. [1, 4, 20] These included residential aged care facilities [1, 4] and mixed settings, including home and residential facilities. [20] Together the evidence suggests communication at end of life is effective when it:

- is person-centred, meaning it is tailored to each person's need and desire for information and their ability to comprehend and manage the impact of receiving a poor prognosis
- is part of a continuous, relational process built on trust
- is undertaken as early as possible and involves advance care planning
- leads to shared decision making
- covers physical, psychological, and spiritual care
- takes place in a dedicated space appropriate for sensitive conversations. [1, 4, 20]

End-of-life conversations are also reported to:

- increase the likelihood that nursing home residents die in their preferred place
- promote patient-centred, less aggressive, and comfort-orientated care at the end of life. This includes a decrease in unplanned hospital admissions and length of hospital stay in the last month of life. [4, 20]
- increase family satisfaction with the end-of-life care received. Satisfaction also increased with the duration and frequency of end-of-life conversations. [4]

The reviews also identified barriers to effective communication at end of life. This includes the need to improve training and guidelines on end-of-life communication for health professionals working with older people. [1, 20] When accompanied by organisational support, education and training can improve staff confidence in initiating discussions and knowing what to say and how to say it. Some health professionals might also gain clarity on their role in taking the initiative for this form of communication, rather than expecting older people to broach what they might consider a difficult topic. [20] One review highlighted the importance of clinicians using simple language and asking questions to understand how well the information has been received. [20] A further significant barrier to discussions on end-of-life issues in residential aged care is the lack of staff time. [1, 20]

One review reported a concern that studies used varying definitions of 'end of life' and what end-of-life conversations should involve. [4] This may reduce the degree of certainty we might have about the reported outcomes of end-of-life communication. For example, communication at end of life might cover the withdrawal of life-sustaining treatments, care goals, advance directives, symptom management, prognosis, or care for psychological, spiritual, and existential problems. Some studies defined end of life communication simply as a 'talk' about the resident's condition and medical treatment. [4]

What can an individual do?

- Investigate opportunities to develop skills and confidence in conducting discussions on end of life with those in your care, their family and other supporters.
- Be aware of the personal impact of conducting emotionally charged discussions on end-of-life issues with people and their families. Reach out for help if you are feeling stressed or experiencing grief. The ELDAC self-care room provides ideas to help, as well as access to relevant resources in a variety of formats.

What can the organisation do?

- Support clinicians working in aged care settings to initiate ongoing conversations around end of life with older people and their families.
- Encourage support for families of people living with advanced dementia in residential aged care through early conversations on the likely course of the condition and the benefits of a palliative approach to care.

- Provide access to regular end-of-life communication training for all aged care clinical and direct care staff to develop their confidence and competence in end-of-life communication. PCC4U provides a range of free education modules for ongoing professional development, including one on Communicating with people affected by life-limiting illnesses.
- Address organisational barriers to communication at end of life such as understaffing and time constraints. Prioritise this communication as a core responsibility of aged care and implement a system for recording these discussions.
- Ensure residential facilities are equipped with a dedicated space for staff to have sensitive palliative and end-of-life care conversations.
- Ensure support is available to staff who may be experiencing emotional or psychological difficulties from engaging in challenging end-of-life conversations.

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