



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 healthcare 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 in aged care settings are willing to discuss the end of life, preferring not to 'leave it too late' and valuing transparency. Other 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 want to receive.
- The evidence suggests that sensitive, ongoing communication about what someone might expect at the end of life can increase the likelihood of receiving high-quality palliative care and care that aligns well with their wishes. Family satisfaction with care also increases 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 healthcare professionals is important for achieving a high quality of palliative care and positive end-of-life experiences for older people and their families. [1-3] Open and sensitive communication can enhance a person's knowledge of their condition, any potential benefits and side effects of treatments, and their prognosis. [1, 4] 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 the future, empowering them to make active plans around any personal life goals and for their future care. [5] Quality communication can also strengthen the relationship and trust between health professionals and those they care for, increasing the likelihood that people will receive needed services. [5]

When healthcare professionals involve families of aged care residents in detailed discussions about goals of care and keep them updated on their worsening quality of life, 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 improve a dying person's quality of life. [6]

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

Most older people in aged care settings are willing to discuss the end of life, preferring not to 'leave it too late' and valuing transparency. [7] The person, a family member, or an informal carer may initiate these conversations. They might also be introduced by a health care professional, such as a Registered Nurse within an aged care facility [1, 4] or the person's regular General Practitioner. [8] It is suggested that goals of care discussions based on a shared understanding of a likely prognosis ideally occur 6 to 12 months before death and before a crisis event such as hospitalisation. [9] They should also continue to take place until the person's death. [10]

Some people will avoid raising the topic of end of life, not wishing to know their prognosis, perhaps to maintain hope and positivity. [11] Here, healthcare professionals may take the initiative, sensitively preparing the person and their family over time for the inevitability of death rather than conveying this information all at once. [10] General Practitioners having 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. [12] However, the effectiveness of General Practitioner end-of-life communication will depend on the clinician's communication skills and ability to create a collaborative relationship with the patient and family. [13] 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 [14] or be unwilling to communicate bad news, potentially risking a loss of hope. [15] Some General Practitioners fear end-of-life communication may damage the patient-clinician relationship; however, honest communication strengthens this association. [16]

For people living with dementia, the evidence suggests that end-of-life conversations involving the family should start as early as possible and be ongoing. [17] 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 a person living with dementia can still make decisions. [2-4, 17] In a crisis, family

members (or a non-family substitute decision-maker) may become central in communicating the person's wishes to aged or acute care staff if the person living with dementia is transferred to the Emergency Department or hospitalised. [18]

End-of-life communication with people from diverse cultural or ethnic backgrounds and their families requires careful consideration. Some cultures exclude the dying person from discussions of prognosis [4], whilst others may express pain and grief or view mental illness or dementia differently from the healthcare team. [3, 19] Language barriers may also be prominent during end-of-life discussions. Professional interpreters may be necessary during these important and sensitive conversations and are preferable to relying on family members to interpret the information. [19]

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

We identified five reviews that discussed communication at the end of life in aged care settings. [1, 4, 20-22] The evidence suggests communication at the 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
- Leads to shared decision-making.
- Covers physical, psychological, and spiritual care.
- Occurs in a dedicated space appropriate for sensitive conversations. [1, 4]

End-of-life conversations are also reported to:

- Increase the likelihood that nursing home residents die in their preferred place.
- Increase the odds of receiving strong opioid analgesics in the last 24 hours of life.
- Decrease unplanned hospital admissions and length of hospital stay in the last month of life (although not significantly).
- Promote patient-centred, less aggressive, and comfort-orientated care at the end of life. [4]
- Increase family satisfaction with the end-of-life care received. Satisfaction also increased with the duration and frequency of end-of-life conversations. [4]
- Increased trust between an older person, their family members, and aged care workers. [20]
- Allows families to receive respite and emotional support (i.e. reassurance) from aged care workers (see evidence theme on Grief and Bereavement). [20]

The reviews also identified barriers to effective communication at the end of life. This includes improving training and guidelines on end-of-life communication for health professionals working with older people. [1] The lack of staff time is a significant barrier to discussing end-of-life issues in residential aged care. [1]

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 the 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 a talk about the resident's condition and medical treatment as 'end-of-life communication'. [4]

Case-conferencing may improve end-of-life care for older people by supporting the assessment and decision-making for older people with dementia. [21, 22] Case-conferencing sessions are delivered to RACF residents through in-person or video consultations. [21] Different tools may be used to assist healthcare professionals with the assessment of the older person – for example, use of electronic health records, digital decision tool/assessment systems. [21]

There are many benefits of having case-conferencing. It may encourage and/or improve:

- Care provision – symptom management (including pain management), ACP, family support, psychological support, and overall terminal care. [22]
- Problem solving – allows effective communication and collaboration between primary care, aged care professionals (especially for General practitioners who often meet for brief ad hoc periods frequently via phone), older person, and families. [21, 22]
- Allow family members to feel respected and trusted. [21]
- Decrease hospitalisation at end-of-life. [21, 22]
- Decrease physical restraints by 75%. [21]
- Promote seamless transition in care if the older people were to be hospitalised. [22]
- Improved medication prescriptions (i.e. to manage pain). [21, 22]

Limitations

The results have informed this evidence theme of a scoping review intended to map the published research in this area. Our findings reflect the current state of the evidence, which we note is limited in breadth and quality.

What can an individual do?

- Investigate opportunities to develop skills and confidence in discussing end-of-life care with older people, their families 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 the 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 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.
- Address organisational barriers to communication at the end of life, such as understaffing and time constraints on non-task-based care.
- Provide a dedicated space for staff to have sensitive palliative and end-of-life care conversations.
- Ensure support is available to staff experiencing emotional or psychological difficulties from engaging in challenging end-of-life conversations.

References

1. Bennett FB, Hadidi NN, O'Conner-Von SK. End-of-life care communication in long-term care among nurses, residents, and families: A critical review of qualitative research. *J Gerontol Nurs.* 2021;47(7):43-49.
2. Gonella S, Campagna S, Basso I, De Marinis MG, Di Giulio P. Mechanisms by which end-of-life communication influences palliative-oriented care in nursing homes: A scoping review. *Patient Educ Couns.* 2019;102(12):2134-2144.
3. Amador S, Sampson EL, Goodman C, Robinson L. A systematic review and critical appraisal of quality indicators to assess optimal palliative care for older people with dementia. *Palliat Med.* 2019;33(4):415-429.
4. Gonella S, Basso I, De Marinis MG, Campagna S, Di Giulio P. Good end-of-life care in nursing home according to the family carers' perspective: A systematic review of qualitative findings. *Palliat Med.* 2019;33(6):589-606.

5. Walczak A, Butow PN, Bu S, Clayton JM. A systematic review of evidence for end-of-life communication interventions: Who do they target, how are they structured and do they work? *Patient Educ Couns*. 2016;99(1):3-16.
6. Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008;300(14):1665-1673.
7. Sharp T, Moran E, Kuhn I, Barclay S. Do the elderly have a voice? Advance care planning discussions with frail and older individuals: A systematic literature review and narrative synthesis. *Br J Gen Pract*. 2013;63(615):e657-668.
8. Rhee JJ, Grant M, Senior H, Monterosso L, McVey P, Johnson C, et al. Facilitators and barriers to general practitioner and general practice nurse participation in end-of-life care: Systematic review. *BMJ Support Palliat Care*. 2020.
9. Woolfield A, Mitchell G, Kondalsamy-Chennakesavan S, Senior H. Predicting those who are at risk of dying within six to twelve months in primary care: A retrospective case-control general practice chart analysis. *J Palliat Med*. 2019;22(11):1417-1424.
10. LeBlanc TW, Tulsy J. Discussing goals of care [Internet]. In: Connor RF editor. UpToDate 2024. Wolters Kluwer; 2023 [updated 2023 September 01, cited 2024 November 27]. Available from: <https://www.uptodate.com/contents/discussing-goals-of-care#H2051255264>
11. Murray CD, McDonald C, Atkin H. The communication experiences of patients with palliative care needs: A systematic review and meta-synthesis of qualitative findings. *Palliat Support Care*. 2015;13(2):369-383.
12. Rhee JJ, Teo PCK, Mitchell GK, Senior HE, Tan AJH, Clayton JM. General practitioners (GPs) and end-of-life care: A qualitative study of Australian GPs and specialist palliative care clinicians. *BMJ Support Palliat Care*. 2018.
13. Johnson CE, McVey P, Rhee JJ, Senior H, Monterosso L, Williams B, et al. General practice palliative care: Patient and carer expectations, advance care plans and place of death—a systematic review. *BMJ Support Palliat Care*. 2018.
14. Lewis ET, Mahimbo A, Linhart C, Williamson M, Morgan M, Hammill K, et al. General practitioners' perceptions on the feasibility and acceptability of implementing a risk prediction checklist to support their end-of-life discussions in routine care: A qualitative study. *Fam Pract*. 2020;37(5):703-710.
15. Deckx L, Mitchell G, Rosenberg J, Kelly M, Carmont SA, Yates P. General practitioners' engagement in end-of-life care: A semi-structured interview study. *BMJ Support Palliat Care*. 2019.
16. Fenton JJ, Duberstein PR, Kravitz RL, Xing G, Tancredi DJ, Fiscella K, et al. Impact of prognostic discussions on the patient-physician relationship: Prospective cohort study. *J Clin Oncol*. 2018;36(3):225-230.
17. Gonnella S, Mitchell G, Bavelaar L, Conti A, Vanalli M, Basso I, et al. Interventions to support family caregivers of people with advanced dementia at the end of life in nursing homes: A mixed-methods systematic review. *Palliat Med*. 2022;36(2):268-291.
18. Pulst A, Fassmer AM, Schmiemann G. Experiences and involvement of family members in transfer decisions from nursing home to hospital: A systematic review of qualitative research. *BMC Geriatr*. 2019;19(1):155.
19. Silva MD, Genoff M, Zaballa A, Jewell S, Stabler S, Gany FM, et al. Interpreting at the end of life: A systematic review of the impact of interpreters on the delivery of palliative care services to cancer patients with limited English proficiency. *J Pain Symptom Manage*. 2016;51(3):569-580.
20. Nicholson CJ, Combes S, Mold F, King H, Green R. Addressing inequity in palliative care provision for older people living with multimorbidity. Perspectives of community-dwelling older people on their palliative care needs: A scoping review. *Palliat Med*. 2023;37(4):475-497.
21. Tunnard I, Gillam J, Harvey C, Davies N, Vickerstaff V, Ellis-Smith C, et al. The acceptability and effectiveness of eHealth interventions to support assessment and decision-making for people with dementia living in care homes: A systematic review. *Front Dement*. 2022;1:977561.
22. Phillips JL, West PA, Davidson PM, Agar M. Does case conferencing for people with advanced dementia living in nursing homes improve care outcomes: Evidence from an integrative review? *Int J Nurs Stud*. 2013;50(8):1122-1135.

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