End-of-life care, long-term care

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Introduction

As a resident approaches the end of life, the resident and family members face the personal and sometimes difficult process of making end-of-life decisions. Nurses and other interdisciplinary team members can help by teaching about the risks and benefits of each intervention and by helping the resident develop a treatment plan. Advance care planning helps the resident and family members through this process, typically by putting these end-of-life decisions into an advance directive.[1] (See *Understanding end-of-life care planning terminology*.) An advance directive should be reviewed periodically, during regularly scheduled care plan meetings, and when changes in the resident's condition occur.[2]

UNDERSTANDING END-OF-LIFE CARE PLANNING TERMINOLOGY

The terminology surrounding end-of-life care planning can be difficult to understand. Fully understanding these terms yourself allows you to guide residents and family members through the end-of-life care decision-making process.

Advance care planning is a process that allows a resident to make plans for future care and treatment, including for a time when the resident may no longer have the capacity to make or communicate health care choices. It requires ongoing dialogue with the resident or family members and the interdisciplinary care team as the resident's condition changes. Advance care planning can help avoid confusion and conflict for the resident, family members, and care providers. It also provides peace of mind, allowing the resident to live more fully in the present because it ensures that if a serious health event occurs, the care provided will be based on the resident's expressed wishes.

An **advance directive** is a legally binding document that a resident completes that describes the health care decisions that the resident wants. It becomes valid when the resident can no longer make those health care decisions and when certain conditions specified in the document are met. Each state has its own requirements for what constitutes a valid advance directive. Several types of advance directives exist:

- A **living will** or **treatment directive** outlines a resident's instructions for treatment.
- A **durable power of attorney for health care** or **health care proxy** authorizes another person to make health care decisions on behalf of a resident if the resident becomes incapacitated.
- A **practitioner's orders for life-sustaining treatment** or **medical orders for life-sustaining treatment** is a legally recognized order for resuscitation, hospitalization, life support, and hydration and nutrition at the end of life; the orders are based on the resident's wishes.[3]

Health care instructions define the resident's wishes for all clinical decision-making. Some states have specific documents that define the resident's wishes and serve as a practitioner's order that's accepted across health care settings. These instructions can help guide several types of decisions:

- Cardiopulmonary resuscitation: Should caregivers use aggressive efforts to restore cardiopulmonary function if the resident undergoes cardiac or pulmonary arrest?
- Endotracheal intubation: Should caregivers artificially ventilate the resident if respiratory function becomes severely compromised?
- Use of IV fluids and nutrition: What level of hydration and nutrition does the resident want in end-of-life situations?
- Transfer between health care facilities: Under what circumstances should the resident be transferred to a higher-level facility?
- Use of antibiotics and other medications: Should the resident receive aggressive treatment with antibiotics or other medications when the likelihood of benefit is small?

A resident's religious beliefs, physical condition, dependency level, and finances all influence advance care planning decisions. Nurses can help guide residents and family members through the advance care planning process and help them understand the associated terminology. The organization Aging with Dignity has a resource titled *Five Wishes* that can also help with planning and is available on the organization's website (https://www.agingwithdignity.org/).[4]

Many states have specific advance directive forms and requirements for witnesses of an advance directive. The local Area Agency on Aging can assist with locating the proper forms. Many states supplement the advance directive with a practitioner's orders for life-sustaining treatment or medical orders for life-sustaining treatment forms that can provide detailed guidance about the resident's medical care preferences. Each state's department of health can provide information about the availability of these forms.[1]

Advance care planning may include palliative and hospice care. Although these terms are sometimes used interchangeably, they're different. Palliative care aims to match medical treatment to the resident's goals and sometimes prolongs life. Hospice care aims to maintain a resident's quality of life while providing care that ensures a comfortable death.[5] Nurses must explain the differences between palliative and hospice care when presenting care options to residents and family members.

Palliative care is a team-oriented treatment approach designed for seriously ill residents who aren't actively dying. With this approach, the health care team provides medical treatment in conjunction with pain and symptom management and psychological and spiritual care with the goal of improving the resident's quality of life. The team also provides support and guidance for the resident's family members. Palliative care may be provided at any time during a resident's illness and may be provided along with curative treatment.

Palliative care should be considered for a resident with one or more of the following criteria:

- uncontrolled dyspnea, nausea, vomiting, or elevated pain level
- a wish not to be resuscitated, intubated, or hydrated as the resident's medical condition deteriorates
- a history of two emergency department visits or health care facility admissions in the previous 6 months for the same or a similar condition

- advanced or end-stage organ disease, such as heart failure, chronic obstructive pulmonary disease, stage 5 kidney disease, liver failure, dementia, multiple sclerosis, or amyotrophic lateral sclerosis[6]
- a poor prognosis and being considered for a tracheotomy and percutaneous endoscopic gastrostomy tube insertion.

Provided by a licensed hospice provider, hospice care is designed to provide psychosocial support and comfort for a resident in the final phase of a terminal illness who is expected to live 6 months or less.[5] The goal is to promote comfort and improve quality of life rather than provide curative treatment. Long-term care residents who receive hospice care experience better pain management than those who don't receive hospice care.[3] Nursing staff members are responsible for ensuring pain and other symptom palliation for all terminally ill residents, regardless of whether residents are enrolled in a hospice program or have an advance directive.[3] Anyone can inquire about hospice care, but a practitioner's order is required to initiate hospice care for a resident.[7]

Equipment

- Disinfectant pad
- Facility-approved pain assessment tool
- Oral care supplies
- Prescribed medications
- Resident's advance directive
- Skin care supplies
- Stethoscope
- Optional: advance directive form, advance directive information forms, personal protective equipment

Preparation of Equipment

Inspect all equipment and supplies. If a product is expired, is defective, or has compromised integrity, remove it from resident use, label it as expired or defective, and report the expiration or defect as directed by your facility.

Implementation

- Review the resident's medical record to determine whether the resident is a candidate for palliative care.
- Review the resident's advance directive (if one exists) and the documentation provided by the multidisciplinary team.
- Gather and prepare the necessary equipment and supplies.
- Perform hand hygiene.[8][9][10]
- Confirm the resident's identity using at least two resident identifiers.[11]
- Provide privacy.[12]
- Provide an environment that's comforting and nurturing to the resident and family members.
- If the resident doesn't have an advance directive, provide the necessary information, advance directive form, and assistance with developing an advance directive.[13] Make sure that the materials are in the resident's preferred language *to promote understanding.*[14] (See the "Advance directives, long-term care" procedure.)
- Perform hand hygiene.[8][9][10]

- Put on personal protective equipment, as needed, *to comply with standard precautions.*[15][16]
- Assess the resident's respiratory status for signs of dyspnea.[17]
- Assess the resident's GI status for signs and symptoms of anorexia, nausea, vomiting, and constipation.
- Screen for and assess the resident's pain using facility-defined criteria that are consistent with the resident's age, condition, and ability to understand.[18]
- Assess the resident's skin for signs of skin breakdown.
- Assess the resident's psychosocial status *to determine psychosocial needs.*[17]
- With the aid of the multidisciplinary team, develop a resident-centered care plan that addresses the resident's decision-making capacity, religious beliefs, cultural preferences, and care instructions.
- If the resident or health care proxy requests hospice care, obtain a practitioner's order and contact the hospice organization of the resident's choice. Alternatively, notify your social services department *so that they can contact the appropriate hospice organization.*
- If the resident qualifies for hospice care and hospice care is initiated, collaborate with the hospice team *to develop a coordinated care plan that reflects and supports the hospice philosophy.*
- Obtain medications, supplies, and medical equipment through hospice services, if indicated.
- Administer medications, as prescribed, following safe medication administration practices, *to relieve the resident's symptoms and to promote comfort.*[19]
- Institute nonpharmacologic comfort measures *to relieve the resident's symptoms and to promote comfort.*
- Provide emotional support to the resident and family and encourage them to verbalize their feelings.
- Reposition the resident frequently and provide skin care *to promote the resident's comfort and prevent skin breakdown.*
- Provide frequent oral care *to promote the resident's comfort.*
- Reassess the resident *to make sure that your interventions are effective.* If they're ineffective, work with the multidisciplinary team to readjust the resident's care plan.
- Remove and discard your personal protective equipment, if worn.[16]
- Perform hand hygiene.[8][9][10]
- Clean and disinfect your stethoscope with a disinfectant pad.[20]
- Perform hand hygiene.[8][9][10]
- Document the procedure.[21]

Special Considerations

- Note that family dynamics and cultural, religious, and spiritual beliefs can all affect the grieving experience. Family members commonly have questions about afterlife concerns, unresolved social and emotional issues, and financial concerns that require discussion.
- Use active listening when communicating with a resident and the resident's family about end-of-life preferences.[3]
- Respect a resident's and family's wishes regarding the use of complementary and alternative therapies. Refer to the National Institutes of Health National Center for Complementary and Integrative Health (https://www.nccih.nih.gov) *to help the resident and family understand and make evidence-based choices related to the use of complementary and alternative therapies.*

- Be culturally sensitive when providing end-of-life care. *Understanding different cultural beliefs can help you deliver culturally sensitive services that can affect residents' and family members' responses to dying, death, illness, loss, and pain.*
- Note that as the end of life nears, a resident and family members will experience feelings of grief. Offer bereavement counseling, as needed.
- Continue to assess and manage a resident's symptoms *to preserve quality of life, regardless of decisions about advance directives and hospice care.*[3]

Documentation

Documentation associated with end-of-life care includes:

- assessment findings
- interventions provided
  - response to those interventions
- teaching provided to the resident and family (if applicable)
  - understanding of that teaching
  - follow-up teaching needed.

Related Procedures

- Advance directives
- Advance directives, long-term care
- Advance directives, oncology
- Advance directives, pediatric
- Advance directives, psychiatric care
- Care of a dying patient
- Care of a dying patient, home care
- Care of a dying patient, neonatal
- Care of a dying patient, pediatric
- Care of a dying resident, long-term care
- Mechanical ventilation discontinuation for end-of-life care, respiratory therapy
- Withholding and withdrawing life-sustaining treatments

Related UpToDate Patient Teaching Handouts

- Advance directives
- Palliative care

References

(Rating System for the Hierarchy of Evidence for Intervention/Treatment Questions)

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Rating System for the Hierarchy of Evidence for Intervention/Treatment Questions

The following leveling system is adapted from *Evidence-Based practice in nursing & healthcare: A guide to best practice,* Fifth edition, by Bernadette Mazurek Melnyk and Ellen Fineout-Overholt (2023).

Level I	Evidence from a systematic review or meta-analysis of all relevant randomized controlled trials (RCTs)
Level II	Evidence from well-designed single RCTs (experimental)
Level III	Evidence from well-designed nonrandomized controlled trials (quasi-experimental), systematic reviews of a complete body of evidence, and intervention studies using mixed methods
Level IV	Evidence from well-designed case-control and cohort studies (observational)
Level V	Evidence from systematic reviews of qualitative and descriptive studies
Level VI	Evidence from single descriptive and qualitative studies, evidence-based practice implementation, and quality improvement projects
Level VII	Evidence from expert opinion, expert committee reports, and literature reviews

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