End Of Life Care Approach

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Introduction

Serious illness changes more than the body. It can alter identity, family roles, work, finances, relationships, beliefs, and a person's sense of the future. Palliative care is a clinical approach designed to improve quality of life by preventing and relieving suffering. It is appropriate for adults and children with serious or life-threatening conditions and can be provided together with treatment intended to cure disease or prolong life. This point is essential because many patients hear "palliative" as a concealed announcement that the medical team has given up (World Health Organization, n.d.).

End-of-life care is a part of palliative care, but the terms are not interchangeable. Palliative care may begin at diagnosis and continue for months or years. End-of-life care generally refers to the period when death is expected and care focuses increasingly on comfort, preparation, and support. Hospice is a particular model of care with eligibility and payment rules that vary by country and program. The purpose of all three is not to abandon treatment. It is to align treatment with the person's condition, goals, values, and acceptable burdens (National Institute on Aging, n.d.; World Health Organization, n.d.).

Defining Palliative Care

The World Health Organization defines palliative care as an approach that improves the quality of life of patients and families facing problems associated with life-threatening illness. It addresses physical, psychological, social, and spiritual suffering through early identification, assessment, and treatment. The approach affirms life, regards dying as a normal process, and neither intends to hasten nor postpone death (World Health Organization, n.d.).

The National Cancer Institute similarly explains that palliative care can be provided from diagnosis, during treatment, through follow-up, and at the end of life. Its role is especially visible in cancer care, but it is not limited to cancer. People with heart failure, chronic lung disease, dementia, kidney disease, neurological conditions, congenital illness, and other serious conditions can benefit (National Cancer Institute, n.d.).

A useful way to explain palliative care is "an added layer of support." The primary team continues to

manage the illness, while palliative specialists or trained clinicians help with difficult symptoms, communication, family needs, and decisions. In some settings, the same team provides both disease-directed and palliative care (National Cancer Institute, n.d.).

Palliative Care, Hospice, and End-of-Life Care

Confusion among these terms can delay referral. Palliative care is based on need rather than a prediction that death will occur within a particular number of months. Hospice generally serves people who are approaching the end of life and have chosen a comfort-focused plan under the rules of the relevant program. In the United States, the Medicare hospice benefit uses a physician-certified prognosis of six months or less if the illness follows its usual course, though patients can receive care longer when eligibility is recertified (National Institute on Aging, n.d.).

End-of-life care may be delivered in a hospital, home, nursing facility, hospice unit, or other setting. It includes symptom relief, treatment decisions, family support, spiritual care, preparation for dying, and care after death. A person does not have to enroll in hospice to receive compassionate end-of-life care, and enrollment does not mean that every medicine or hospital service is automatically prohibited. The plan depends on goals, benefits, burdens, and program rules (National Institute on Aging, n.d.).

Who Should Be Referred and When

A palliative referral should not be reserved for the final days. Useful triggers include uncontrolled pain or breathlessness, repeated hospital admissions, progressive loss of function, difficult treatment decisions, caregiver exhaustion, serious uncertainty about prognosis, and conflict about goals. Early referral allows relationships to develop before crisis (National Cancer Institute, n.d.; World Health Organization, n.d.).

Illness trajectories are unpredictable. A person with cancer may experience relatively stable function followed by decline, while heart failure or lung disease may involve repeated crises and partial recovery. Dementia can progress slowly over years. Prognostic uncertainty should lead to parallel planning rather than silence: clinicians can continue treatment while preparing for what may happen if the illness worsens.

Needs should guide timing. A patient receiving curative therapy can still have severe nausea, fear, insomnia, or family distress. Treating those concerns is not inconsistent with hope. In fact, symptom control can help a person continue therapy or spend time on activities that matter (National Cancer Institute, n.d.).

Goals of Care

Goals of care are the outcomes a patient values, not simply the treatments a clinician can offer. One person may prioritize living as long as possible even if treatment is burdensome. Another may prioritize mental clarity, being at home, communicating with family, or avoiding hospitalization. These preferences can change as illness and experience change.

Clinicians should translate broad values into clinical decisions. “I want everything” may mean the patient is afraid of abandonment or wants every treatment likely to restore meaningful function. “I do not want machines” may require clarification about temporary ventilation during a reversible problem. A careful conversation asks what the patient understands, what matters most, what outcomes would be unacceptable, and who should speak if capacity is lost.

Goal-concordant care is not the same as granting every requested intervention. Clinicians must explain whether a treatment is likely to achieve the desired outcome and what burdens it carries. When a treatment cannot accomplish the patient’s goal, the team should still offer active care directed toward achievable priorities.

Communication About Prognosis

Patients differ in how much detail they want, and cultural expectations about disclosure vary. The clinician can begin by asking permission: “Would it be helpful to discuss what we expect in the coming months?” Information should be clear, compassionate, and free of false precision. Ranges and scenarios are often more honest than an exact date.

A useful structure is to describe the best case, worst case, and most likely case, then explain what signs would indicate change. Prognostic information should be followed with support and a plan. Delivering bad news without explaining what will be done next can create avoidable despair.

Hope does not require denial. The focus of hope can shift from cure to time, comfort, reconciliation, a family event, or freedom from a frightening symptom. Clinicians should not force optimism, but they can remain present and identify realistic possibilities.

Shared Decision-Making and Capacity

Shared decision-making combines clinical evidence with the patient’s values. It does not transfer the entire burden to the patient or allow the clinician to decide without discussion. The team explains options and likely outcomes, the patient explains priorities, and together they select a plan.

Decision-making capacity is specific to the decision and can fluctuate. A patient may be able to choose a meal but not understand a complex high-risk procedure. Pain, medication, infection, low

oxygen, or delirium can temporarily impair capacity. Clinicians should address reversible causes and communicate in accessible ways before concluding that capacity is absent.

When a patient lacks capacity, an authorized surrogate uses the patient's known wishes or, when those are unknown, the patient's best interests. The surrogate's task is not to choose what the surrogate would want personally. Advance directives and prior conversations can guide this process.

Advance Care Planning

Advance care planning is an ongoing conversation about future healthcare, not merely the completion of a form. It includes identifying a trusted decision-maker, discussing values, documenting preferences, and ensuring that records are available across settings. A directive that cannot be found during an emergency has limited value (National Institute on Aging, n.d.).

Documents should be reviewed after major changes in diagnosis, function, family circumstances, or treatment goals. Patients should understand that they can revise choices while they have capacity. Families should also know where documents are stored and whom to contact.

Advance planning does not guarantee that every future situation can be predicted. It improves the quality of surrogate judgment by providing a clearer picture of the person. It can also reduce family guilt because decisions are based on the patient's voice rather than guesswork.

Pain Assessment and Management

Pain is common but not inevitable at the end of life. Assessment should include location, severity, quality, timing, triggers, functional effect, prior response, and the patient's own goals. Nonverbal patients require observation of movement, facial expression, breathing, vocalization, and behavior, while recognizing that these signs are not perfectly specific (World Health Organization, n.d.).

Management may include acetaminophen, anti-inflammatory medicines, opioids, adjuvant medicines, radiation, procedures, physical approaches, and psychological support. Opioids are often appropriate for moderate to severe pain, but dosing must be individualized. Renal or hepatic impairment, prior exposure, age, interactions, and the type of pain influence selection (World Health Organization, n.d.).

Fear of addiction should not lead to untreated suffering, and concern about safety should not be dismissed. Clinicians should explain expected effects, constipation prevention, sedation, safe storage, and monitoring. A patient using opioids for serious illness under supervision is not automatically experiencing addiction. At the same time, past substance-use disorder requires thoughtful planning rather than stigma.

Breathlessness

Breathlessness can be frightening for the patient and family. Assessment should consider reversible causes such as fluid overload, infection, bronchospasm, anemia, or airway obstruction. Treatment may include disease-specific therapy, positioning, airflow from a fan, relaxation, oxygen when hypoxemia is present, and opioids for selected patients (World Health Organization, n.d.).

Families may focus on oxygen saturation, but the patient's distress is also important. Oxygen does not relieve every form of breathlessness. Calm presence, explanation, and reduced exertion can help. Severe respiratory distress requires rapid access to medicines and a plan for whom to call.

Clinicians should explain that appropriately titrated opioids can reduce the sensation of breathlessness. The goal is comfort, not respiratory suppression. Monitoring and careful adjustment remain necessary.

Nausea, Constipation, and Other Symptoms

Nausea may result from medicines, bowel obstruction, metabolic disturbance, intracranial disease, anxiety, or gastrointestinal problems. Treatment works best when directed at the likely mechanism. Constipation is common because of opioids, immobility, dehydration, and illness. Preventive bowel regimens are often needed when opioids begin.

Other symptoms include fatigue, dry mouth, itching, swelling, cough, weakness, insomnia, and loss of appetite. Each can affect dignity and family interaction. Small interventions—mouth care, repositioning, skin care, a bedside commode, or adjusting the timing of medicines—can make a substantial difference.

Symptom management should not become a list of medicines without reassessment. The team should ask whether the intervention improved what matters to the patient. A lower pain score is useful, but being able to speak with family or sleep may be the more meaningful outcome.

Delirium, Anxiety, and Depression

Delirium is an acute disturbance in attention and cognition that fluctuates. Causes include infection, medicines, organ failure, dehydration, and metabolic change. It can be frightening and may impair decision-making. Treatment includes identifying reversible causes when consistent with goals, reducing unnecessary medicines, creating a calm environment, and using medication selectively for severe distress or dangerous agitation.

Anxiety may be related to symptoms, uncertainty, trauma, or fear of dying. Listening, breathing techniques, spiritual care, counseling, and medication may help. Depression should not be assumed

to be a normal or inevitable response to terminal illness. Persistent hopelessness, loss of interest, guilt, or suicidal thinking requires assessment and treatment.

Existential distress can resemble depression but may involve meaning, identity, regret, or fear. Chaplaincy, psychotherapy, dignity therapy, life review, and family conversation can be valuable. The person should not be told simply to remain positive.

Nursing Care at the End of Life

Nurses often spend more time at the bedside than any other professional. They observe changes, administer medicines, assist with personal care, teach families, and hear concerns that patients hesitate to raise during a brief medical visit. This position gives nurses a central role in palliative and. end-of-life care (World Health Organization, n.d.).

Nursing assessment includes symptoms, skin, swallowing, elimination, cognition, mobility, sleep, family understanding, and response to treatment. Nurses should anticipate needs rather than wait for crisis. When oral medicines become difficult, the team may need alternative routes. When mobility declines, equipment and caregiver teaching become urgent.

Care includes ordinary acts that preserve dignity: asking permission before touch, explaining procedures to an unresponsive person, keeping the mouth moist, providing clean clothing, protecting privacy, and helping family members participate if they wish. These actions are not lesser forms of treatment. They are part of skilled care.

The Interdisciplinary Team

Palliative care is interdisciplinary because suffering has multiple dimensions. Physicians and advanced practitioners address diagnosis, treatment options, and medical management. Nurses provide continuous assessment and coordination. Social workers address family, financial, housing, and practical needs. Chaplains support meaning and spiritual concerns. Pharmacists, psychologists, therapists, dietitians, aides, and volunteers may contribute (World Health Organization, n.d.).

Teamwork requires more than referring the patient to several professionals. Members need shared goals, communication, and clarity about roles. Regular meetings can identify contradictions—for example, when one clinician says the aim is comfort while another continues tests that do not affect care.

Continuity is especially important across hospital, home, clinic, and nursing facility. Medication lists, advance directives, emergency plans, and contact information must follow the patient. Poor transitions can cause untreated symptoms or unwanted readmission.

Family Caregivers

Families may provide medication, lifting, bathing, feeding, and overnight monitoring with little preparation. Caregiving can be meaningful and also exhausting. The team should assess willingness, ability, health, work obligations, and financial strain. A family member should not be assumed to be available simply because they are related (National Institute on Aging, n.d.).

Teaching should be practical: what each medicine is for, how to measure it, what changes are expected, what indicates emergency, and whom to call at night. Written instructions and demonstration are more reliable than a rapid verbal explanation during discharge. Respite services can protect both patient and caregiver.

Family conflict can reappear under stress. The team should keep the patient's goals central and provide a structured meeting where concerns can be heard. Agreement cannot always be achieved, but confusion can be reduced.

Bereavement care begins before death. Anticipatory grief, guilt, anger, relief, and exhaustion can exist together. After death, support may include practical information, follow-up calls, counseling, spiritual care, or referral for complicated grief. Not every bereaved person needs formal therapy, but everyone deserves clear information about available help.

Spiritual, Cultural, and Existential Care

Serious illness raises questions that medicine cannot answer through laboratory tests. Patients may ask why the illness happened, whether their life mattered, what happens after death, or how to repair a damaged relationship. Spiritual care does not require the patient to belong to a religion. It concerns meaning, identity, hope, guilt, connection, and transcendence (World Health Organization, n.d.).

Chaplains and faith leaders can provide specialized support, but spiritual care is not theirs alone. Any clinician can ask, "What gives you strength?" or "Is there anything important about your beliefs that we should know?" The purpose is not to offer the clinician's own theology. It is to understand the patient's sources of meaning and practices.

Cultural humility is preferable to a checklist. A family's preferences about truth-telling, touch, food, prayer, gender, decision-making, and care of the body after death may be influenced by culture without being determined by it. Staff should ask rather than assume. Professional interpreters are important when language barriers affect consent or complex decisions; children should not be placed in the position of interpreting life-changing information.

Food, Fluids, and the Meaning of Care

Eating and drinking carry emotional meaning. Families often express love by providing food, so reduced appetite near the end of life can feel like starvation or neglect. In many dying patients, the body gradually becomes less able or willing to use food and fluid. Forcing intake may cause discomfort, coughing, aspiration, swelling, nausea, or repeated procedures without restoring strength (National Institute on Aging, n.d.).

This does not mean that food and water should be withheld automatically. The cause of poor intake should be considered, and the patient's wishes should guide decisions. Small favourite foods, sips, ice chips, and mouth care may offer comfort. Artificial nutrition or hydration may be helpful in selected situations and burdensome in others.

The team should explain what is happening and continue visible care. Mouth care, positioning, symptom treatment, and presence demonstrate that the patient has not been abandoned. Families need permission to understand that declining intake can be part of the illness rather than something they have caused.

Place of Care and the Wish to Be at Home

Many people say they would prefer to remain at home, but preference alone does not make home care possible. Symptoms may become complex, housing may be unsuitable, caregivers may be unavailable, or professional support may not reach the area. A hospital or inpatient hospice can sometimes provide better comfort and safety (National Institute on Aging, n.d.).

Home care works best when medicines, equipment, nursing advice, emergency contacts, and respite support are organized in advance. Families should know what changes to expect and when to call. Without this support, a frightening symptom may lead to an emergency admission even when everyone hoped to avoid hospital.

The goal should not be to treat home death as a success and hospital death as a failure. The better measure is whether care matched the patient's informed priorities and whether distress was addressed. Preferences can also change. A patient who once wanted to remain home may later feel safer in a facility, and that change should be respected.

Ethical Questions and Proportionate Treatment

Palliative care does not aim to hasten death, and it does not require treatment to continue regardless of burden. Ethical practice distinguishes between intending to relieve suffering and intending to cause death. Medicines used for symptom control should be selected and adjusted according to clinical

need, with monitoring and explanation (World Health Organization, n.d.).

Withholding a treatment and withdrawing one that has become burdensome are generally treated as ethically comparable when the treatment no longer supports the patient's goals. Emotionally, stopping a machine may feel different from deciding not to start it. Families and staff may need time and support to understand that the underlying illness, not the decision to remove a nonbeneficial treatment, is causing death.

Conflict sometimes arises when a family requests treatment that clinicians consider futile or harmful. The word "futile" should be used carefully because treatment may achieve a biological effect without achieving the outcome the patient values. A second opinion, ethics consultation, and a clear explanation of benefits and burdens may help. Disagreement should not be treated as misconduct simply because people are grieving.

Evidence-Based Practice and Quality Improvement

Evidence-based palliative care combines research, clinical expertise, and patient preferences. Outcomes include symptom relief, communication quality, caregiver burden, place of care, emergency use, and whether treatment matches documented goals. Survival is not the only measure, although palliative care should not be assumed to shorten life (World Health Organization, n.d.).

Organizations should examine how long patients wait for consultation, whether referrals are limited mainly to cancer, whether language services are available, and whether patients from rural or low-income communities receive equivalent support. A hospital may report having a palliative-care team while leaving it too understaffed to reach most eligible patients.

Triggers can help identify people who may benefit: repeated admissions, severe symptoms, progressive illness, difficult decisions, or caregiver distress. A trigger should prompt assessment, not replace judgment. Algorithms may support referrals, but they should not label a person as dying without human review and sensitive communication.

Access and Inequality

Access to palliative care remains uneven. Services may be concentrated in large hospitals and cities. Opioid regulations, medicine shortages, limited specialist training, cost, transportation, and cultural mistrust can leave patients without adequate relief. Children and people with non-cancer illnesses have historically received less access in many systems (World Health Organization, n.d.).

Inequality also shapes the choices available. A wealthy family may arrange paid home support, while another family must choose between caregiving and employment. A patient in unstable housing cannot receive the same home-care plan as someone with space, refrigeration, and reliable

electricity. Calling both situations “choice” hides the structural difference.

Health systems should integrate basic palliative skills into primary care, nursing, emergency medicine, oncology, cardiology, respiratory care, and long-term care while maintaining specialist teams for complex cases. Palliative care becomes sustainable when it is part of ordinary serious-illness care rather than an isolated service reached only near death (World Health Organization, n.d.).

Conclusion

Palliative care is best understood as an added layer of support for serious illness. It can begin early, continue alongside active treatment, and later become the main focus if the burdens of treatment outweigh the likely benefit. Hospice and end-of-life care overlap with palliative care but are not identical to it. Clear language prevents patients from hearing a referral as a concealed announcement that nothing more will be done (National Cancer Institute, n.d.; National Institute on Aging, n.d.).

A strong end-of-life approach combines symptom control, honest communication, advance planning, nursing care, family support, spiritual attention, and respect for culture and personal priorities. It also recognizes practical limits: home care requires resources, caregivers require support, and choices are shaped by inequality. The central commitment is not to perform the greatest number of interventions. It is to remain attentive to the person whose life is being lived—to relieve suffering, protect dignity, and make sure that care continues even when cure is no longer possible (World Health Organization, n.d.).

References

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