



Understanding palliative care

An option that provides individuals with support
and services that might not otherwise be possible.

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Palliative care offers an unmatched way to deliver much-needed support and better quality of life at a time when it's greatly needed

Quality of life

Each year, nearly two million older adults die from non-traumatic causes, many from chronic progressive illnesses. Sadly, individuals with complex illness are often unaware of palliative care services that can lend much-needed support and serve to enhance their quality of life over the course of their illness.

Designed to meet the comprehensive spiritual, emotional and physical needs of those with complex illnesses, as well as the needs of their family caregivers, palliative care is a service whose value cannot be overestimated. Unfortunately, it's one that is still being underutilized.

Nowhere is that more apparent than in the realm of pain management. Research consistently shows that pain — a seriously debilitating symptom for many with chronic or progressive illness — is frequently undertreated in the long-term care environment, and beyond. It's been shown that between 33% and 83% of nursing home residents experience ongoing pain that impairs mobility, leads to depression and diminishes quality of life. The fact that people are living longer with chronic illness further underscores the need for palliative care.

"Pain is a big problem for many and that's a real shame because it's absolutely unnecessary. Just because someone has a (complex) illness that does not mean suffering needs to go along with it," stressed Diane Meier, MD, FACP, director of the Center to Advance Palliative Care, New York.

Pain isn't the only symptom that can be alleviated through a well-designed and well-implemented palliative care program, however. Depending upon the illness, individuals may also suffer from nausea, breathing problems, digestive disturbances, depression, anxiety and scores of other unpleasant and distressing symptoms that can rob them of their quality of life and make getting through each day a challenge.

Not surprisingly, these disease management shortcomings dramatically differ from the needs and wants of individuals with complex illness. Numerous studies indicate that people with serious illness want vigorous treatment of pain and symptoms; relief from worry, anxiety and depression; ongoing communication about their illness and care options; coordinated, multidisciplinary care throughout their illness course, with anticipation of future care needs; decision-making support and assistance for themselves and their family caregivers; and closely monitored, highly communicated care that lends a sense of safety and security in a sometimes confusing healthcare system.

A case for compassion

Concerned that palliative care is a costly program? Think again. Studies consistently show that patient-centered management of complex cases can reduce costs without shortening life. In fact, it's been shown that reduced inpatient symptoms and fewer admissions, hospital days and emergency department visits are all benefits of patient-centered management. This approach has also been shown to cost \$18,599 less over an 18-month period than non-patient-centered management of complex cases.

Source: Sweeney, AMJC, February 2007

Overcoming misconceptions

So why — despite palliative care's far-reaching benefits — is the service still not being offered or accessed to its fullest? Experts believe misinformation and lingering misconceptions are, in great part, to blame.

For starters, palliative care is often confused with hospice care. "Hospice is a form of palliative care, but it's important to realize that palliative care is not synonymous with hospice. They are not one and the same," said Stephen Connor, Ph.D., vice president for research and international development, National Hospital and Palliative Care Organization, Alexandria, VA.

"What some people don't understand is you can receive palliative care while still receiving or seeking curative treatments," Connor added. He noted that those receiving palliative care not only benefit from relief of suffering, but also care teams working in tandem to devise the best care and support plans throughout the course of illness.

The CAPC stresses that palliative care actually affirms life by supporting the patient's and family's goals for the future, including their hopes for cure or life-prolongation, as well as their hopes for peace and dignity throughout the course of illness, the dying process and death.

At the heart of those goals are interdisciplinary care teams that include medical and nursing specialists, social workers, counselors, pharmacists, therapists, nutritionists, clergy and other health professionals as needed.

The team works in partnership with the patient or resident's primary physician to expand traditional disease-model medical treatments to include the goals of enhancing quality of life for patients and family members, help with decision-making, and provide opportunities for personal growth.

Another common and damaging misconception is that managing pain with opioid analgesics poses a toxicity risk that can hasten the dying process and place patients in a drug-induced fog.

"People believe that pain medication kills, but the reality is pain is (what's very bad for a person's health)," Meier stressed. She explained that more than 90% of pain episodes and other symptoms can be effectively treated with standard analgesic therapies provided and closely monitored by a palliative care program. "Pain that goes untreated is the problem — not the drugs that manage it."

at the core

Improving care, curbing costs

The benefits of palliative care programs reach into fiscal realms as well. Research shows that because palliative care works to prevent and relieve suffering, fewer people receiving the services require hospital visits and stays. Palliative care also helps ease the transition between care settings, which can further drive patient satisfaction while steering them to the most appropriate healthcare resources throughout their illness course.

Even if a patient does require hospitalization, the costs for those receiving palliative care consultation are significantly less than for those who don't. Live discharge costs for palliative care patients who receive intensive care are roughly \$183 less per day than those who receive usual care. Care for end-of-life palliative care patients who receive intensive care and die in a hospital is approximately \$446 less per day than those non-palliative care patients, according to a 2007 study published in the *Journal of the American Geriatrics Society*.

"Complex patients with advanced illness and multiple comorbidities are among the most expensive cases in healthcare," confirmed Mark Leenay, M.D., MS, chief medical officer, Evercare Hospice and Palliative Care, citing a study published in the February 2007 issue of the *American Journal of Cardiology*.

"There's no correlation between the prevalence of severe chronic illness and total Medicare spending," continued Dr. Leenay. He did point out, however, the high correlation between Medicare spending and days spent in the hospital in the last six months, and an even stronger correlation between Medicare spending and doctor visits in the last six months of life.

According to the 2006 Dartmouth Atlas of Health Care, if the resource utilization of efficient providers and systems was implemented nationally, it would reduce spending for those with severe chronic illness by 30%.

Pain by numbers

33-88: Percentage of nursing home residents with ongoing pain that impairs mobility and robs quality of life^{1,2}

50: Percentage of patients who report moderate or severe pain at least half the time in their last three days of life³

65: Percentage of caregivers of dying patients who cite inadequate control of suffering³

References

1. Miller SC, Mor V, Teno J. Hospice enrollment and pain assessment and management in nursing homes. *J Pain Symptom Manage.* 2003;26:791-799.
2. Teno JM, Weitzen S, Wetle T, Mor V. Persistent pain in nursing home residents. *JAMA.* 2001;285:2081.
3. Leenay M. *Opening a Dialogue: Advance Care Planning.* 2007

Finding its stride

Although palliative care is still underutilized, there's no question the benefits, both to the patient and families and to the healthcare system, have led to greater penetration.

A 2007 survey of 4,103 hospitals by the American Hospital Association revealed more than 30% have a palliative care program. The amount jumps to 70% for hospitals with more than 75 beds. VA hospitals reported almost 100% palliative care penetration.

Still, Meier and Connor stressed there's a well-documented need for evidence-based palliative care research to promote more wide-spread support, access and implementation of the program across the care continuum.

The National Consensus Project for Quality Palliative Care states that further promotion and support of palliative care in the U.S. can be driven by ongoing health professional education in palliative care principles and practice; increasing access to palliative care specialists across the care continuum; and promoting timely access to hospice services to all eligible patients.

Some of those goals are currently being addressed by the Joint Commission. Later this year, the agency will be implementing palliative care standards as part of its new Health Care Services Certification Program.

"The proposed standards emphasize the importance of patient-centered care and teamwork in focusing on the front line of service delivery," noted Chuck Mowll, executive vice president, Business Development, Government and External Relations, The Joint Commission.

The standards, expected to be launched in August, cover important aspects related to program management, providing care, managing patient information, and improving performance.

Meeting the needs of individuals — while focusing on what's important

The most physically, emotionally and spiritually fulfilled individuals are those who are able to stay focused on the things they love — and those who are chronically or terminally ill are certainly no exception.

Palliative care should embrace each individual's needs, while encouraging them, whenever possible, to stay engaged in their favorite activities or interests. More specifically, palliative and hospice care should be shaped by a deep commitment to celebrate who a patient is as a complete person, emphasizing not just what they need while they are ill or in their end stages of life, but what has been meaningful to them throughout their life.

For 89-year-old Virginia Frizzell, it was the company and comfort of a volunteer and her therapy animals — a horse and a dog — that helped create an enriching hospice experience (see her photo on page 2). Despite being very weak from incurable pancreatic cancer, Frizzell was able to live independently with the support of in-home care and spend quality time with friends and family.

"A large part of what we do is spend time one-on-one with patients, reflecting on their lives to get a better understanding of what will help them most as they approach this final phase," noted Anne Kidd, the hospice social worker who coordinated Virginia's home services and regularly monitored her overall condition and well being.

Knowing Frizzell's love of horses and riding, Kidd contacted the volunteer coordinator for their hospice program to determine whether a horse visit could be arranged. They immediately reached out to another volunteer who jumped at the chance to bring her horse, Cody, to Frizzell's home.

"Because Virginia wasn't able to travel much, we knew we'd need to bring the horse to her," Kidd explained. The joy in Virginia's face as she connected with Cody was unmistakable, she added. "It was so wonderful for her, so rewarding and calming. In fact, Virginia told us: 'This is the best day of my life.'"



Hospice care should be about giving, not giving up.

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5 Unique features

Palliative care is different, notes Dr. Mark Leenay

1 Palliative care is appropriate at any point in an illness and can be administered in conjunction with curative treatments. The goal of palliative care is to anticipate, prevent and relieve suffering and symptoms — regardless of the stage of a disease — and optimize a patient’s quality of life. Palliative care is not restricted to end-of-life care and often is provided alongside curative and disease-modifying treatments. It is generally high-touch and low-tech, focusing on the right care for the right patient at the right time.

2 Pain management is often inadequate in individuals who could benefit from it the most. Although pain is highly prevalent in patients with advanced illness, undertreatment is common. According to the *Journal of Pain and Symptom Management*, undertreatment of pain in those with advanced disease is a far more pressing concern than the risk of hastened death.* Palliative care includes very aggressive, individualized measures to control a patient’s pain and other distressing symptoms.

3 Palliative care is not a one-size-fits-all approach. Palliative care addresses the continuum of physical, social and spiritual needs and facilitates patient autonomy, access to information and personal choice. It is highly customized, with the utmost respect for a patient’s values, culture, wishes and dignity. Palliative care also reaches out to family members and loved ones, recognizing their unique concerns and issues.



“Palliative care empowers patients with advanced illness to live as fully and comfortably as possible.”

*Dr. Mark Leenay,
Chief Medical Officer
Evercare Hospice
and Palliative Care*

4 The most effective palliative care involves advanced care planning and multi-disciplinary involvement. Palliative care revolves around the “whole person” and is provided by interdisciplinary teams. Care includes physician consultation and a broad range of services for the patient and family, including the support of nurses, chaplains, social workers, therapists and volunteers. Palliative care also can be a time to gather information about how an illness is likely to progress, including initial planning for long-term care needs.

5 Effectively administered palliative care can offer a cost benefit to healthcare organizations, while also enhancing quality of life for those who receive it. Patients with advanced illness generally have the highest costs in healthcare. Studies demonstrate that a patient-centered approach to care can reduce patient symptoms; lower hospital admissions, total hospital days and ER visits, and eliminate inappropriate or unnecessary interventions — all with no reduction in the length of a patient’s life. Palliative care can play a direct role in lowering overall costs without shortening life.

* Portenoy RK, Sibirceva U, Smout R, et al. *Opioid Use and Survival at the End of Life: A Survey of a Hospice Population.* *J Pain Symptom Manage.* 2006; 32:532-540.

There when you need us most

Evercare Hospice & Palliative Care provides compassionate, individualized services to those with advanced illnesses and those nearing end-of-life, wherever they reside — whether in a private home, nursing home, assisted living facility or inpatient setting. Evercare's experienced staff is part of an interdisciplinary team dedicated to meeting the physical, psychological and spiritual needs of residents and their families. By working closely with residents and their family members, Evercare provides a tailored, personal approach that delivers comprehensive care solutions. Evercare Hospice & Palliative Care is available in many major U.S. cities:

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