

# Palliative Care Promotes Quality of Life for those with Advanced Illness

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## Accounting for Physical, Emotional, and Mental Wellbeing

Advancements in medicine allow people with chronic and complex conditions to live longer than ever before. But longer life for people who are sick may bring challenges, such as pain, stress, and other symptoms that accompany serious illness. Meeting those challenges and making people with advanced illness as comfortable as possible requires providing full access to care that accounts for their physical, emotional, and mental wellbeing. Palliative care does just that.

"I heard about palliative care through one of the counselors at the hospital. Having Stacey [the palliative care coordinator] as a resource has been very, very helpful to us. She definitely brought up the idea that I might need emotional or spiritual help as I go through this. Stacey is integrated right into everything that is happening. She can talk to my doctor, she can talk to the other social workers. My satisfaction with KP and Palliative Care, and Stacey in particular, on a scale of 1-10 is a 10. At this point, it is all about living the best that we can. I feel like I'm doing what I need to do, and I feel like I'm supported."—*Pamela, a Kaiser Permanente member with end-stage Chronic Obstructive Pulmonary Disease*

### WHAT YOU SHOULD KNOW

- **Palliative care is a team-based medical subspecialty focused on providing relief from the symptoms, pain, suffering, and stress of serious, advanced illness.**
- **Palliative care is appropriate at any point in a serious, advanced illness, and can be provided alongside curative treatment.**
- **Kaiser Permanente provides palliative care in hospital and ambulatory settings and has found that doing so has resulted in improved quality of care, higher patient satisfaction, improved communication and advance planning, fewer hospital admissions, decreased emergency room visits, and lower costs.**
- **Continued work is needed to identify and spread best practices in palliative care, strengthen the palliative care workforce, and augment the evidence-base that supports the benefits of this approach.**

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## What is Palliative Care?

Palliative care is a team-based medical subspecialty focused on providing relief from the symptoms, pain, suffering, and stress of serious, advanced illness. It is intended to improve quality of life and can be provided alongside curative treatment. Palliative care services address the physical symptoms of advanced illness, such as pain, nausea, difficulty breathing, fatigue, insomnia, and bowel or bladder issues.

Just as importantly, palliative care services also address the emotional or spiritual stress and mental health symptoms – such as fear, anxiety, and depression – that often accompany advanced illness. Palliative care providers work with patients and their families or natural support systems, helping them to better understand their illness, talk more openly about their feelings, and decide what treatments they do or do not want. Given the all-inclusive nature of palliative care, it is increasingly called “supportive care” in some health systems and patient circles.

It is important to distinguish palliative care from “hospice care,” a term with which it is often confused. Hospice is a Medicare benefit that provides a specific set of services for patients whom a physician has certified as terminally ill, having a prognosis of no more than six months. Many of the services provided under hospice are palliative services. However, to be eligible for hospice under Medicare, a patient must not only have a six-month prognosis but must also be willing to forego curative treatment. This is a key distinction between hospice and palliative care. As noted, palliative care can be provided alongside curative treatment if the patient wishes, and it can happen at any time during the course of advanced illness – it is not reserved solely for the end of life.

A growing body of literature indicates that palliative care has benefits for patients. For example, one study showed that providing palliative care services to older adults admitted to the Intensive Care Unit reduced length of stay, total costs, and mortality.<sup>1</sup> The well-known Temel study from Massachusetts General found that metastatic lung cancer patients who received palliative care showed improvement in their quality of life – including fewer depressive symptoms – and outlived those who received usual care alone, by three months.<sup>2</sup> A 2014 report from the Center to Advance Palliative Care concluded that palliative care improves health care quality by: effectively relieving physical and emotional suffering; strengthening patient-family-physician communication and decision making; and, ensuring well-coordinated care across health care settings.<sup>3</sup>

## Policy Landscape: Raising the Profile of Palliative Care

Several prominent multi-stakeholder groups have been working for more than a decade to raise the profile of palliative care among patients and providers, increase awareness of its benefits, and advance best practices. For example:

- The Coalition to Transform Advanced Care (C-TAC), comprised of health systems, medical and nursing groups, health plans, employers, faith-based leaders, consumer advocates, and hospital and palliative care organizations, disseminates best practices in palliative care.<sup>4</sup> The group also advocates for value-based payment and quality measurement, promotes professional development, and builds public demand.
- Ten years ago, the National Quality Forum endorsed a list of 38 preferred practices for palliative care programs.<sup>5</sup> The list is based on the recommendations of the National Consensus Project for Quality Palliative Care, which examined and defined the components of a quality palliative care program, including quality monitoring, staffing requirements, and clinical care, among others.
- The Center to Advance Palliative Care (CAPC) is a member based organization that provides tools, technical assistance, and online training to assist its members with implementation of palliative care programs.<sup>6</sup>
- In 2014, the Institute of Medicine (IOM) issued a report, “Dying in America: Improving Quality and Honoring Individual Preferences near the End of Life,” in which it made recommendations to improve care for patients with advanced illness.<sup>7</sup> As a follow-up to this work, the IOM is now looking to create a roundtable on Quality Care for People with Advanced Illness. [www.iom.nationalacademies.org](http://www.iom.nationalacademies.org).

The biggest and most recent change in the palliative care policy landscape came in October 2015, when the Centers for Medicare and Medicaid Services (CMS) issued a final rule increasing the availability of advance care planning sessions for Medicare beneficiaries.<sup>8</sup> Advance care planning – in which patients explore and document their goals and desires around medical care in the event of an unforeseen health crisis — gives patients an opportunity to express their wishes for palliative and other types of care. Under the new rule, providers and patients have flexibility to engage in advance care planning when patients are ready, not just at the time of initial enrollment in the Medicare program, as was previously the case. In addition, CMS finalized payment for advance care planning when it is included as an optional element of the “Annual Wellness Visit.” This change is effective January 1, 2016.

These efforts are having an impact. Across the United States, the availability of—and access to—palliative care programs has grown significantly, with The

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Center to Advance Palliative Care projecting that 80 percent of hospitals with 50 or more beds would have a palliative care program by year end 2015.<sup>9</sup>



### The Kaiser Permanente Palliative Care Model: Embedding Supportive Services within Standard Care

Kaiser Permanente, the nation's largest, private integrated health care delivery system, has provided palliative care in hospital settings for over a decade and is now at the forefront of expanding across

the care continuum. Today, we have palliative care programs in hospital and ambulatory settings, as well as in home-based care. Though the programs vary in intensity across locations, the essential components embody the principles of team-based care, bringing together physicians, nurses, social workers, chaplains, and pharmacists. Palliative care teams provide consultation services to physicians and other providers who manage highly complicated patients. The long-term organizational goal for palliative care is to embed these supportive services within usual care, rather than making them available only when requested by a treating physician. The organization is also testing a number of new models in palliative care delivery, such as using specially-trained social workers to perform triage, improving palliative care documentation in the electronic health record, and developing new education curricula for physicians.

As noted, advance care planning plays an important role in ensuring that patients' desires for palliative care are articulated and subsequently met. Ideally, these conversations between patient and provider start long before a decision-point or crossroads and occur over the course of several sessions that may include the patient's family or other support system as well. As a more systematic approach to advance care planning conversations, Kaiser Permanente is implementing the Respecting Choices model across its facilities.<sup>10</sup> This model is an internationally recognized, evidence-based approach to advance care planning produced by Gundersen Health System. The goal is for advance care planning conversations to take place always in non-crisis situations, comparable to screening for breast cancer in a primary care setting.

"Kaiser Permanente has made great strides in its efforts to enhance support for patients facing serious and advanced illnesses. We continue to incorporate specialized, team-based support across hospital, home, clinic and other settings. Our teams – physicians, nurses, social workers, pharmacists, chaplains and others – work to

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proactively understand what is most important to patients and their loved ones. By listening and learning to their concerns, their hopes, and their fears, we can provide more comprehensive and personalized support.” —*Daniel Johnson, MD, FAAHPM, Physician Lead for Palliative Care, Care Management Institute, Kaiser Permanente*



### **Outcomes: Improving Quality, Satisfaction, Advance Planning, Admissions, ER Visits, Lowering Costs**

In three randomized controlled clinical trials of patients in hospital, home, and clinic settings, Kaiser Permanente found that palliative care resulted in improved quality of care, higher patient

satisfaction, improved communication and advance planning, fewer hospital admissions, decreased emergency room visits, and lower costs.<sup>11</sup> In keeping with Kaiser Permanente’s goal of ensuring that the advance care planning wishes of palliative care and other patients are met, the organization has started to measure how often patients’ stated preferences match up to their actual care experience. This type of “concordance measurement” has begun in Kaiser Permanente service areas in Southern California, Northern California, and Colorado. We are still learning about our performance relative to this measure, but Southern California has preliminarily reported 98 percent concordance rates for the period January 1 – September 30, 2013.<sup>12</sup>

Our internal data show improvements in the percent of decedents enrolled in hospice or palliative care 31 or more days before their death, increasing from 44 percent in 2008, to 65 percent in 2015.<sup>13</sup> Kaiser Permanente continues to refine and develop new quality measures, as it works to fully integrate palliative care processes into usual care.

### **Policy Implications: Care Rooted in Patient and Family Wishes that Promotes Quality of Life**

With the burgeoning Accountable Care Organization (ACO) movement underway, providers, health systems, and health plans are being challenged to pay attention to the patient as a whole. Palliative care has always been about treating the whole patient, but has typically taken place in a hospital setting. The palliative care community has started exploring providing care in non-hospital settings, specifically, community-based palliative care (out-patient, home-based, or in skilled nursing facilities). Kaiser Permanente has a jump-start in this area,

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and we anticipate that over the next two to three years, we will publish more findings about our experience in non-hospital settings. As more organizations are pivoting their focus in this new direction, there is a need for more information about best practices and how to operationalize these programs.

Other targeted areas of focus for policy moving forward include workforce development and research. Despite significant improvements in the number of palliative care programs in existence, there is still a need for investment in a palliative care workforce and in further research to establish the scientific evidence-base to expand palliative care services.<sup>14</sup>

As the population ages, we can expect to see an increase in the prevalence of chronic and serious illnesses. Most individuals facing serious illness will be hospitalized at some point and/or deal with their conditions at home on an ongoing basis. Palliative care offers one possible approach to maximizing hospital efficiency (reduced lengths of stay, reduced costs per hospital stay), while addressing the sometimes under-appreciated physical symptoms and emotional toll that serious illness has on patients and families. We expect the use of palliative care services to increase as consumers become more knowledgeable about its benefits and as programs become more ubiquitous. In fact, once people are informed about palliative care, 92 percent indicate that if they had a serious illness, they would be highly likely to consider it for themselves or their families.<sup>15</sup>

Real-world examples of successful programs, such as Kaiser Permanente's, can provide useful information and guidance to health care institutions looking to initiate or expand their palliative care offerings. A care approach that is rooted in patient and family wishes and promotes quality of life for those living with advanced illness is the ideal standard of care.

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<sup>1</sup> Ravakhah K, Chideme-Munodawafa A, Nakagawa S. Financial Outcomes of Palliative Care Services in an Intensive Care Unit. *Journal of Palliative Medicine*. 2010;13(1).

<sup>2</sup> Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*. 2010;363 (8): 733-42.

<sup>3</sup> Center to Advance Palliative Care. Growth of Palliative Care in U.S. Hospitals: 2014 Snapshot. July 2014. [https://media.capc.org/filer\\_public/6d/db/6ddbba1-0c03-4e34-9186-696bbc158950/capc\\_growth\\_snapshot\\_2014.pdf](https://media.capc.org/filer_public/6d/db/6ddbba1-0c03-4e34-9186-696bbc158950/capc_growth_snapshot_2014.pdf)

<sup>4</sup> See: [www.thectac.org.](http://www.thectac.org/)

<sup>5</sup>The National Quality Forum, Palliative and End of Life Care (website), [www.qualityforum.org/Topics/Palliative\\_Care\\_and\\_End-of-Life\\_Care.aspx](http://www.qualityforum.org/Topics/Palliative_Care_and_End-of-Life_Care.aspx).

<sup>6</sup> See: [www.capc.org.](http://www.capc.org/)

<sup>7</sup> Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences near the End of Life. Washington, DC: National Academies Press; 2015 ([www.nap.edu/catalog/18748/dying-in-america-improving-quality-and-honoring-individual-preferences-near](http://www.nap.edu/catalog/18748/dying-in-america-improving-quality-and-honoring-individual-preferences-near)).

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<sup>8</sup> Centers for Medicare and Medicaid Services. Proposed policy, payment, and quality provisions changes to the Medicare Physician Fee Schedule for Calendar Year 2016 (press release). October 30, 2015, [www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-10-30-2.html](http://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-10-30-2.html).

<sup>9</sup> Center to Advance Palliative Care. Growth of Palliative Care in U.S. Hospitals: 2014 Snapshot. July 2014. [https://media.capc.org/filer\\_public/6d/db/6ddbbaa1-0c03-4e34-9186-696bbc158950/capc\\_growth\\_snapshot\\_2014.pdf](https://media.capc.org/filer_public/6d/db/6ddbbaa1-0c03-4e34-9186-696bbc158950/capc_growth_snapshot_2014.pdf)

<sup>10</sup> See [www.gundersenhealth.org/respecting-choices](http://www.gundersenhealth.org/respecting-choices).

<sup>11</sup> Gade G, Venohr I, Conner D, McGrady K, et al. Impact of an inpatient palliative care team: a randomized control trial. Journal of Palliative Medicine. 2008;11(2):180-90; Brumley RD, Enguidanos S, Cherin DA. Effectiveness of a home-based palliative care program for end-of-life. Journal of Palliative Medicine. 2003;6:715-724; Englehardt J, Rizzo VM, Della Penna RD, Feigenbaum PA, et al. Effectiveness of care coordination and health counseling in advancing illness. American Journal of Managed Care. 2009;15(11):817-25.

<sup>12</sup> Turley M, Wang S, Meng D, Kanter MH, et al. Research and Applications. An information model for automated assessment of concordance between advance care preferences and care delivered near the end of life. Journal of the American Medical Informatics Association. 2015;0:1-8.

<sup>13</sup> Kaiser Permanente Care Management Institute, unpublished data, 2015.

<sup>14</sup> See [www.capc.org/policymakers/overview](http://www.capc.org/policymakers/overview).

<sup>15</sup> Center to Advance Palliative Care. Public Opinion Research on Palliative Care. April 2011, [www.Media.capc.org](http://www.Media.capc.org).

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